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Embracing life after breast cancer: Exploring the holistic health of survivors

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Embracing Life after Breast Cancer:
Exploring the Holistic Health of Survivors

By:

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Bachelor of Science, Wilfrid Laurier University, 2003

THESIS

Submitted to the Department of Psychology

In partial fulfillment of the requirements

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Abstract

Health, from a holistic perspective, is more than physical well-being. The experience and treatment of breast cancer has an impact beyond physical health, with psychological, social, and spiritual factors playing a role in wellness. Physically, treatment such as surgery, radiation and chemotherapy often have disruptive side effects such as, fatigue, breast soreness, nausea, vomiting, hair loss and weight gain, as well as the possibility of losing one or both breasts (Mustian et al., 2002). Psychologically and emotionally, women may experience anxiety, depression, anger, guilt, fear and repression, psychological distress and persistent fears of recurrence (Glanz & Lerman, 1992). The goal of the study was to promote holistic understanding regarding women's experience of breast cancer. 101 breast cancer survivors in Ontario completed a quantitative survey that was developed with the participation of women with breast cancer, and included measures of quality of life, mental adjustment to cancer, post-traumatic stress disorder and self-transcendence. The findings indicate that lifestyle choices, socio-demographic variables and breast cancer history and treatment all play a role in predicting quality of life. Specifically, women who exercise frequently, live alone and are significantly involved in volunteering and breast cancer support and advocacy have a better quality of life. Increasing age and experiencing post-treatment lymphedema were consistently associated with poorer quality of life. The findings have implications for women's post-treatment lifestyle choices, as well as post-treatment service and support needs of breast cancer survivors.

Acknowledgements

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This research would not have been possible without the incredible support of the local breast cancer community. Thank you to the breast cancer survivors from the Knot-a-Breast dragon boat team in Hamilton that participated in my Community Advisory Group. Their feedback and help in distributing surveys made a significant contribution to the research. A very sincere thank you to the Juravinski Cancer Centre for their amazing help in distributing surveys at the "Life after Breast Cancer" conference; without your help I may have never reached my goal. Many other community organizations generously helped me reach women with breast cancer, including the Breast Cancer Support Services in Burlington, Willow support services in Toronto, Wellspring Halton-Peel, Hopespring of the Waterloo Region and the Cancer Assistance Program in Hamilton. Thank you for being so helpful and kind and for all the work you do for breast cancer survivors in your communities. Most of all, I would like to thank the women who took the time to fill out a survey and share their experience with me. This research is for you. I hope my findings will improve life for you and all the women who will face this disease in the future.

I would like to thank my family and friends for their unconditional love and encouragement that have made all of my achievements possible. Thank you to Peggy Weston for your amazing friendship, inspiration and support.

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INTRODUCTION

Standpoint: Positioning the Researcher

As a community psychology student, my values and life experiences contribute significantly to my interest in studying breast cancer, and holistic health. I am a young woman with a pronounced family history of dealing with cancer. On my father's side, I have lost two aunts, two uncles and my grandfather to various types of cancer. My grandmother is a breast cancer survivor. I am familiar with the ins and outs of a cancer diagnosis, the implications, the treatments, and the side effects. However, my parents have always shielded me from the cancer experience itself, especially when I was younger. I have never witnessed the battle, the victories, the fear, the uncertainty, and the pain resulting from treatment and the realization that life is ending. I have felt the loss and have been filled with questions, on why her or him, how could we lose them so young, could my dad be next and could this happen to me? Studying breast cancer is not just an academic interest for me; it is a personal interest stemming from experiences that I have a need to understand. I value the opportunity to contribute to ongoing cancer research and possibly make a difference for cancer survivors.

My research focuses on women and the effects of breast cancer that not always, but most of the time affects women. As a feminist, I believe in the strength of women, in the benefits of having the support of other women and the value of femininity. Most women I know place significant importance on emotional relationships and are negatively affected when something threatens these bonds. Since I believe that wellness is holistic, if one aspect of life is off-balance, I believe that it often influences well-being on other levels. In my eyes, a physical threat tips the balance of psychological, emotional, spiritual and social connections, many of which may be central to purpose and meaning in life.

Over the years, I have had the chance to work with women, both younger and older. As a Coordinator of Events and Issues at the WLU Women's Centre, I organized events addressing issues of violence against women, eating disorders and celebrating the female spirit. Working at Illahee Lodge, a program for multicultural seniors organized through the Family Service Association, I planned and implemented a health and wellness retreat for diverse seniors living in Toronto. I worked with mostly women and many who did not speak English, leading them in aerobics, tai chi, crafts, walks and talent shows. I learned that the female spirit transcends culture, language and most of all age. Furthermore, I realized that in the future I wanted to study women's health and empowerment, and to ultimately contribute to understanding holistic health and the connections between mind, body and spirit.

My interest in health, wellness and the female spirit arose initially from my life as an athlete, spanning as early as the t-ball years and as late as my current participation in sports. In grade six, I started joining my school sports teams, and in middle school participated in nearly every sport including, volleyball, soccer, swimming, cross-country, track and field, basketball, gymnastics, and softball in the summers. This participation continued through my high school years, in which I was a dedicated member of the basketball, volleyball, water polo and soccer teams. Being an athlete, I strongly believe that there is nothing in this world like the thrill of competition, to be completely in-sync with teammates and to feel the rush of adrenaline that creates a sense of invincibility. At that moment, you can do or accomplish anything in this world, regardless of pain or exhaustion. There is no doubt in my mind that there are physical, psychological and spiritual benefits of exercise and competition.

As a Masters student in the discipline of Community Psychology, I study at Wilfrid Laurier University in Waterloo, Ontario. In my academic, work and personal life I value health, well-being, holism, caring and compassion, social justice, community, social support and diversity; ideally, a balance of these values. I have a Bachelor of Science degree in Biology & Psychology and have conducted animal research in both the lab and the field. I feel that theoretically and practically, there are different principles that apply to human research. I have more experience studying and conducting quantitative research, although I believe in the value of both quantitative and qualitative methods.

Epistemologically, my beliefs fit well with the critical paradigm in which objective, numerically measurable data and subjective, experiential data are both valid and subsequently applied in the pursuit of human liberation and social justice. Therefore, my research is value-laden and situated in a moral and political position. I must consider the relationship between myself and those I research. In general, methodology in the critical paradigm includes dialogue and dialectical processes and is reflexive and transformative. Methods in the present study are not directly characteristic of the critical paradigm, although the underlying values of the research are fairly representative.

In order to study the psychosocial experience of cancer, I will use the survey that was given to breast cancer survivors in the Ontario Breast Cancer Survivor Dragon Boat Study. In terms of the critical paradigm, I will use quantitative methods in this study as the most efficient means to give voice to as many women with breast cancer as possible. I believe in the validity of the survey and that it speaks to the issues most relevant to breast cancer survivors because they participated in the selection of the survey tool. In my opinion, the survey is sufficiently detailed and informative to describe the psychosocial experience of women with breast cancer.

The study is rooted in values of health, well-being, caring, compassion, holism, community, social support and social justice, which is meaningful to me because it is an extension of my personal values. Given my interests, personal experiences and beliefs, studying the holistic health of breast cancer survivors is an ideal fit for me. It will give me the opportunity to understand more about the breast cancer experience, specifically physical, psychological and spiritual aspects that contribute to the quality of life of survivors.

BACKGROUND RESEARCH

Community Perspective

Holistic Health

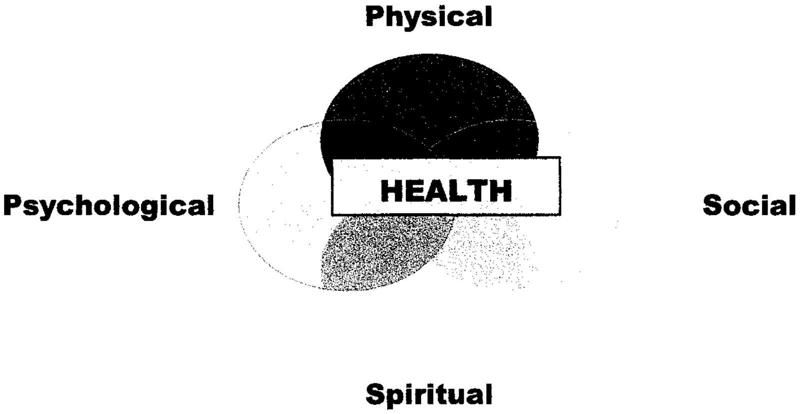


Figure 1. The Holistic Perspective of Health

Health is more than the absence of illness; it encompasses social, physical, psychological and spiritual aspects (World Health Organization, 1946). Therefore, it is important to consider the psychological and social experience of health and illness, specifically breast cancer, in order to promote well-being in women. As well as health, survivorship may also be defined from a holistic perspective, in order to understand that it is more than the successful treatment of the disease and the healing of the physical body. The National Cancer Institute defines survivorship as "covering the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It includes issues related to the ability to get health care and follow up treatment, late effects of treatment, second cancers, and quality of life". According to this definition, survivorship includes holistic elements, corresponding with the impact of breast cancer on the various aspects of health. A traditional medical model focus of breast cancer research emphasizes the individual experience of the woman, her lifestyle behaviours, post-treatment outcomes and ability to cope. A more inclusive model of well-being in breast cancer survivors may promote well-being through feelings of self-confidence and purpose, healthy family and social relationships, and a positive sense of community. Community Psychology (CP) emphasizes this value of holism in considering well-being at the multiple levels of analysis of the ecological model to create inclusive and holistic models of health.

Ecological Model

In 1979, Bronfenbrenner proposed a theory of development-in-context, which considers the broader perspective of phenomena at multiple levels of analysis, including micro, meso, exo and macro. CP has adopted this theory as central to its study by considering the ecological context of experience, which is based on the individual (micro), personal (meso, close relationships, family and friends), relational (exo, work, school, or small social settings) and community (macro, participation in larger community, society) levels (Nelson & Prilleltensky, 2005). To study breast cancer from a community perspective, it is necessary to examine the experience of survivors at each ecological level, and the interaction between levels. For example, individually, women diagnosed with breast cancer may have an internal struggle in dealing with the implications of cancer, such as losing her breasts and the possibility of death. On a personal level, her family and friends may or may not be there to provide social support, creating potential for isolation. As a result of breast cancer treatment, a woman may take time off work or other commitments, which may have implications for personal relationships and take away from individual goals. In the bigger picture, a woman with breast cancer may feel isolated from her community or there could be social constructions of breast cancer and femininity that affect her.

Community Context

Community Health Psychology is an emerging field that incorporates community values into the study of health psychology. Table 1.1 (Murray et al., 2004) illustrates the assumptions and values that depict a Community Health Psychology.

Table 1. Assumptions and Practices of Community Health Psychology

Assumptions and Practices	Community Health Psychology
Levels of Analysis	Ecological (micro, meso, macro)
Problem Definition	Problems are reframed in terms of social context and cultural diversity
Timing of Intervention	Prevention (early)
Focus of Intervention	Competence / strengths
Goals of Intervention	Promotion of competence and well-being
Type of Intervention	Self-help / community development / social action
Role of "Client"	Active participant who exercises choice and self direction
Role of "Professional"	Resource collaborator (scholar – activist)
Type of Research	Participatory action research based on critical and constructivist assumptions
Ethics	Emphasis on social ethics, emancipatory values and social change

Interdisciplinary Ties	Critical sociology, health sciences, philosophy, social work, political science, planning and geography

Source: Adapted from Prilleltensky & Nelson (1997)

The discipline focuses on the study of health and illness from a community perspective, in which strength, competence and well-being are promoted through research of contextualized social problems in the pursuit of social change. Community Health Psychology calls for action at the community level to develop healthy and supportive community contexts (Campbell & Murray, 2004).

A community can be defined as a locality, as in those people living in a particular geographic area, or can be relational in nature. In the latter, a community is joined by qualities of human interaction and social ties that bring a group together (Heller, 1989). A sense of community refers to the extent to which individuals feel membership, influence, integration and the fulfillment of needs and shared emotional connection, in a group (McMillan & Chavis, 1986), and is a valued indicator of quality of community life (Perkins & Long, 2002). In a relational community, group members who share a common history and common experiences, and who develop emotional connections and a common destiny ultimately develop a sense of community (McMillan & Chavis, 1986). Breast cancer survivors share an experience that few can relate to. When united by a common goal, a relational community of breast cancer survivors may have an increased potential to develop a sense of community, through the life-altering event that ties them together. Building on this concept may increase post-treatment options available to breast cancer survivors that would promote a process of holistic healing.

Women's Health & Empowerment

A common experience of women with breast cancer is feeling a loss of control and power over their body in response to diagnosis and treatment (Kinney et al., 2003). Surviving, recovering and finally healing require a woman to draw on many resources, both externally and within herself. Due to the disempowering nature of the breast cancer experience, empowerment both physically and psychologically should be a primary outcome of post-treatment interventions. Physically, empowerment would involve feeling strong and able, specifically in the upper body, which could be weak due to treatment. To feel psychologically empowered, women with breast cancer need to build self-esteem and confidence with respect to body image, to gain a sense of control over life and to feel a sense of purpose, meaning and personal accomplishment. Physical and psychosocial interventions designed for women with breast cancer should facilitate empowerment in order to promote well-being. Overall, studying women's experience of breast cancer in the context of community psychology promotes a holistic understanding of health in breast cancer survivors.

Quality of Life and Breast Cancer

Quality of life (QOL) is a holistic term that is used to measure satisfaction with four domains, physical, social, psychological and spiritual aspects of life. It has been studied extensively in breast cancer research to determine the short and long-term impacts of surviving the disease. Throughout the breast cancer experience, diagnosis, treatment, recovery and possible recurrence have significant physical, psychosocial and spiritual impacts on the quality of life of survivors.

Diagnosis

The point of diagnosis of breast cancer is commonly described as a “crisis”, through which most women experience shock and bewilderment, followed by fear, dread and devastation (Lethborg et al., 2000). A sudden realization of mortality also elicits uncertainty, as women face the possibility of multiple physical and social losses (Arman & Rehnsfeldt, 2003). At this point, women may feel that all significant aspects of their lives are challenged, as they face important life-altering decisions (Loveys & Klaich, 1991). In a study of the early adjustment to breast cancer, women reported higher psychiatric morbidity, which includes anxiety and depression among other quality of life issues, during the time prior to diagnosis, rather than after a definitive diagnosis of breast cancer had been made (Nosarti et al., 2002). Support from family and friends is critical at this moment. According to findings from a study of women coping with a diagnosis of breast cancer, having a higher perception of poor family functioning led to higher scores of helplessness and hopelessness on the Mental Adjustment to Cancer (MAC) Scale (Inoue et al., 2003). This indicates that dealing with a diagnosis of breast cancer is a particularly difficult time for women. Furthermore, communication and social support are significant factors that promote better adjustment to cancer at the time of diagnosis.

Stage of Disease at Diagnosis

Stage of disease at diagnosis has significant implications for women, considering that the overall 5-year survival rates after surgical treatment for breast cancer are dependent on stage. For those diagnosed at Stage I, the survival rate ranges between 84 – 93%, Stage II approximately 75%, Stage III approximately 50% and at Stage IV only 18% of women survive breast cancer after surgery (Taucher & Jakesz, 2004). A greater burden of disease, measured by stage at diagnosis, was able to predict symptoms associated with post-traumatic stress disorder (Amir & Romati, 2001; Andrykowski & Cordova, 1998). These findings warrant further investigation into the effect of stage of disease at diagnosis on post-traumatic distress and the quality of life of breast cancer survivors.

Breast Cancer Experience

The experience and treatment of breast cancer has an impact beyond physical health, with psychosocial side effects that often affect emotional well-being (Kornblith et al., 2003). In a critical review of literature concerning the topic, Glanz & Lerman (1992) discussed a characteristic set of emotional reactions in women with breast cancer, which include anxiety, depression, anger, guilt, fear and repression, psychological distress and persistent fears of recurrence. Furthermore, they explain how treatment such as surgery, radiation and chemotherapy often have disruptive side effects such as, fatigue, breast soreness, nausea, vomiting, hair loss, weight gain, nervousness, irritability and emotional distress. Body changes associated with treatment cause some women to struggle with decreased self-esteem, loss of sense of control, poor body image and decreased femininity (Mustian et al., 2002). In a study with older adult cancer survivors, 25% displayed evidence of clinical levels of depression (Deimling et al., 2002). The diagnosis, experience and treatment of breast cancer reflect significant psychosocial issues for survivors.

An American qualitative study investigating the breast cancer experience of women from diverse backgrounds, including African-American, Asian, Latina and Caucasian, emphasized a characteristic set of concerns across all groups (Ashing-Gawa et al., 2004). These included worries about overall health, moderate physical concerns, cancer recurrence or metastases, worry about children and burdening the family, body image and sexual health concerns. Some additional challenges voiced by the women were a lack of knowledge about breast cancer, medical care issues related to insurance and cost and time spent with physicians. Cultural concerns were raised regarding the sensitivity of providers, language barriers, factors related to beliefs about illness, gender role and family obligations. Spiritual beliefs and practices were central to coping, particularly with women of colour.

Treatment

Modality of treatment also makes a difference with regards to psychosocial adjustment for breast cancer survivors. After a diagnosis of breast cancer, a woman may have several options for treatment. Surgically, a woman may undergo a lumpectomy or partial mastectomy (breast conserving surgery), mastectomy, or bilateral mastectomy. Adjuvant treatment may involve radiation therapy or chemotherapy. Several studies have been conducted to determine differences in psychosocial functioning due to treatment with varying results. In research comparing quality of life following surgery, women who had undergone breast conserving surgery scored higher on issues associated with body image than those who had a mastectomy followed by reconstructive surgery (Janz et al., 2005). However, in a study of breast cancer survivors at least five years after surgery, women who had breast conserving surgery had an increase in psychological distress after time, while the level of psychological distress decreased in survivors who had a mastectomy (Cohen et al., 2000). Furthermore, women who were actively involved in choosing their own treatment had a better body image pre-operatively and were less likely to be depressed in the long-term (Deadman et al., 2001). A deeper analysis into issues associated with receiving the various treatments would promote a better understanding of post-treatment psychosocial functioning.

Lymphedema

Lymphedema, a painful and chronic swelling of the arm, is a common side effect of treatment for breast cancer (Harris & Niesen-Vertommen, 2000). Studies indicate that anywhere from 6% to 30% of women experience lymphedema secondary to breast cancer treatment (Petrek & Heelan, 1998). Although the majority of breast cancer survivors will not be affected by lymphedema, for the women that experience this condition, functioning can severely deteriorate (Radina & Armer, 2001; Velanovich & Szymanski, 1999). In a study of 101 breast cancer patients, researchers found that 8.3% of women were suffering from lymphedema and that those women had significantly diminished physical and mental quality of life (Velanovich & Szymanski, 1999). Furthermore, lymphedema affects both women and their families, since they are no longer able to perform many daily tasks without the help of others, which leads to a change in family functioning and relationships (Radina & Armer, 2001). Research also focuses on the management and treatment for lymphedema, which commonly includes complex decongestive physiotherapy (CDP) (Cheville et al., 2003). CDP includes bandaging, manual drainage, exercise and skin care in order to relieve the painful swelling. Previous studies emphasize the deteriorating effects that lymphedema has for women that experience it after breast cancer surgery.

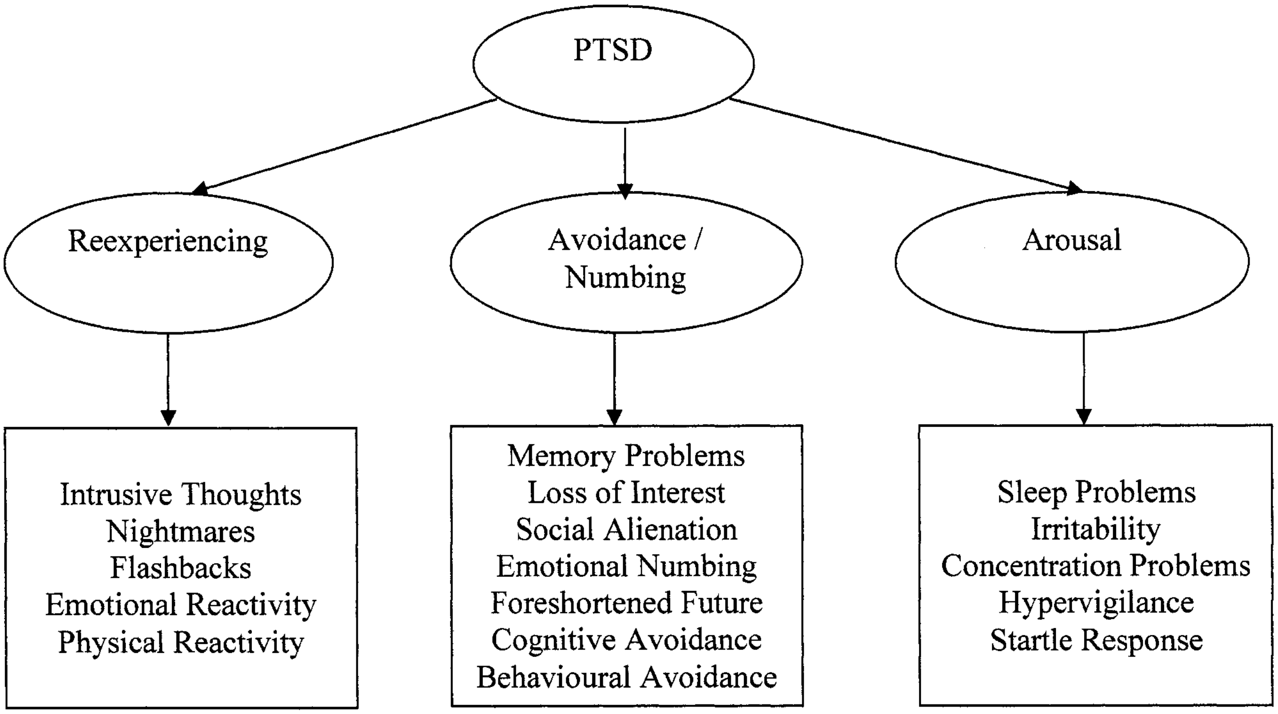
Recurrence

Recurrence of breast cancer is an ongoing fear of survivors, as each are prescribed to "wait five years" before being given a clean bill of health (Ashing-Gawa et al., 2004). In a study with 179 breast cancer survivors, those women who had experienced a serious illness within the last year, such as a recurrence, reported disturbingly high levels of psychological distress (Kornblith et al., 2001). Women with breast cancer who have experienced a recurrence have scored lower on scales of health-related quality of life, particularly on those domains of cancer-specific stress, than women who had remained disease-free (Oh et al., 2004). Within a month after recurrence, women with breast cancer reported significant impairments with respect to physical, functional, and emotional well-being (Northouse et al., 2002). Furthermore, self-efficacy, social support and family hardiness have a positive effect on quality of life, while symptom distress, hopelessness and negative appraisal of illness had a negative impact. The negative psychosocial issues associated with recurrence of breast cancer reflect significant post-treatment needs for survivors.

Post-Traumatic Stress Disorder

As with most life-threatening illnesses, women with breast cancer are a population at-risk for developing symptoms associated with post-traumatic stress disorder (PTSD). As is illustrated in Figure 2, the main symptoms of PTSD are the re-experiencing of the tragic, life-threatening event, avoidance or numbing of dealing with issues associated with the experience, and arousal, which includes a disruption to normal functioning through sleep problems, irritability or lack of concentration.

Figure 2. Post-Traumatic Stress Disorder Symptoms



Source: Cordova et al. (2000)

In a longitudinal study of breast cancer survivors 20 years after chemotherapy treatment, the results indicated that 5% of the survivors still suffered from clinical distress, 15% reported two or more PTSD symptoms that were moderate to extremely bothersome, and 29% reported sexual problems attributed to their experience with cancer (Kornblith et al., 2003). In research involving 133 breast cancer survivors and 64 daughters of breast cancer survivors, 21% of women with breast cancer reported symptoms consistent with PTSD, as well as 13% of their daughters (Boyer et al., 2002). This indicates that a high number of breast cancer survivors, 1 in 5, are affected by PTSD. A number of daughters, who breast cancer survivors may depend on to provide emotional support, were also prone to experiencing post-traumatic distress. Clearly, PTSD is a serious and significant concern for women with breast cancer.

Age and Coping with Breast Cancer

A focus of recent studies has been how age affects a woman's ability to cope with the diagnosis and experience of breast cancer (Wong-Kim & Bloom, 2005; Thewes et al., 2004; Maly et al., 2005). In a qualitative study of the psychosocial needs of breast cancer survivors, Thewes et al. (2004) found both older and younger women had a need for practical support from family and friends, professional support to learn coping strategies, and informational support regarding potential physical and emotional consequences after treatment ends. Younger women reported an increasing need for emotional support from counselors, informal, holistic and activity-based supports for survivors, and more age-appropriate support groups that will address the diverse needs of pre-menopausal women. In a study of women who were newly diagnosed with breast cancer, younger women who experienced side effects of treatment and had low self-esteem and less emotional support were more likely to suffer from depressive symptoms than their older counterparts in similar situations (Wong-Kim & Bloom, 2005). Researchers of a study of over 1000 women with breast cancer support this evidence with respect to age and breast cancer, finding that women who are younger at diagnosis (those 40 years-old and under) experience more significant functional declines (Kroenke et al., 2004). On the other hand, there is also evidence to suggest that older women are more severely affected physically and mentally in the months that follow treatment and adjustment to life after breast cancer (Ganz et al., 2003). Both younger and older women have on-going needs throughout the experience of breast cancer that may be related to age, which has implications for services providing pre- and post-treatment support.

Spirituality

As well as the physical, psychological and emotional aspects of the breast cancer experience, there is a spiritual component often associated with facing the disease (Kinney et al., 2003). For many women, the experience of breast cancer was a critical event that reframed their focus from taking care of others to embrace their own life (Mitchell & Nielson, 2002). When the mortal body is threatened, perspectives change and living suddenly holds more purpose. Wellness is not only physical, but encompasses psychological, social and spiritual values. Table 2 illustrates a model for understanding typical stages of transition for women adjusting to life with breast cancer.

Table 2. Life Levels of Reported Changes after Transition to Breast Cancer

Level of Life	Sign
Sudden existential disruption	Shock, trauma, uncertainty; multiple losses; sudden awareness of mortality; disruption and interruption of earlier beliefs; disintegration
Actions	Changes in daily routines; health habits, such as diet exercise, and relaxation; slowing down; alternative treatment; seeking support and information from others; changed priorities; focusing more on self
Values and cognitions	Facing reality, expanded consciousness, changes in self, increased openness to the environment, appreciation of life, full responsibility, transforming of the cancer from threat to benefit
Spirituality / existence	Facing suffering and death, finding meaning in the experience, closeness in relationships, acceptance of circumstances of life and death, religiousness and spiritual thoughts

Source: Arman & Rehnsfeldt (2003)

This model of transitional stages was derived from a literature review of research with the goal of understanding women's experience of breast cancer (Arman & Rehnsfeldt, 2003). Long, unstructured interviews conducted with women who had received a cancer diagnosis, which focused on a holistic perspective of the women's social world and concept of self, resulted in similar findings with respect to the cancer experience (Clarke, 1985). Feelings of shock and uncertainty led to a change in perception of time, which influenced daily routines. The transition phase was dominated by a loss of control, denial and a distrust of the body, which led to a change in self-identity, a re-examination of life, and interpretations of meaning and purpose. Given the spiritual aspects of the acceptance process, interventions that involve a spiritual component may provide increased potential for healing.

In research involving a holistic self-empowerment program for breast cancer survivors, Kinney et al. (2003) describe facing a serious illness as a "soul event" that may encourage women to pay more attention to existential concerns, such as finding one's meaning and purpose in life. The program introduced multiple strategies for creating balance among mental, emotional, spiritual and physical health. It resulted in reduced distress, improved quality of life, a deeper sense of meaning in life and a greater sense of perceived wellness among the women participating in the study. In a study of 142 patients diagnosed with breast cancer, researchers found that spiritual well-being (existentialism, purpose and meaning) was positively correlated with quality of life and the fighting spirit adjustment style, measured by the Mental Adjustment to Cancer (MAC) scale (Cotton et al., 1999). In phenomenological research with 15 Taiwanese women with breast cancer, four themes emerged with respect to transcendence: giving meaning to suffering, liberating a clinging nature (letting go of grasping onto the world), opening to life and death, and healing with compassion (balance, wholeness and harmony allowed them to generate love towards others) (Chiu, 2000). Based on a few studies, evidence suggests that spirituality is a significant aspect of the healing process in women with breast cancer.

Post-Treatment Options

Breast Cancer Support Groups

Beyond physical treatment for breast cancer, there are limited options for women needing extra support to cope with the experience. Breast cancer support groups have been studied and associated with both positive and negative outcomes (Gray et al., 1997). Through qualitative interviews with women participating in breast cancer self-help groups, Gray et al. (1997) found that feeling understood and sharing experiences, hope and laughter with other breast cancer survivors were positive aspects of support groups. On the other hand, dealing with deaths of group members and balancing competing goals of the group were problems identified by women in the study. In an intervention designed to determine the benefits of support groups for women diagnosed with early stage breast cancer, two groups were created: an educational group and a peer emotional support group (Helgeson, Cohen, Schulz & Yasko, 1999). The educational group facilitated better adjustment to breast cancer by providing information to enhance control over the illness experience, while no benefits were observed for women in the emotional support groups. In other research studies, natural, rather than artificially created, environments in which individuals are integrated and actively involved that are socially supportive are a strong predictor of better health outcomes (Cohen, 2004).

Social Support

An important aspect of a positive community environment is social support, which refers to a social network's ability to provide resources that will enhance an individual's coping skills (Cohen, 2004). This definition reflects a functional approach to the concept of social support, in which one's social network and relationships serve important support functions (Orford, 1992). There are five main functions of social support, which are as follows: *Instrumental*: material or tangible support or aid, *Emotional*: expressive, or caring support, *Affirmation*: esteem or value support, acknowledgement, *Informational*: advice, guidance or cognitive support, and *Companionship*: support through positive social interaction. This concept can also work at multiple levels of analysis, meaning that an individual, relationship, or community can all be described as socially supportive.

Several hypotheses have also been proposed to describe the impact of social support on an individual's emotional state and ability to adjust. In the *Additive Model*, social support and stressful life events both directly influence an individual's adjustment, regardless of the magnitude of the other (Kornblith et al., 2001). On the other hand, the *Buffering Hypothesis* states that stressful events occurring in the presence of social support should produce less distress than if they occur in its absence (Gore, 1981). In a study of 179 breast cancer survivors, Kornblith et al. (2001) found support for the additive model. Both social support and stressful life events affected emotional states of the survivors independently of each other. Furthermore, the women had to have a high level of social support for it to significantly influence their adjustment to stressful life events.

The impact of social support on the adjustment of survivors has been reviewed fairly extensively in the breast cancer literature. Functional social support, which includes feeling cared for and loved and being able to express feelings and discussing fears, can be a predictor of health outcomes (Trunzo & Pinto, 2003). There is also evidence that friendship relationships often lead to heightened mental, physiological and sociological well-being (Knickmeyer et al., 2002), which could benefit breast cancer survivors. In women with metastatic breast cancer that have undergone significant life stress, having more people in one's social support network was associated with less mood disturbance (Koopman et al., 1998).

Breast Cancer Support & Advocacy

After surviving breast cancer, many women make a decision to share that experience with others by volunteering in peer support groups and help-lines to assist others in coping with the disease (Anglin, 1997). There are also a variety of events held each year to raise funds for breast cancer research, support and advocacy, such as fundraising runs and walks.

Several researchers have investigated the psychosocial benefits of giving support to others (Brown et al., 2003; Graff, 1991; Kielburger & Kielburger, 2004). In a study of older married women, investigators compared the effects of providing and receiving social support on longevity (Brown et al., 2003). They found that women who reported providing instrumental support to family and friends and emotional support to their spouse significantly reduced their mortality. In contrast, receiving support had no effect on longevity. Findings from a study of volunteering and health in Ontario also confirm the benefits of being a supporter (Graff, 1991). Researchers conducted focus group sessions with volunteers in five Ontarian communities and found that volunteering facilitates empowerment, offers new perspectives on personal problems, creates feelings of being needed and productive and provides social contact that helps with rehabilitation, including providing physical benefits such as lower blood pressure and a stronger immune system. Graff (1991) also identified target populations, such as seniors, youth, and other vulnerable groups, that can particularly benefit from volunteering support to others. In the book “Me to We: Turning Self-Help on Its Head”, Kielburger and Kielburger (2004) tell people’s stories of helping others and how the benefits in relationships, health, business and self-esteem can lead to a better quality of life. Volunteers describe how helping others transformed their lives, fulfilled their search for “something more” and enhanced their physical and psychological well-being in the process.

Exercise

There are several studies that indicate that exercise has the potential for the holistic healing of breast cancer survivors (Mustian et al., 2002; Courneya & Friedenreich, 1999). Physical exercise can have a positive effect on quality of life following cancer diagnosis by improving physical and functional abilities, building capacity and muscular strength and decreasing nausea and fatigue (Courneya & Friedenreich, 1999). Exercising also has an impact on maintaining physical well-being for long-term survivors (Kendall et al., 2005). Findings from another study of exercise participation after diagnosis of breast cancer confirmed these results; exercise led to increased physical functioning, although exercise participation was below recommended levels (Pinto et al., 2002). This indicates that there are physical benefits of exercise for women with breast cancer, given that women have the motivation to establish a regular routine that includes exercise.

Physical exercise can also be beneficial for psychological well-being. In a literature review, Mustian et al. (2002) discuss the ability of exercise to shift the battle away from fear of living to living fully by enhancing perceptions of capabilities and control and empowering women to create their own lives. Exercise can also improve emotional well-being through mood states, self esteem and quality of life (Courneya & Friedenreich, 1999). A 12-week tai chi program, which integrates moderate exercise with relaxing movements and poses, improved health-related quality of life and self-esteem in breast cancer survivors (Mustian et al., 2004). Overall, exercise can holistically benefit breast cancer survivors by increasing both physical and psychological functioning.

Breast Cancer Survivor Dragon Boating

Dragon boating is a team sport involving the participation of twenty people paddling in unison to move the boat forward. It is a physically demanding and vigorous sport, focusing on upper body exercise, which has a special significance for women overcoming breast cancer. Traditionally, survivors have been told to avoid strenuous upper body training due to the risk of lymphedema. In 1996, a sports medicine physician at the University of British Columbia challenged this assumption by training women who had been treated for breast cancer in a team sport requiring strenuous upper body exercise and monitoring each woman for lymphedema (McKenzie, 1998). The findings indicated that vigorous, repetitive or excessive upper body exercise did not increase the risk of lymphedema (Harris & Nieson-Vertommen, 2000). Soon-after the first breast cancer survivor dragon boat team emerged, in Vancouver, British Columbia (McKenzie, 1998). Currently across Canada and internationally, breast cancer survivors are forming dragon boat teams and creating a tradition that appears to have the potential for holistic healing after the experience of breast cancer (Mitchell & Nielson, 2002).

In essence, dragon boating transforms these women into athletes, pushing their physical boundaries to paddle their team towards victory. In a preliminary study evaluating the psychosocial impact of dragon boating on breast cancer survivors, Mitchell and Nielson (2002) found promising results. Survivor dragon boating provided the benefits of a common bond between survivors, camaraderie, reclaiming control of their lives, embracing life, facing their disease, and having fun (Mitchell & Nielson, 2002).

The Ontario Breast Cancer Survivor Dragon Boat Study

The Ontario Breast Cancer Dragon Boat Study (OBCS DBS) was developed to study the psychosocial impact of dragon boating on breast cancer survivors throughout Ontario (Mitchell & Nielson, 2002). To begin the study, over 60 qualitative interviews gave the breast cancer survivor dragon boaters a voice in the research, and contributed to the development of a survey that speaks to the issues most relevant to breast cancer survivors.

Community Advisory Group & Breast Cancer Survivor Participation

Since the beginning of the three-year study, the Community Advisory Group (CAG), comprised of 5 survivor dragon boaters from three Ontario teams, has been actively involved in all aspects of the research, including survey development, participant recruitment, community outreach, funding proposal development and conference and community presentations. Members of the advisory group and their lived experience as breast cancer survivor dragon boaters were a resource to the research team processes and decision-making and acted as gatekeepers to provide access to the dragon boating communities.

Survivor dragon boaters also participated in the development of a survey tool that would measure the psychosocial impact of dragon boating on breast cancer survivors. 13 survivor dragon boaters from 11 communities in Ontario participated in a day-long workshop to create a survey tool that would reflect the input and experience of the women. Four instruments, selected for their relevance, clarity and comfort among the study population, were chosen to be included in the quantitative survey. The selected scales were: (i) Quality of Life (Ferrell, 1995), (ii) Mental Adjustment to Cancer, MAC Scale (Watson, 1988), (iii) Post-Traumatic Stress Disorder, PTSD Checklist (Weathers, 1991) and (iv) Self-Transcendence Scale, STS (Reed, 1989). A demographic questionnaire that was generated by the research team was also in the survey. These instruments were approved for use by all women at the workshop and received a majority vote.

Key Findings from the Study

The qualitative interviews and quantitative results indicate that breast cancer dragon boating has potential benefits for the holistic health of survivors. By conducting over 60 qualitative interviews with survivor dragon boaters, the researchers found that dragon boating was a vehicle to promote holistic health and to bring the private experience of breast cancer into the public forum. Women were attracted to the positive and symbolic nature of the sport and the camaraderie of other breast cancer survivors, among other aspects. The following themes were expressed by breast cancer survivors as benefits of dragon boating: belonging, uplifting, living joyfully, transcendence, reframing reoccurrence, accomplishment and reclaiming of the body (Mitchell et al., 2005).

After analyzing the quantitative survey, researchers also found some statistically significant findings important for breast cancer survivors in general, as well as breast cancer dragon boaters. In this study with over 400 breast cancer dragon boaters, those who had either radiation treatment or a bilateral mastectomy reported a higher degree of trauma and stress

(Mitchell, Gebotys, Fitch & Franseen, 2005). The researchers also identified that their sample had a greater burden of disease, with 17% of participants being diagnosed with Stage III or Stage IV, than other published studies of breast cancer and PTSD (Sharih, 2005; Andrykowski & Cordova, 1998; Andrykowski et al., 2000; Cordova et al., 1995). Despite this finding, the breast cancer dragon boaters had a lower degree of trauma and stress than other reported breast cancer populations. Dr. MacKenzie's (1998) finding that strenuous upper body exercise did not cause lymphedema was also statistically confirmed with the breast cancer dragon boat population. Furthermore, women who trained with the team to a higher degree had a lower rate of breast cancer recurrence than other women who trained less frequently (Mitchell, Gebotys, Fitch & Franseen, 2005). Further research is required to determine the implications that breast cancer dragon boating has for recurrence and survivorship.

The Present Study

In the present study, the survey developed with the help breast cancer survivors in the Ontario Breast Cancer Survivor Dragon Boat Study was replicated in a population that does not dragon boat to further explore holistic health issues for breast cancer survivors. The goal was to promote understanding regarding women's experience of breast cancer with respect to post-treatment quality of life issues. It also explored social and demographic factors that had the potential to significantly impact the holistic health of survivors, such as education, work status, type of treatment, and stage of the disease.

This research is novel for several reasons: (i) breast cancer survivors participated in developing the survey, ensuring that it addresses significant concerns of the study population, (ii) it has a broad focus on holistic health, including all aspects of quality of life, as opposed to the limited focus of much of the current breast cancer research, and (iii) the study examined these issues at individual, personal, relational and community levels of analysis.

METHODOLOGY:

Assumptions Underlying the Research

This research is designed to study the holistic health of breast cancer survivors. It is interpretive and works to uncover the psychosocial impact of the disease on women. An interpretive hermeneutical approach (Reason, 1988) is taken to address the fact that a positivistic, objective, value-free perspective is insufficient to increase understanding of the psychosocial experience of women who have battled breast cancer. In the study of human experience, such as breast cancer, subjectivity is of particular value, since it focuses on a particular aspect of the women's experience of the disease, which is known only by the women themselves. The research also works from the critical paradigm, which values women's experience to establish the potential to empower breast cancer survivors. In this respect, raising awareness to issues that significantly affect the holistic health of women with breast cancer may promote well-being in survivors. Ultimately, learning more about the psychosocial experience of surviving breast cancer may prioritize the improvement of post-treatment support for women.

Consistent with critical theory, the values of the researcher include caring, compassion, holism, health and well-being, social justice, diversity and community (Morrow & Brown, 1994). Qualitative methods are commonly used in critical research due to their participatory, empowering and meaningful nature. However, quantitative methods are valued, so long as they contribute to the goal of social justice. The use of a quantitative survey in this research enabled me to access the experience and responses of many more breast cancer survivors on the psychosocial impact of breast cancer than would be possible if I had conducted a strictly qualitative study. As a community psychology student, I am aware of the epistemological challenge to work with quantitative methods, which have traditionally been used in an 'objective' and value neutral manner, to study women's health experience. By developing research tools with a respect for subjectivity and engaging participants in the process, the validity and relevance of quantitative measures is increased, as well as the potential to provide statistical support for survivorship issues and advocacy. Therefore, I position myself as a researcher who values the use of both quantitative and qualitative methods to provide a more holistic understanding of experience with the added advocacy potential of the generalization of findings for social change.

RESEARCH QUESTIONS

- Do lifestyle choices, such as exercise participation, work status and social / political involvement, predict post-treatment quality of life for breast cancer survivors?

A linear regression analysis was conducted with exercise, work status and social political involvement as the independent variables and determined if breast cancer survivors who exercise, work or were involved in breast cancer support and advocacy have increased quality of life, on the subscales (physical, psychological, spiritual and social) and overall. Of the independent variables significantly affecting quality of life, positive coefficients indicate that an increase in exercise, different work statuses and/or involvement in breast cancer support and advocacy are correlated with an increase of quality of life.

- What is the relationship between social and demographic factors, such as age, marital status, living conditions, level of education and income and quality of life in breast cancer survivors?

A linear regression analysis was conducted, including measures of social support, participation in the work force, level of education, income, age and social / political involvement as independent variables, to determine the extent to which these variables are able to predict the four subscales of quality of life.

- Does type of treatment (i.e. type of surgery, radiation, chemotherapy etc.) and other variables associated with breast cancer history and health status predict post-treatment quality of life in breast cancer survivors?

A linear regression analysis was conducted with the treatment variables and breast cancer history and health status variables, such as stage at diagnosis, years since diagnosis, lymphedema and recurrence, determining the extent to which the proposed model can predict each domain of quality of life (physical, psychological, social and spiritual). The R^2 value in the Analysis of Variance (ANOVA) table determined the extent to which the variance in quality of life is explained by type of treatment.

An analysis including descriptive statistics measured the key socio-demographic variables, such as type of treatment, age, education, income, recurrence, social support, lymphedema, work status and participation in exercise. Cross-tabulations conducted between some of the key variables, determined if there are significant correlations between important factors. For example, cross-tabulations determined if there is a correlation between participation in physical activity and recurrence.

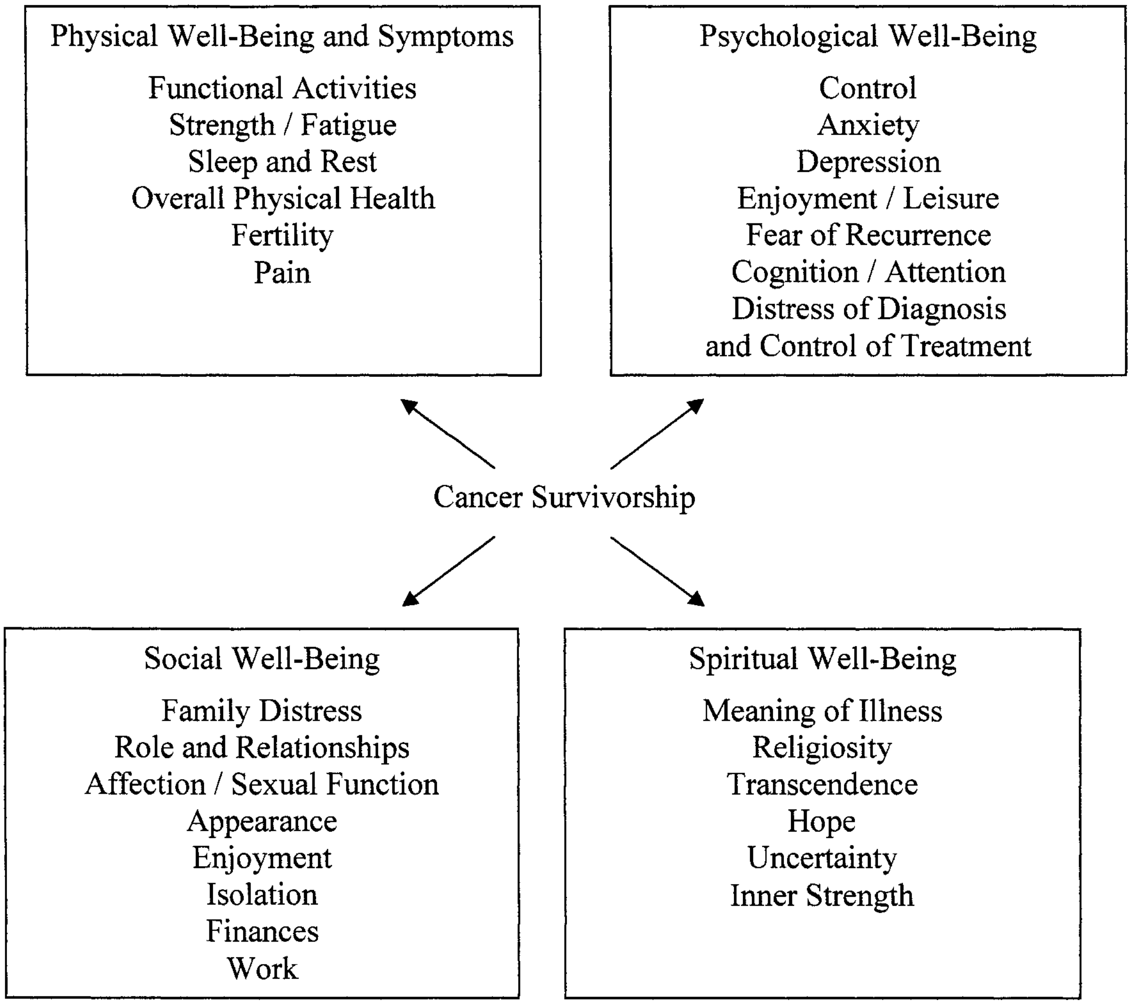
METHODS

The quantitative survey that was used in the study is based on the survey developed for use in the Ontario Breast Cancer Survivor Dragon Boat Study (Mitchell & Gebotys, 2005), in collaboration with breast cancer survivors. The survey consists of four measures of the psychosocial impact of breast cancer, including the Quality of Life Scale (Ferrell et al., 1995), the Mental Adjustment to Cancer Scale (Watson et al., 1996), the Post-Traumatic Stress Disoder Check List, Civilian Version (PCL-C) (Weathers et al., 1993) and the Self-Transcendecne Scale (Reed, 1987), as well as a demographic information sheet (See Appendix A). For the purposes of my master's thesis, I have chosen to analyze 3 of the 4 scales, omitting the Mental Adjustment to Cancer Scale.

Quality of Life Scale

The Quality of Life Scale (Breast Cancer Patient Version) developed by Ferrell et al. (1995) is a 46-item ordinal scale measuring the four domains of quality of life, including physical well-being, psychological well-being, social well-being and spiritual well-being (See Figure 2). The scale was developed through the City of Hope National Medical Center in California and was based on previous measures of quality of life and revised to incorporate specific issues for breast cancer survivors (Ferrell et al., 1995). The original study including the survey was conducted through a mail out to members of the National Coalition for Cancer Survivorship. The total number of participants was 686, 204 of which were breast cancer survivors.

Figure 3. Quality of Life Model Applied to Cancer Survivors



Source: Ferrell, Dow & Grant (1995)

Psychometric analysis, including reliability and validity, was performed on the 686 respondents. Test re-test and internal consistency measures of reliability were conducted with the surveys. To measure test re-test reliability, 70 randomly selected participants who completed the initial QOL survey repeated the tool two weeks later. The overall test re-test reliability was 0.89, with subscales of physical r =.88, psychological r =.88, social r =.81, spiritual r =.90 (Ferrell et al., 1995). Chronbach's Alpha measured the overall internal consistency of the scale to be 0.93. Subscale alphas ranged from r =.71 for spiritual well being, r =.77 for physical, r =.81 for social, and r =.89 for psychological. Validity was also measured in several ways. A panel of nurses with expertise in oncology assessed the content validity. In the second measure, stepwise regression was used to determine the factors most predictive of quality of life. 17 variables were found to be statistically significant and accounted for 91% of the variance in quality of life. Overall, Ferrell et al. (1995) demonstrated the Quality of Life Scale (Breast Cancer Patient Version) to be both reliable and valid.

Post-Traumatic Stress Disorder (PTSD) Checklist, Civilian Version (PCL-C)

The Post-Traumatic Stress Disorder (PTSD) Checklist, Civilian Version or PCL-C was developed by Weathers and his colleagues in 1993, and includes 17 questions that correspond to the DSM-IV diagnosis of PTSD. In this scale, respondents are asked how often they experienced each symptom of PTSD (See Figure 2) in the past month. The PCL-C has scored consistently high on measures of reliability and validity (Norris & Hamblen, 2004) and is used often in cancer research (Cordova et al., 2000; Andrykowski et al., 2000).

Self-Transcendence Scale

The Self-Transcendence Scale is a 15-item scale that broadly measures self-transcendence in intrapersonal, interpersonal and transpersonal experiences that indicate an expansion of personal boundaries, developed by Reed (1987). It has been widely used to study self-transcendence in several populations, such as depressed individuals (Ellerman & Reed, 2001), patients inflicted with HIV (Mellers et al., 1997), men with prostate cancer (Chin-A-Loy & Fernsler, 1998), as well as women with advanced breast cancer (Coward, 1991). Reliability, estimated by Cronbach's Alpha, has been found to range in between 0.80 and 0.88 (Coward, 1991).

Participants

Community Advisory Group

To provide guidance and input into the research, I formed a Community Advisory Group (CAG) consisting of breast cancer survivors. Participants for the CAG were recruited through the Knot-A-Breast survivor dragon boating team in Hamilton, Ontario. The Knot-A-Breast team was chosen for recruitment of the CAG for several reasons, including their accessibility to the researcher, their willingness to participate, and lastly due to their ineligibility, as dragon boaters, to complete surveys. After attending and even participating in several Knot-A-Breast team practices and getting to know some of the women, I sent out an email invitation via the team captain for women to participate in the CAG. Nine women from the team responded to the email, wishing to contribute to the research in some way. I decided on corresponding through email, since it was a convenient and easy way for the women to participate in the tasks at hand, especially since the dragon boating season was coming to an end. The role of the CAG was to provide input into the development of an open-ended question to be included in the survey, to help with the distribution of surveys and to possibly assist in the dissemination of the results of the study.

Several women in the Community Advisory Group contributed input into the clarity and relevance of the open-ended questions for breast cancer survivors. Many of the members helped to distribute the surveys to women they knew, support groups they attended, or other connections they had in the community. Members of the CAG that followed through with their participation received a small gift (a pink ribbon or symbolic ornament and a thank you card) for their time and participation in the research.

Recruitment & Sampling of Survey Participants

The goal was to have 100 breast cancer survivors fill out the survey. The participants were women, at least six months post-treatment, any age or race, were diagnosed at any stage of cancer and received any treatment type. Women with breast cancer were recruited to participate through the Juravinski Regional Cancer Centre in Hamilton, Ontario, a number of community cancer organizations, informal contacts and the Community Advisory Group members. Therefore, the study population includes a treatment centre / hospital sample and a community sample of participants. In October 2005, the Juravinski Regional Cancer Centre held a conference "Life after Breast Cancer" for survivors at which 500 people affected by breast cancer attended. The coordinators of the event were happy to include my survey (including the information letter and a self-addressed envelope with return postage) in the registration package, which was given to each person attending. Many other community organizations generously helped me reach women with breast cancer, including the Breast Cancer Support Services in Burlington, Willow support services in Toronto, Wellspring Halton-Peel, Hopespring of the Waterloo Region and the Cancer Assistance Program in Hamilton. Otherwise, informal contacts such as family and friends helped to put me in contact with a number of eligible women who completed and returned the survey.

Ethical Issues & Confidentiality

An ethics review was completed and approved by the Ethics Review Committee at Wilfrid Laurier University (WLU), prior to beginning the study. Throughout the research, all guidelines set by the Tri-Council Policy Statement for the "Ethical Conduct for Research Involving Humans" were consistently followed. The research and work with breast cancer survivors was approached with sensitivity and respect for the difficult issues they may have faced throughout the breast cancer experience.

Prior to participating in the research, all women were given an information letter, which outlined the goals and procedures involved in the study, all risks and benefits, issues related to confidentiality, contact information and plans for dissemination of the results. It also informed them that by completing and returning the survey, they are consenting to participate in the study. Informed consent forms were not required for the survey participants, due to the plan for distribution. Because of strict confidentiality guidelines of most organizations that helped with recruitment, many of the surveys were distributed to women anonymously. Therefore, rather than maintaining confidentiality, the participants completing the survey remained anonymous. Breast cancer survivors who were recruited to participate in the Community Advisory Group reviewed an informed consent letter via email and checked the appropriate box to indicate consent prior to participating in the study. These consent forms and other material that contains participants' names or any other identifying information will be kept in a secure location and eventually destroyed.

Survey participants were asked to complete all four scales, the demographic information sheet, and two open-ended questions. The Quality of Life Scales, the PCL-C and the Self-Transcendence Scale were analyzed for the purpose of this thesis, omitting the MAC Scale. The data from the open-ended question will be analyzed to submit a paper based on the things that breast cancer survivors feel can contribute to the well-being of women after breast cancer. The data collected in this study may be used in a broader research context by my thesis supervisor, Dr. Terry Mitchell, to inform other work with breast cancer survivors. Therefore, although all of the data was not be used in the current study, it will serve other purposes.

RESULTS

Statistical Analysis & Cross-Sectional Data

It is important to note while interpreting the results and discussion of this study that this research is working with correlational data, which reflects only a cross-section of the population of breast cancer survivors. The data is only correlational due to the fact that it is impossible to control all of the factors and interactions of factors that could be playing a role in predicting quality of life in breast cancer survivors. Therefore, the results should be interpreted with caution; it cannot be concluded that any of the factors are causally related to the dependent variables. There are also limitations related to the fact that the research design did not incorporate a randomized probability sample that would be representative of the breast cancer population in Ontario in terms of age, race, income and education, among other demographic characteristics. Traditionally, it is not a convention of psychology to utilize randomized probably samples, although this sampling technique is a priority to related disciplines that may also benefit from this research, such as sociology and medicine. Despite these limitations, this study of 101 women who completed and returned the survey is a strong sample of the breast cancer population in Ontario and can offer important findings with respect to holistic well-being throughout the years of survivorship.

Demographics

Characteristics of Participants

101 women completed and returned the survey package, including demographic data. The following table illustrates socio-demographic characteristics of the participants.

Table 3. Demographic Characteristics of Participants (N = 101).

AGE	Mean Age: 58 Range: 37 - 85
COUNTRY OF BIRTH	78 % Born in Canada 6 % Born in England 6 % Born in the Netherlands 3 % Born in United States
RELATIONSHIP STATUS	79 % Married or Living with a Partner 9 % Divorced 6 % Single 6 % Widowed
EDUCATION	11 % Less than High School 17 % High School Graduate 6 % Trades Certificate or Diploma 33 % College Certificate or Diploma 33 % University Certificate, Diploma or Degree

EMPLOYMENT STATUS	31 % Employed Full-Time 20 % Employed Part-Time 12 % Volunteer in the Community
ANNUAL GROSS FAMILY INCOME	14 % Less than $30,000 16 % $30,000 - $45,000 8 % $46,000 - $60,000 14 % $61,000 - $70,000 40 % More than $70,000
SOCIAL & POLITICAL INVOLVEMENT	27 % Not at all Involved 47 % Occasionally Involved 26 % Significantly Involved

* The N for some variables is slightly less than 101 because of missing data, consequently the sum of percentages is not always 100% .

The mean age of the women was 58 years-old, although participants ranged in age between 37 and 85. Majority of the participants (80%) were born in Canada, with 6% of the sample being born in England, 6% in the Netherlands and 3% in the United States. 1% of the women came from each of the following countries: Czechoslovakia, Colombia, North Ireland, Denmark, Hong Kong, Italy, and Scotland. Approximately 80% of the women were married, while 9% were divorced, 6% single and 6% were widowed. 13% of the participants live alone. The women were highly educated; 33% of the sample completed a college program, and 33% graduated from university. Only 11% of the participants had not completed high school, while 17% were high school graduates. A small number of women (6%) had a trade certificate or diploma. In terms of employment, 31% of the participants had full-time jobs, 20% of women were working part-time and 12% volunteer in the community. Majority of the participants were financially secure, with over 50% of the sample in the two highest family income brackets, earning more than $61 000 annually. Almost half of the women were occasionally involved and 26% of the women were significantly involved in breast cancer support and advocacy.

Breast Cancer History and Health Characteristics

The demographic data also included information about the breast cancer history and other health characteristics of the participating women. In Table 4, an overview of this information is provided.

Table 4. Breast Cancer History and Health Characteristics of Participants (N = 101).

YEARS SINCE INITIAL DIAGNOSIS	Mean: 5 years Range: 1 – 23 years
STAGE AT INITIAL DIAGNOSIS	1 % DCIS 30 % Stage One 45 % Stage Two 17% Stage Three 1 % Stage Four 5 % Unsure
TREATMENT TYPE	64 % Lumpectomy 43 % Mastectomy 10 % Bi-Lateral Mastectomy 65 % Radiation Therapy 60 % Chemotherapy 54 % Hormone Therapy 19 % Alternative Complementary Therapy
EXPERIENCED LYMPHEDEMA SINCE INITIAL DIAGNOSIS	18 % Yes 81 % No
EXPERIENCED A RECCURENCE SINCE INITIAL DIAGNOSIS	14 % Yes 86 % No

PTSD (Based on Score of 50 or more)	10 % Yes 90 % No
PTSD (Based on Score of 44 or more)	15 % Yes 85 % No

* The N for some variables is slightly less than 101 because of missing data, consequently the sum of percentages is not always 100% .

*The sum of percentages for treatment type exceeds 100% because many women have multiple treatments.

The women ranged from experiencing six-months to 23-years of survivorship, with a mean of 5 years since initial diagnosis of breast cancer. The majority of participants were diagnosed with Stage I (30%) or Stage II (45%) breast cancer, although a significant percentage (17%) were diagnosed with a greater burden of disease in Stage III and 1% in Stage IV. In terms of surgery for treatment of the cancer, 64% of women had a lumpectomy, 43% had a mastectomy and 10% had a bilateral mastectomy. Majority of participants went through adjuvant therapies, including 65% who had radiation therapy, 60% who had chemotherapy, and 54% who continued treatment with hormone therapy. Almost 20% of women turned to alternative therapies, such as massage therapy, reiki, therapeutic touch, meditation and reflexology. Close to 20% of the women suffered from lymphedema at some point since treatment for breast cancer, ranging from one month of swelling to continual suffering years after surgery. In terms of recurrence, almost 15% of participants had a repeat episode of their breast cancer. Despite completing treatment and many experiencing a number of years of survivorship, 10% of women could still be clinically diagnosed as suffering from post-traumatic stress disorder by scoring 50 or more on the PCL-C scale. Furthermore, some researchers suggest that a score of 44 or more indicates PTSD (Blanchard et al., 1996). Based on this figure, the proportion of women suffering from PTSD increases significantly with 15% of the sample affected.

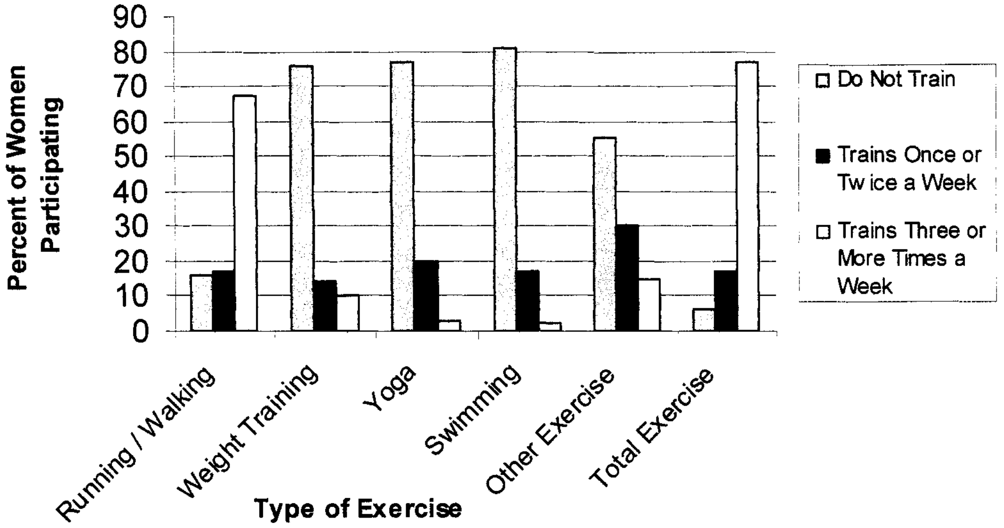
Exercise Participation

Determining if exercise can contribute to post-treatment quality of life for breast cancer survivors is a key research question in this study. The following table summarizes how often the breast cancer survivors participated in specific exercises.

Table 5. Exercise Participation by Participants (N = 101).

RUNNING / WALKING	16 % Do Not Run or Walk 17 % Run or Walk Once or Twice a Week 67 % Run or Walk Three or More Times a Week
WEIGHT TRAINING	76 % Do Not Weight Train 14 % Weight Train Once or Twice a Week 10 % Weight Train Three or More Times a Week
YOGA	77 % Do Not do Yoga 20 % Do Yoga Once or Twice a Week 3 % Do Yoga Three or More Times a Week
SWIMMING	81 % Do Not Swim 17 % Swim Once or Twice a Week 2 % Swim Three or More Times a Week
OTHER EXERCISE	55 % Do Not do Other Exercise 30 % Do Other Exercise Once or Twice a Week 15 % Do Other Exercise Three or More Times
TOTAL EXERCISE PARTICIPATION	6 % Do Not Exercise 17 % Exercise Once or Twice a Week 77 % Exercise Three or More Times a Week

Figure 4. Exercise Participation by Participants



Running and/or walking were by far the most popular form of exercise, with 67% of the women running or walking three or more times a week and a total of 84% participating in the exercise. 24% of women weight trained, 23% practiced yoga and 19% swam at least once a week. 45% of survivors participated in other exercise at least once a week; 15% of those women exercised three or more times a week. Other exercises included primarily cardio aerobics, circuit training, pilates and spinning, among other outdoor sports and activities. Overall, 77% participants reported exercising three or more times a week, while 17% exercised once or twice a week. Only 6% of women did not exercise at all.

Cross Tabulations

A cross tabulation analysis was conducted with a number of variables that were significant in the regression analyses. The variables were chosen out of interest to determine if specific demographics influence each other. Table 6 illustrates the variables that were analyzed and the resulting Chi-Square statistics.

Table 6. Cross Tabulations of Variables Significant in Regression Analyses

VARIABLES ANALYZED	PEARSON CHI-SQUARE VALUE	DF	SIGNIFICANCE p-value
Exercise & Lymphedema	7.814	8	.452
Bi-Lateral Mastectomy & Lymphedema	.030	1	.862
Radiation Therapy & Lymphedema	2.171	1	.141
Age & Community Volunteer	55.381	68	.864
Age & Social / Political Involvement	79.022	68	.170
Education Level & Social / Political Involvement	11.198	8	.191
Year of Diagnosis & Social / Political Involvement	42.239	32	.106
Year of Diagnosis & Age	605.160	528	.011

The cross tabulation results indicate that most of the variables that were analyzed are not significantly correlated. Variable pairs such as exercise by lymphedema, bi-lateral mastectomy by lymphedema and age by working as a community volunteer were far from significance (.452 or greater), indicating no relationship between these demographics. Radiation therapy by lymphedema, age by social / political involvement, education level by social / political involvement and year of diagnosis by social / political involvement are slightly closer to approaching significance. However, the only analysis that was significant was the cross tabulation between year of diagnosis and age, which were positively correlated, p = .011.

Quality of Life Scales: Regression Results & Reliability

For each of the four subscales of quality of life, physical, psychological, social and spiritual, questions pertaining to each specific subscale were totaled to create a score (refer to Appendix II). In these cases, a higher score on each of the subscales, as well as the total score, represent poorer quality of life. In each of the regression analyses, the required statistical assumptions of normality, homogeneity and independence have been met, as indicated by the graphs and Durbin-Watson values, respectively. The residuals were examined for each analysis, revealing no outliers or influential observations affected the regression analyses, according to the standardized residuals, leverage and Cook's Distance values. The regressions were conducted using the stepwise method of analysis, with the value for inclusion in the model set at p = .10 and the value for exclusion from the model set at p = .20. Therefore, it should be noted there are several variables included in the models that are close to, but not statistically significant at the standard value, $p \leq .05$. The following socio-demographic variables were tested for their ability to predict quality of life as independent variables in each of the regression analyses: age, relationship status, living alone, highest level of education, annual family income, working full-time, working part-time, working as a community volunteer, stage of disease at diagnosis, treatment variables including lumpectomy, mastectomy, bilateral mastectomy, radiation therapy, chemotherapy, hormone therapy and alternative therapy, experience of lymphedema, experience of recurrence, social / political involvement, exercise variables (measured by # of times they train per week) including running / walking, weight training, yoga, swimming, other exercise and total exercise, which is the number of times women participated in all exercises per week. Some questions, specifically those related to treatments, were not applicable or were not completed by a few of the participants. There was no significant pattern to indicate that the questions were not completed for a specific reason. Therefore, missing data was replaced with the mean throughout the analysis.

Physical Quality of Life

A stepwise linear regression analysis determined the ability of the socio-demographic factors to predict physical quality of life. Table 7 and Table 8 illustrate the model statistics, the reliability of the subscale and the variables that significantly influence physical quality of life.

Table 7. Prediction of Physical Quality of Life, Model & Scale Statistics

R^2	SUM OF SQUARES	DF	MEAN SQUARE	F	SIGNIFICANCE	CRONBACH'S ALPHA RELIABILITY
0.194	5789.442	3	1929.814	7.780	.001	.842

The R^2 value indicates that the model is able to predict approximately 20% of the variance in physical quality of life. According to the ANOVA table, the model is adequate in predicting physical quality of life, F (3,97) = 7.780, p = .001. In a reliability analysis, a Cronbach's Alpha value of .70 or more indicates that the scale reliably measures the dependent variable in question. The physical quality of life scale is highly reliable, with a Cronbach's Alpha of .842.

Table 8. Prediction of Physical Quality of Life by Regression, Significant Effects

SOURCE	**B**	**SIGNIFICANCE**	**CONFIDENCE INTERVALS**	
			Lower Bound	**Upper Bound**
Total Exercise	-.813	.001	-1.292	-.335
Age	.415	.020	.066	.764
Lymphedema	8.765	.036	.574	16.957

A higher score on the physical quality of life scale represents poorer physical quality of life

$$E(y/x) = -769.103 - .813\ x_1 + .415\ x_2 + 8.765x_3$$

where x_1 = total exercise, x_2 = age and x_3 = lymphedema

There were three main effects that were significantly correlated with physical quality of life: exercise, age and lymphedema. From the model, we see that for each increase of a day a week of exercise, there is an increase in physical quality of life increases by .813 units. Each year of age decreases physical quality of life by .415 units. If the woman has experienced lymphedema, her physical quality of life decreases substantially by a score of 8.765, compared to a woman who never had lymphedema following treatment for breast cancer.

Psychological Quality of Life

The second subscale of the quality of life scale measures psychological quality of life. Conducting a stepwise regression analysis with the socio-demographic variables established several effects that are able to significantly predict psychological quality of life in breast cancer survivors. The following table is an overview of the model statistics and reliability of this subscale.

Table 9. Prediction of Psychological Quality of Life by Regression Analysis, Model Statistics

R^2	SUM OF SQUARES	DF	MEAN SQUARE	F	SIGNIFICANCE	CRONBACH'S ALPHA RELIABILITY
0.284	32787.379	6	5464.563	6.201	.001	.921

Based on the R^2 value, the independent variables were able to predict 28% of the variance in psychological quality of life. In the ANOVA table, F(6,94) = 6.201, p = .001, which indicates that the model is adequate in predicting psychological quality of life. The psychological subscale is highly reliable, with a Cronbach's Alpha score of 0.921.

Table 10. Prediction of Psychological Quality of Life by Regression, Significant Effects

SOURCE	B	SIGNIFICANCE	CONFIDENCE INTERVALS	
			Lower Bound	Upper Bound
Age	1.111	.002	.415	1.808
Lymphedema	22.162	.006	6.563	37.761
Bi-Lateral Mastectomy (Approaching Significance)	18.428	.067	-1.311	38.167
Relationship Status (Approaching Significance)	10.477	.073	-1.013	21.966
Living Alone	-30.460	.003	-50.076	-10.845
Total Exercise	-2.132	.022	-3.944	-.320

A higher score on the psychological quality of life scale represents poorer psychological quality of life

$$E(y/x) = -2076.000 + 1.111\, x_1 + 22.162x_2\ (+\ 18.428x_3 + 10.477\, x_4) - 30.460x_5 - 2.132x_6$$

where x_1 = age, x_2 = lymphedema and x_3 = bi-lateral mastectomy, x_4 = relationship status, x_5 = living alone and x_6 = total exercise

The model illustrates that a number of factors significantly affect psychological quality of life. Both age and lymphedema are significantly correlated with poorer psychological quality of life following treatment for breast cancer. For each year of age, psychological quality of life decreases by one point on the scale. Psychological quality of life was extremely poor (by 22 units) for women who experienced lymphedema. Bilateral mastectomy and relationship status were both included in the model, since cut-off levels for inclusion were $p \leq .10$ using a stepwise regression analysis. However, they are only approaching significance at $p = .067$ and $p = .073$, respectively. If they were to be included in the model, having a bilateral mastectomy to treat breast cancer would decrease psychological quality of life by 18 units. Similarly, depending on relationship status, psychological quality of life decreases by 20 to 40 units. Single women fared the best psychologically, with married women not far behind. Separated or divorced women and widowed women had poorer psychological quality of life. Living alone increased women's post-treatment psychological functioning by 30 units. Exercise was a significant predictor of psychological quality of life, with each extra exercise session per week leading to increased psychological benefits.

Social Quality of Life

The socio-demographic variables in question were also run in a stepwise regression to determine their ability to predict social quality of life. Refer to Table 11 for the model and reliability statistics.

Table 11. Prediction of Social Quality of Life by Regression Analysis, Model Statistics

R^2	SUM OF SQUARES	DF	MEAN SQUARE	F	SIGNIFICANCE	CRONBACH'S ALPHA RELIABILITY
0.223	6274.176	3	2091.392	9.271	.001	.803

According to the R^2 variable, the socio-demographic variables were able to predict 22% of the variance in social quality of life. From the F-statistic, it is clear that the model is adequate to explain the dependent variable, F(3, 97) = 9.271, p = .001. Furthermore, the social subscale of the quality of life scale is fairly reliable, with a Cronbach's Alpha of 0.803.

Table 12. Prediction of Social Quality of Life by Regression, Significant Effects

SOURCE	B	SIGNIFICANCE	CONFIDENCE INTERVALS	
			Lower Bound	Upper Bound
Age	.640	.001	.307	.974
Lymphedema	12.307	.003	4.386	20.227
Community Volunteer	-3.471	.036	-6.709	-.232

A higher score on the social quality of life scale represents poorer social quality of life

$$E(y/x) = -1214.490 + .640\, x_1 + 12.302\, x_2 - 3.471 x_3$$

where x_1 = age, x_2 = lymphedema and x_3 = community volunteer

As was the case with the physical and psychological quality of life scales, age and experiencing lymphedema significantly influenced participants' post-treatment social quality of life. Each year of age reflects a slight decrease in social quality of life. Women who experienced lymphedema after surgery for breast cancer had significantly decreased social quality of life by 12 units. Working as a community volunteer was the only variable found to significantly increase social quality of life, which does so by approximately 3.5 units.

Spiritual Quality of Life

The last subscale of the quality of life instrument pertains to spiritual quality of life. Table 13 outlines the statistics of the model and reliability analysis.

Table 13. Prediction of Spiritual Quality of Life by Regression Analysis, Model Statistics

R^2	SUM OF SQUARES	DF	MEAN SQUARE	F	SIGNIFICANCE	CRONBACH'S ALPHA RELIABILITY
0.188	3343.909	4	835.977	5.559	.001	.721

The significant socio-demographic variables that make up the model were able to explain 18% of the variance in spiritual quality of life. The model is adequate to predict spiritual quality of life, F(4, 96) = 5.559, p = .001. The reliability of this subscale is lower than others, although is still acceptable with a Cronbach's Alpha of 0.721.

Table 14. Prediction of Spiritual Quality of Life by Regression, Significant Effects

SOURCE	B	SIGNIFICANCE	CONFIDENCE INTERVALS	
			Lower Bound	Upper Bound
Social / Political Involvent	-8.503	.001	-13.140	-3.866

Exercise	-1.339	.002	-2.185	-.493
Relationship Status	-4.643	.026	-8.711	-.576
Social / Political Involvement & Exercise Interaction	.245	.017	.045	.446

A higher score on the spiritual quality of life scale represents poorer spiritual quality of life

$$E(y/x) = 51.080 - 8.503\ x_1 - 1.339\ x_2 - 4.643x_3 + .245x_4$$

where x_1 = social / political involvement, x_2 = exercise, x_3 = relationship status and

x_4 = interaction b/w social/political involvement & exercise

Several socio-demographics variables were found to significantly increase spiritual quality of life, including social / political involvement, exercise and relationship status. Women that were more frequently involved socially or politically in breast cancer support and advocacy had better scores with respect to spiritual functioning by 17 to 25.5 units accordingly (17 = occasionally involved , 25.5 = significantly involved). For each exercise session per week that women participated in, their spiritual quality of life score improved by approximately 1 unit. Relationship status was also positively correlated with increased spiritual quality of life. Compared to being single, spiritual growth increased 5 units for married women, 10 units for separated or divorced women and 15 units for widowed women. To determine if being involved socially or politically and exercising significantly contributed to spiritual quality of life, a variable representing the interaction between the two independent variables was created and tested in the model. The interaction was found to be significant, although unexpectedly, women who are both socially / politically involved and exercise have a slightly poorer spiritual quality of life by about .25 units for each increase in either.

Quality of Life Scale Total

After analyzing each subscale, a total score for all questions of the quality of life scale was created to determine which socio-demographic factors significantly contribute to quality of life in general.

Table 15. Prediction of Quality of Life by Regression Analysis, Model Statistics

R^2	SUM OF SQUARES	DF	MEAN SQUARE	F	SIGNIFICANCE	CRONBACH'S ALPHA RELIABILITY
0.277	105086.5	4	26271.618	9.216	.001	.916

Table 13 illustrates that the model is adequate to predict quality of life, F(4, 96) = 9.216, p = .001. Approximately 28% of the variance in quality of life can be explained by the significant variables in the model. The quality of life scale is very reliable, with the analysis resulting in a Cronbach's Alpha of 0.916.

Table 16. Prediction of Quality of Life by Regression, Significant Effects

SOURCE	B	SIGNIFICANCE	CONFIDENCE INTERVALS	
			Lower Bound	Upper Bound
Age	1.880	.002	.679	3.081

Total Exercise	-4.973	.003	-8.229	-1.716
Lymphedema	38.260	.007	10.628	65.892
Living Alone	-36.428	.026	-68.444	-4.412

A higher score on the quality of life scale represents poorer quality of life

$$E(y/x) = -3452.784 + 1.880\,x_1 - 4.973\,x_2 + 38.260\,x_3 - 36.428x_4$$

where x_1 = age, x_2 = exercise, x_3 = lymphedema and x_4 = living alone

Several variables play a significant role in predicting quality of life, including age, lymphedema, exercise and living alone. As is consistent with the analysis of the subscales, increasing age and the experience of lymphedema are correlated with a significant decrease in overall quality of life. For each year of age, quality of life decreases by approximately 2 units. Having experienced lymphedema at some point after surgery predicts a substantial decrease in quality of life, 38 units. Conversely, exercise and living alone have consistently predicted an increase in the subscales of quality of life, which is also the case with overall quality of life. With each additional session of exercise per week, quality of life increases by approximately 5 units. For those women who live alone, their overall quality of life score was significantly better, by 36 units.

PCL-C Results & Scale Reliability

The Post-Traumatic Stress Disorder Checklist, Civilian Version (PCL-C) was analyzed in a similar way to the quality of life scales. The responses to each question were totaled to create a total score (See Appendix II). To determine which socio-demographic factors could predict increased distress for breast cancer survivors, a regression analysis was run with their PCL-C score as the dependent variable. As was the case with the quality of life scales, the socio-demographic factors in question were included in the analysis as the independent variables. The regression was conducted using the stepwise method, again with an inclusion cut-off of $p \leq .10$ and an exclusion cut-off of $p \geq .20$ for the model. As a result of the cut-off, several variables included in the model were approaching, but not quite significant, at the standard of $p \leq .05$. The regression analysis satisfied all three statistical assumptions of normality, homogeneity and independence. With respect to residuals, there were no outliers or influential observations.

The following table provides an overview of the model and reliability statistics of the PCL-C results.

Table 17. Prediction of PTSD by Regression Analysis, Model & Reliability Statistics

R^2	**SUM OF SQUARES**	**DF**	**MEAN SQUARE**	**F**	**SIGNIFICANCE**	**CRONBACH'S ALPHA RELIABILITY**
0.263	3606.861	7	515.266	4.732	.001	.918

According to the R2 value, 26% of the variance in post-traumatic distress can be explained by the socio-demographic variables. The model is significantly adequate to predict post-traumatic distress in the breast cancer survivors, F(7, 93) = 4.732, p = .001. The PCL-C scale is highly reliable, scoring a Cronbach's Alpha of 0.918.

Table 18. Prediction of PTSD by Regression Analysis, Significant Effects

SOURCE	B	SIGNIFICANCE	CONFIDENCE INTERVALS	
			Lower Bound	**Upper Bound**
Year of Diagnosis	.591	.015	.118	1.064
Bi-Lateral Mastectomy	10.708	.003	3.644	17.773
Social / Political Involvement	3.630	.020	.572	6.688
Level of Education	-2.239	.006	-3.827	-.652
Lymphedema	6.210	.029	.645	11.774
Working Part-Time (Approaching Significance)	5.263	.056	-.140	10.666
Radiation Therapy (Approaching Significance)	4.169	.068	-.310	8.647

A higher score on the pcl-c scale represents a higher degree of distress

$$E(y/x) = -1473.276 + .591\, x_1 + 10.708\, x_2 + 3.630\, x_3 - 2.239\, x_4 + 6.210\, x_5$$

$$(+\, 5.263\, x_6 + 4.169\, x_7)$$

where x_1 = years since diagnosis, x_2 = bi-lateral mastectomy and x_3 = social / political involvement, x_4 = level of education, x_5 = lymphedema, x_6 = working part-time (approaching sig.), and x_7 = radiation therapy (approaching sig.)

Years since diagnosis, having a bi-lateral mastectomy, social / political involvement and experiencing post-treatment lymphedema all increased distress in survivors. Treatment by bilateral mastectomy increased post-traumatic distress by almost 11 units. The women who have suffered from lymphedema scored roughly 6 points higher on the PCL-C scale. Being socially or politically involved in breast cancer support and advocacy was also significantly correlated with increased distress in survivors, increasing by 3 units. With each year after diagnosis, women's risk of post-traumatic distress increased by .591 of a unit. On the other hand, level of education seems to be protective for post-traumatic distress, decreasing risk of PTSD by roughly 2 points for each higher level of education as follows (2 = no formal education, 4 = up to high school, 6 = high school diploma, 8 = trade certificate or diploma, 10 = college diploma, 12 = university degree). Two variables, treatment with radiation therapy and working part-time were approaching significance, p = .056 and p = .068 respectively. Both socio-demographic variables increased post-traumatic distress for survivors by approximately 4 – 5 units.

Self-Transcendence Scale: Regression Results & Reliability

The Self-Transcendence Scale was analyzed using the same procedures that were followed with the Quality of Life Scale and PCL-C. The participants' responses were added up to create a self-transcendence score (See Appendix II), which served as the dependent variable in the final regression analysis. The same socio-demographic factors were entered as independent variables to test their adequacy in predicting self-transcendence in the breast cancer survivors. The charts and Durbin-Watson value illustrate that the analysis of the self-transcendence scale satisfies the statistical assumptions of normality, homogeneity and independence. The residual statistics show no outliers or influential observations. Tables 17 and 18 provide an overview of the model, reliability and regression statistics.

Table 19. Prediction of Self-Transcendence by Regression Analysis, Model & Reliability Statistics

R^2	SUM OF SQUARES	DF	MEAN SQUARE	F	SIGNIFICANCE	CRONBACH'S ALPHA RELIABILITY
0.241	938.930	4	234.732	7.603	.001	.841

According to the R2 value, 24% of the variance in self-transcendence can be explained by the significant socio-demographic variables. This model is adequate to predict self-transcendence, F(4, 96) = 7.603, p = .001. Cronbach's Alpha at 0.841 is an indication that the scale reliably measures self-transcendence.

Table 20. Prediction of Self-Transcendence by Regression, Significant Effects

SOURCE	B	SIGNIFICANCE	CONFIDENCE INTERVALS	
			Lower Bound	Upper Bound
Social / Political Involvement	2.393	.002	.869	3.917
Relationship Status	2.944	.002	1.124	4.765
Community Volunteer	1.284	.032	.109	2.459
Exercise: Swimming	.659	.045	.016	1.303

A higher score on the self-transcendence scale represents a higher degree of self-transcendence

$$E(y/x) = 37.963 + 2.393\, x_1 + 2.944\, x_2 + 1.284\, x_3 + .659\, x_4$$

where x_1 = social / political involvement, x_2 = relationship status,

x_3 = community volunteer and x_4 = swimming

The significant variables that were relevant in the model all contributed positively toward self-transcendence. Women that were social / politically involved to a greater extent scored 4 – 6 points higher on the self-transcendence scale accordingly (4 = occasionally involved, 6 = significantly involved). Relationship status also significantly contributed to self-transcendence. Married women scored approximately 3 points higher, separated or divorced women scored 6 points higher and widowed women scored 9 points higher on the self-transcendence scale, compared to single women. Participants who volunteered in the community increased their score by approximately 1 unit on the self-transcendence scale. Despite the fact that total exercise was not a significant factor in this analysis, participating in swimming contributed towards self-transcendence, increasing it by .659 units for each swim session per week.

Correlations between Subscales of Quality of Life

In order to determine how the different subscales of quality of life scale are related, a simple correlational analysis was conducted to create a matrix of the Pearson's R correlation coefficients for each set of scales. The following table illustrates the correlations between the dependent variables.

Table 21. Pearson's Correlation Coefficients for Quality of Life Subscales

	Physical Quality of Life	**Psychological Quality of Life**	**Social Quality of Life**	**Spiritual Quality of Life**
Physical Quality of Life	1.000	.602	.568	-.043
Psychological Quality of Life	.602	1.000	.720	.084

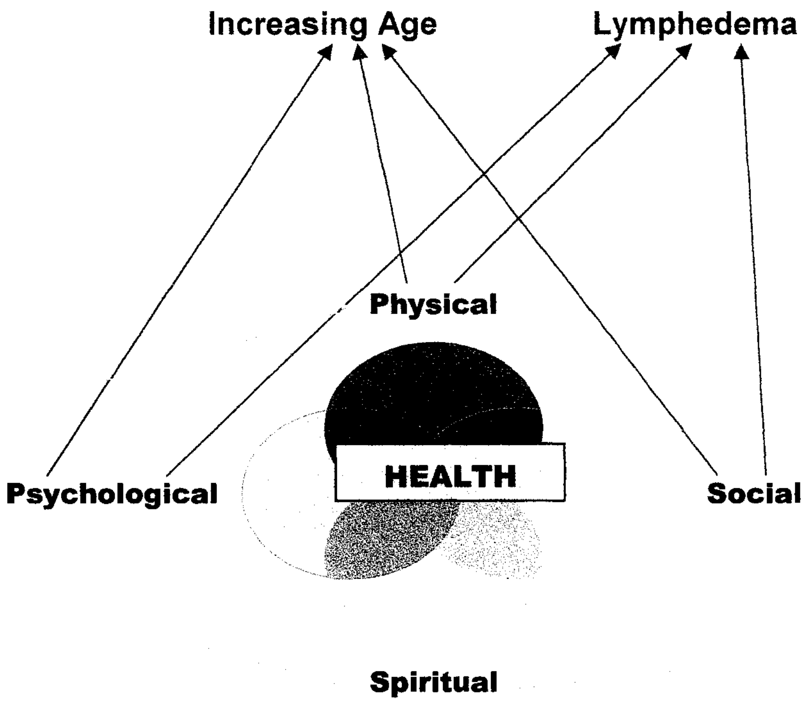
Social Quality of Life	.568	.720	1.000	-.090
Spiritual Quality of Life	-.043	.084	-.090	1.000

The results indicate that physical quality of life is strongly and positively correlated with psychological and social quality of life, r = .602 and r = .568, respectively. Psychological well-being is also strongly and positively correlated to social quality of life, r = .720. On the other hand, there appears to be little relationship between spiritual quality of life and the other subscales, r = -.043, .084 and -.090 for physical, psychological and social quality of life, respectively.

Summary of Results

Figure 5 illustrates the variables that significantly affected holistic health, which includes measures of quality of life and self-transcendence. Variables highlighted in red indicate that the factor was associated with a significant decrease in the corresponding measure. The factors highlighted in blue significantly contributed towards the indicated measure of holistic health.

Figure 5: Significant Variables and their Effect on Holistic Health



DISCUSSION

The results and the impact of the socio-demographic variables on quality of life, post-traumatic stress disorder and self-transcendence have a number of implications for women's health and breast cancer survivorship. In the following discussion, I will explore each factor that had a significant effect on the holistic health of survivors, including previous research and future directions. These findings will be incorporated into the community context of the study and how community psychology theories can contribute to the understanding of survivorship. Building on the community concepts, the discussion will be brought back to the central theme of holistic health and the relevance of this study to women's physical, psychological, social and spiritual well-being. I will highlight the limitations of the study and lessons learned from my experience and research in the community. The discussion will conclude with a plan for dissemination of the results to the academic and breast cancer communities and recommendations for future research and interventions to improve life for breast cancer survivors. I will provide some personal reflections, insights and lessons learned concerning breast cancer, women's health and community research in my concluding paragraphs.

Survivorship

The findings from the study are a clear indication that breast cancer is not an acute or temporary condition; it is a chronic disease that affects women many years beyond treatment. There are a number of survivors who adjust well to life after breast cancer, even those that benefit and enhance their quality of life after the disease (Urcuyo et al., 2005). On the other hand, 10% of the women in the sample were identified as suffering from post-traumatic stress disorder, which actually increased with years after diagnosis, an alarming finding. Almost 20% of women had experienced lymphedema or were currently suffering from it, while 14% of women in the sample had a recurrence of their cancer. There is an abundance of research on the breast cancer experience, including diagnosis, treatment, coping and adjustment. However, there is a gap in addressing issues of survivorship. We need more studies to understand how breast cancer affects women over their lifetime and the holistic experience of being a survivor. It is important to focus on the factors that can predict a diminished quality of life after treatment for breast cancer to determine which women may need extra support as survivors. More research on survivorship can lead to some options for women to be proactive in their health, and create opportunities and an evidence base for the medical community to provide lifetime services and support for breast cancer survivors.

Lifestyle Factors

Exercise

The research findings confirmed the results of previous studies and the psychosocial benefits that frequent exercise has for women who have survived breast cancer (Mustian et al., 2002; Courneya & Friedenreich, 1999; Kendall et al., 2005). Physical, psychological, spiritual and total quality of life all increased with each additional day of exercise per week. Swimming contributes towards increased self-transcendence. This finding is further evidence that being physically active improves physical functioning (Courneya & Friedenreich, 1999; Kendall et al., 2005), as well as facilitating psychological well-being (Mustian et al., 2002), which includes feeling in control, enjoying life and experiencing less anxiety and depression (Ferrell et al., 1995). Exercise also plays a role in spiritual well-being and self-transcendence, an association that has not yet been a major focus of most breast cancer research. However, researchers working with breast cancer dragon boaters found that the sport facilitated transcendence, allowing survivors to feel a part of something greater than themselves (Mitchell & Nielson, 2002; Mitchell et al., 2006). Furthermore, transcendence was sometimes associated with being out on the water and feeling a connectedness to nature, which may explain why swimming contributes significantly to this phenomenon. This idea integrates eastern ideas of health, which require the balance of natural elements, such as water, to balance the holistic aspects of health (Chan et al., 2001).

The finding that regular exercise increases quality of life and self-transcendence is beneficial for understanding women's holistic health after treatment for breast cancer. Understanding how women can take action to improve quality of life is important; it gives women choices to enhance their own well-being, which is vital after experiencing an illness that can be seen as limiting options and sense of control over life itself (Kinney et al., 2003).

Volunteerism

Working as a community volunteer was associated with better social quality of life, as well as contributing toward self-transcendence for breast cancer survivors. This finding provides some support for previous studies regarding the benefits of providing social support and helping others (Brown et al., 2003; Graff, 1991; Kielburger & Kielburger, 2004). Volunteering in the community potentially expands a women's social network, creating relationships with those with similar interests, and decreasing isolation, which may enhance social well-being (Kielburger & Kielburger, 2004). Getting involved and helping others can also help women to see the bigger picture and put their disease and life into perspective, which may explain the increase in self-transcendence. Graff (1991) identified vulnerable populations that could specifically benefit from volunteering, including seniors and youth, among others. These groups specifically benefit from being able to cope with isolation, give back to the community, gaining a new perspective on personal experience and personal empowerment. Experiencing breast cancer often puts women in a vulnerable position (Arman & Rehnsfeldt, 2003), which may identify survivors as a target population who can benefit significantly from volunteering (Graff, 1991). On the other hand, working as a volunteer in the community did not enhance physical and psychological quality of life for breast cancer survivors, as is suggested in the literature (Graff, 1991; Brown et al., 2003). Further study is required to determine if volunteering is linked to specific health outcomes for breast cancer survivors.

Social & Political Involvement

From the findings it is clear that it is not only volunteerism, but also being significantly involved in breast cancer support and advocacy that contributes to the holistic health of survivors. Social and political involvement in activities associated with breast cancer, such as volunteering with a support organization, fundraising walks or runs, lobbying for funding and health promotion and prevention increased survivors' spiritual quality of life and self-transcendence. This again might be explained by women's ability to see the bigger picture, and to put their life and own experience of the disease into perspective when helping others going through the same situation (Graff, 1991). Participating in support groups, on teams or in large events connects women with other breast cancer survivors, which can create a sense of community (McMillan & Chavis, 1986) and contribute to women expanding their boundaries and changing their priorities (Coward & Kahn, 2005). On the other hand, women who were socially or politically involved in breast cancer support and advocacy had a higher degree of post-treatment distress. This finding may indicate that women who suffer more from their experience of breast cancer are more likely to get involved in support and advocacy to help others in similar circumstances or to prevent breast cancer in future generations. Furthermore, social and political involvement significantly interacted with exercise to predict spiritual quality of life. Unlike the main effects, exercising and being involved in breast cancer support and advocacy to higher degree was associated with a decrease in spiritual quality of life. It could be that too many activities decrease women's ability to focus on themselves, which may have negative implications for spirituality. Additional research into the impact of social and political involvement on spirituality, transcendence and quality of life in general may provide more insight into the health benefits of support and activism.

Work Status

Unlike the findings of the Ontario Breast Cancer Survivor Dragon Boat Study, the results did not indicate any potential quality of life benefits for the women working full-time (Mitchell et al., 2005). Furthermore, those breast cancer survivors working part-time were extremely close to having a significantly increased risk of suffering from post-traumatic distress, p = .056. A possible explanation is that women who are experiencing distress are more likely to be working part-time, rather than at a full-time job. More research is required to determine the impact that suffering from post-traumatic has on work status and to identify how working influences quality of life.

Demographic Factors

Age

Quality of life often decreases with age, as physical and mental functioning declines, and social support diminishes with a smaller social network (Rieker & Bird, 2005). Since women live longer than men, they are more likely to experience acute and chronic conditions, such as cancer, which significantly impact quality of life (Rieker & Bird, 2005). Similarly in this study, increasing age was consistently associated with poorer quality of life throughout the analysis. Age was a significant factor in predicting decreased physical, psychological, social and overall quality of life for breast cancer survivors. This finding does not support earlier studies that identify younger women as having higher post-treatment needs than older breast cancer survivors (Thewes et al., 2004; Wong-Kim & Bloom, 2004; Kroenke et al., 2004). However, most of these studies that focused on the needs of young women were conducted with participants who were newly diagnosed with breast cancer (Thewes et al., 2004; Wong-Kim & Bloom, 2004). There is evidence that older women have more difficulties adjusting physically and mentally following treatment for breast cancer (Ganz et al., 2003). The results of this study show that as age increases, breast cancer survivors in this sample have significant post-treatment needs that must be addressed by the provision of services and support to increase quality of life for women. There is a need for further research focusing on older women and issues of survivorship in the years following diagnosis and treatment.

Living Alone

Women who live alone scored better on the total quality of life scale, as well as the psychological and spiritual quality of life subscales than those living with others. At first glance, this finding seems unusual, if living with others is associated with an increase in the level of social support available to a woman. As was reviewed in the literature, there is evidence that social support can improve physical, psychological and social functioning for women after breast cancer (Trunzo & Pinto, 2003; Knickmeyer et al., 2002; Koopman et al., 1998). One explanation is that living alone is not necessarily predictive of a women's available social network and level of support. Another theory that might provide better insight into the benefits of living alone for women is Relational-Cultural Theory (formerly "Self-in-Relation theory"). This theory suggests that for women, cultural expectations emphasize a growth towards connections and relationships with others, often to the neglect of their own needs (Jordan, 2001). Therefore women, who commonly fill the role of caregiver, have less time to focus on themselves and their own psychological and spiritual fulfillment. Depending on others for social support can also cause guilt, anxiety and the feeling of being a burden to others (Brown et al., 2003), which may be an issue for women throughout the cancer experience and survivorship. More social support research with breast cancer survivors, both qualitative and quantitative, may help to determine why living alone serves as a protective factor for women's post-treatment quality of life and how these benefits may be extended to others.

Relationship Status

Relationship status affected psychological quality of life, spiritual quality of life and self-transcendence, although the effect was different depending on the measure. The prediction of psychological quality of life was approaching significance (p=.073), finding that women who were single had the best psychological quality of life, with married women adjusting almost as well. Divorced or separated and widowed women had poorer psychological functioning. On the other hand, women who were separated or divorced had increased spiritual quality of life, and a higher level of self-transcendence. Women who were widowed had the most spiritual fulfillment, compared to all other relationship statuses. There is evidence that recently losing a significant other or facing death oneself leads to spiritual exploration (Moremen, 2005). Therefore, breast cancer survivors who are widows may experience a need to feel connected and engage in spiritual and existential questioning, contributing towards self-transcendence. Several previous studies have been conducted with women to determine how marital status affects breast cancer, quality of life and spirituality (Foley, 2000; Cui et al, 2004; Osborne et al., 2005). In a study of older women and spirituality, Foley (2000) investigated marital status (married versus non-married) and found that married women had higher spirituality scores. A study of Chinese women two years after treatment for breast cancer found a similar result; women who were married had a better quality of life (Cui et al., 2004). Another study even suggests that unmarried women are at a higher risk of death from breast cancer (Osborne et al., 2005).

After reviewing the literature, it was not clear if comparing all relationship statuses (single, married, divorced / separated and widowed) led to different results than a simplified analysis of marital status. A new set of regression analyses were run with the present study, in order to determine if the results would be different with marital status (married versus non-married), rather than relationship status. The results were clear; in the current sample, marital status did not significantly affect quality of life, self-transcendence or post-traumatic distress. Most research with breast cancer survivors and women in general focuses only on marital status, categorizing women as married or unmarried. The results of the present study emphasize the need to look at how single, separated, divorced and widowed women adjust to survivorship, as well as married women. Additional research into more diverse relationship circumstances will help to identify and provide for those who need more support to increase quality of life in the years following breast cancer.

Level of Education

Having a higher level of education was the only factor in the current study that was protective against post-traumatic distress for breast cancer survivors. This finding has also been the case in past studies, where lack of education has been associated with post-traumatic stress disorder in different populations (Bolton et al., 2004; Njenga et al., 2004). Education has also been identified as a protective factor for PTSD in long-term research with breast cancer survivors

(Kornblith et al., 2003; Andrykowski & Cordova, 1998). A number of interventions designed to treat post-traumatic stress disorder have an informational / educational component (Acierno et al., 2004; Carr, A., 2004) and can potentially increase healthy coping strategies for patients (Acierno et al., 2004). In a study of breast cancer patients, women with a higher education level had a greater need for more information throughout the breast cancer experience (Salminen et al., 2004). Therefore, women with more education may be more active in gathering information throughout their experience with breast cancer, which may enhance their ability to cope with post-treatment issues. This finding emphasizes the need for further research into potential educational and informational interventions for breast cancer survivors suffering from post-traumatic distress.

Breast Cancer History & Treatment Factors

Bilateral Mastectomy

As is the case in previous research, type of treatment had an effect on post-treatment outcomes for breast cancer survivors. Specifically, women who had a bilateral mastectomy had a higher degree of distress than those who had other surgeries. Bilateral mastectomy was also approaching significance in predicting decreased psychological quality of life. In the Ontario Breast Cancer Dragon Boat Study, Mitchell et al. (2005) also found that breast cancer survivor dragon boaters who had a bilateral mastectomy had more trauma and stress than those who had other surgeries. Researchers in a study of 133 women who had been treated for breast cancer identified having a mastectomy as opposed to a lumpectomy as a risk factor for PTSD (Leiderman-Cerniglia, 2002). These studies provide substantial evidence that having a bilateral mastectomy as treatment for breast cancer increases post-traumatic distress throughout survivorship. Unfortunately, most women have limited options when it comes to treatment for breast cancer. However, some women, including those who have a pre-cancerous condition known as ductal carcinoma in situ (DCIS), choose to have a bilateral mastectomy to decrease the risk that the cancer will develop, despite the fact that the treatment is often unnecessary (Verkooijen et al., 2002). Therefore, it is important that women who choose to have a bilateral mastectomy are aware of the post-treatment risks associated with the surgery. Having identified bilateral mastectomy as a risk factor for PTSD, more research is required to identify protective factors that can decrease post-traumatic distress and improve life for women who have undergone this surgery.

Radiation Therapy

Treatment with radiation therapy did not significantly affect women's post-treatment quality of life, although the factor was approaching significance in the prediction of PTSD. In previous research with breast cancer dragon boaters, women who had radiation therapy had an increased risk of post-traumatic distress (Mitchell et al., 2005). Further research with respect to radiation therapy is important to determine its effect on breast cancer survivors and post-traumatic distress.

Lymphedema

Lymphedema, a painful chronic swelling of the upper arm following treatment for breast cancer, is commonly associated with decreased quality of life and increased risk for post-traumatic stress disorder in the breast cancer literature (Kornblith et al., 2003; Radina & Armor, 2001; Wilson et al., 2005). The current study supports previous research; women who experienced lymphedema after treatment for breast cancer scored poorly on almost every scale that was analyzed. Almost 20% of the women who completed the survey had experienced or continued to suffer from lymphedema on an on-going basis. Physical, psychological, social and total quality of life all significantly decreased for those women who experienced lymphedema. The condition was also predictive of post-traumatic distress. To make matters worse, women with post-treatment lymphedema have traditionally been told to avoid intense upper body exercise (Harris & Niesen-Vertommen, 2000). Researchers are now finding that upper body exercise does not negatively affect lymphedema (MacKenzie, 1998; Harris & Niesen-Vertommen, 2000; Mitchell & Gebotys, 2006), which has implications for survivors, given the positive physical and psychological effects of being active.

Based on this study and the existing evidence, it is clear that lymphedema is extremely debilitating, physically, psychologically and even socially. It is vital that women who are suffering from lymphedema after breast cancer be given options for managing the condition itself, and getting the support they need to improve their quality of life and decrease trauma and stress. Additional studies into methods of preventing and relieving lymphedema, such as complex decongestive physiotherapy, are vital to decrease suffering in breast cancer survivors. Identifying opportunities to improve physical and psychological well-being, such as exercise and other interventions should also be a priority for breast cancer research.

Years Since Diagnosis

Surprisingly in the prediction of PTSD, the number of years since being diagnosed with breast cancer was positively associated with a higher degree of distress. This is a disturbing finding, since it indicates that these negative thoughts and reactions that are associated with breast cancer and disrupt daily life do not decrease, but actually get worse years after diagnosis. In some studies, researchers have found that post-traumatic distress either decreases or does not vary with years since diagnosis (Kornblith et al., 2003; Cordova et al., 1995). On the other hand, results of a follow-up study of breast cancer survivors one year after treatment indicate that PTSD symptoms did not diminish with time (Andykowski et al., 2000). There is also evidence that symptoms of post-traumatic distress related to the effects of cancer and its treatment continue for long-term cancer survivors into later life (Deimling et al., 2002). In the present study, a cross tabulation between years since diagnosis and age indicated that the variables are positively correlated. Therefore, given the negative quality of life outcomes associated with age, it is possible that the effect of years since diagnosis on post-traumatic distress is related to the aging process. However, age itself was not a significant factor in the analysis and does not sufficiently explain the effect of years since diagnosis on PTSD. Further investigation into symptoms of post-traumatic distress throughout survivorship is essential to help those who continue to suffer with negative and intrusive thoughts and reactions years after breast cancer and its treatment.

Other Factors: What was not Significant

At this point, it seems appropriate to note a few of the variables that were expected to affect quality of life and post-traumatic distress in breast cancer survivors, but were not significant in this particular study. For example, stage of the disease at diagnosis of breast cancer was not associated with quality of life or post-traumatic distress in survivors. A greater burden of disease has implications for the survival rate of women post-surgery (Taucher & Jakesz, 2004) and has been predictive of post-traumatic distress in other research with breast cancer survivors (Amir & Romati, 2001; Andrykowski & Cordova, 1998). Given that almost

20% of the current sample was diagnosed with Stage III or Stage IV breast cancer, it is interesting that this factor was not predictive of quality of life or post-traumatic distress. Furthermore, experiencing a recurrence of breast cancer was not associated with diminished quality of life or increased trauma and stress in the current sample, of which 14% had a recurrence, as was found in other studies (Kornblith et al., 2001; Oh et al., 2004). In the Ontario Breast Cancer Dragon Boat Study, women who were working full-time had an increased quality of life, compared to other survivors (Mitchell et al., 2005). This finding was not replicated in the current study, which indicated no potential benefits of working on a full-time or part-time basis for breast cancer survivors. It is important that these socio-demographic factors be investigated further to determine their impact on quality of life and to identify potential interventions that will contribute to the well-being of breast cancer survivors.

Community Psychology: Theories in Action

From a community perspective, it is important to discuss how community psychology theories contribute to the understanding of the current research and findings. Working with the ecological model (Bronfenbrenner, 1979) the results have implications for each level of analysis. Individually, the findings give women choices to improve their own quality of life by participating in regular exercise, volunteering for a cause they believe in or getting involved with breast cancer support and advocacy. The findings can also influence relationships with the medical community, with insights regarding treatment options, such as bilateral mastectomies, and their consequences for survivors. The identification of socio-demographic variables that contribute to or diminish quality of life and post-traumatic distress for survivors can help breast cancer support organizations provide effective services that address post-treatment needs. The current study emphasizes that breast cancer survivors who are older or have experienced lymphedema require more support than other women. On a community level, getting breast cancer survivors involved socially and politically in the breast cancer movement can potentially empower women and create sustainable, community-driven solutions that will contribute to well-being for all those affected by breast cancer.

73% of breast cancer survivors in the sample were socially or politically involved in breast cancer support and advocacy, which clearly indicates that these women are active participants in creating change and promoting health and well-being in their community. As breast cancer survivors come together to lead support groups, in runs and walks to raise awareness and funds for research and services and in breast cancer dragon boat teams, there is the potential to build a strong psychological sense of community among women who face the disease (McMillan & Chavis, 1986). These women send a powerful message to others; that they are not alone and they embrace life fully, working together to conquer breast cancer. These interventions are participant-driven, work at all ecological levels of influence, focus on the strengths of survivors and contribute toward health, competence and well-being, which is consistent with many of the values of community health psychology (Prilleltensky & Nelson, 1997). The findings from this study can affect change individually among women with breast cancer, within medical and breast cancer support organizations, and throughout communities at large.

Holistic Health

For many survivors, healing is an on-going process that includes physical, psychological, social and spiritual elements. Life has changed for these women. Breast cancer leaves a lasting effect on the body, mind and spirit, as well as social relationships for a number of survivors.

Body

Physically, breast cancer can affect the quality of life of survivors by decreasing functioning and strength, disrupting sleep patterns and increasing pain as a result of treatments, which can have a diminishing effect on overall health (Ferrell et al., 1995). Although a number of women in the current study rated their physical health as excellent, it is important to identify the factors that will improve life for other survivors. With increasing age and the experience of lymphedema, there was a decrease in women's physical health, while frequent exercise significantly contributed toward physical quality of life. Providing increased support for the unique needs of older women, managing and preventing post-treatment lymphedema and encouraging breast cancer survivors to exercise regularly can improve the physical health of breast cancer survivors.

Mind

Issues associated with psychological quality of life for breast cancer survivors include aspects of control over life, enjoyment, cognition, anxiety, depression, distress and fear of recurrence (Ferrell et al., 1995; Glanz & Lerman, 1992). A number of socio-demographic factors played a role in predicting psychological quality of life in breast cancer survivors. Frequent exercise and living alone were associated with increased psychological functioning.

Increasing age, lymphedema and being divorced or widowed (approaching significance) were predictive of negative psychological effects, such as anxiety, depression and distress. In order to improve life for breast cancer survivors, it is important to understand why living alone contributes towards women's mental health in this sample. The findings indicate that exercising and having time to focus on the self and fulfilling personal needs have the potential to enhance psychological quality of life. In addition to the physical detriments of aging and lymphedema, these factors are significantly related to poor psychological functioning, increasing the need for appropriate supports and services.

Spirit

Following breast cancer diagnosis and treatment, spiritual quality of life and self-transcendence often become an increasing priority for survivors (Kinney et al., 2003; Arman & Rehnsfeldt, 2003). According to the Quality of Life Scale (Ferrell et al., 1995), spiritual well-being for breast cancer survivors involves finding meaning in the illness, religiosity, transcendence, hope, uncertainty and inner strength. In the current study, several factors contributed towards increased spiritual well-being, including social and political involvement in breast cancer support and advocacy, regular exercise and being divorced or widowed. Women who were socially and politically involved, volunteered in the community, divorced or widowed and swam regularly had a higher degree of self-transcendence in the current sample. Being active socially, politically and physically in activities that women enjoy or feel passionate about may help them to feel connected to others and part of something beyond themselves. Facing separation or the death of a loved significant other can lead to spiritual questioning and a search for meaning in life (Moremen, 2005), which may explain the benefits for divorced or widowed women. The findings indicate that for the most part, breast cancer survivors can enhance spiritual well-being by getting involved in activities they enjoy, such as volunteering, exercising and being socially and politically active.

Social Relationships

Having supportive social relationships with family and friends are often associated with increased ability to cope (Cohen, 2004) and better health outcomes for women experiencing breast cancer (Trunzo & Pinto, 2003). However, a diagnosis and treatment for breast cancer can have an impact on important relationships and aspects of social quality of life, such as family distress, role and relationships, affection and sexual function, appearance, enjoyment, isolation and financial and work status (Ferrell et al., 1995). Volunteering in the community was the only factor in the current study that contributed significantly to social well-being for breast cancer survivors. On the other hand, women who were older or had experienced lymphedema had significantly diminished social quality of life. Women cannot control their age or whether they suffer from lymphedema, although they can enhance their social quality of life by volunteering in the community. Connecting with others over similar interests and causes they care about can decrease isolation and contribute to holistic well-being. The findings of the current study are significant for all aspects of women's health and can contribute to future research and interventions to improve holistic well-being after breast cancer.

Connection between Body, Mind, Spirit and Social Relationships

In order to provide an overview of holistic health in breast cancer survivors, health has been broken down into subscales that together provide a picture of well-being. In this sense, it is important to understand the relationship between the subscales of holistic well-being, as well as understanding each independently. The Pearson's correlation coefficient analysis of the quality of life subscales is an indication of the relationship between the holistic aspects of quality of life (Table 21). In this study of breast cancer survivors, physical, psychological and social measures of well-being of the quality of life scale are strongly and positively correlated. This finding indicates that well-being with respect to the body, the mind and social relationships is connected. However, it is interesting to note that spiritual quality of life has little relationship with the other variables of quality of life in this particular sample. Despite these findings, specific factors still have a similar effect on various aspects of health. For instance, exercise contributes toward physical, psychological and spiritual well-being. Volunteering also had a positive effect on both social and spiritual quality of life. Consistent with the correlational analysis, the factors that had a negative impact on health, increasing age and lymphedema, significantly affected the physical, psychological and social subscales of quality of life. Finding that there is a strong relationship between physical, psychological and social well-being supports the theory that health is holistic (World Health Organization, 1946). Further research is required to determine how spiritual quality of life fits in with holistic well-being.

Limitations of Study

The current research has many implications for the holistic health and post-treatment quality of life for breast cancer survivors, although the study has some limitations. The sample was not overly diverse, with the majority of participants born in Canada or of European descent. Most of the women were highly educated in college or university, were financially secure and were married. In terms of recruitment, many of the women were participants at a "Life after

Breast Cancer" conference held by the Juravinski Regional Cancer Centre in Hamilton or were volunteering or participating in the activities of breast cancer support organizations. Therefore, the sample may not be representative of those women not currently receiving post-treatment support. Time was limited in this particular study. Therefore, the research analyzed was quantitative, allowing a lot of important information to be collected with many statistical implications for the sample and population. Cross-triangulation of methods to include qualitative findings to complement the statistical data would have offered a more in-depth and subjective explanation of the quantitative results.

Community Research: Lessons Learned

An important component of this thesis in Community Psychology was the opportunity to work with community organizations and to apply and integrate concepts, theories and community-based research skills learned through the program. I realized the value of both quantitative and qualitative data. Quantitatively, it is possible to reach a greater number of people, although qualitative results provide a more in-depth perspective into the data. Analyzing and publishing the qualitative results from the open-ended questions is a priority for me, to ensure that the women's voices from this research are heard.

Through this research, I had an opportunity to get actively involved in the breast cancer community. I worked with Knot-a-Breast, the Hamilton breast cancer dragon boat team, volunteered at the "Life after Breast Cancer" conference and attended local seminars. I was also in touch with most breast cancer support organizations in Hamilton and the surrounding area. After awhile, I was seeing familiar faces and felt very connected with the community, which was rewarding. Working with participants from the Knot-a-Breast team in the Community Advisory

Group was a great experience. I realized that it is sometimes difficult to recruit participants, since some are intimidated by the idea of research, so it is important to keep things interesting and make the women feel comfortable to share ideas. It is necessary to build these relationships over time, which was difficult in this particular study, although the women gave some great feedback and helped a lot in distributing the surveys to other breast cancer survivors. Overall, the breast cancer community is a very caring, helpful and supportive one that I hope will benefit from the research findings.

Dissemination Plan

Dissemination of the research results will help to achieve the overarching goals to promote understanding of the breast cancer experience and raise awareness to issues related to the holistic health of survivors. Academically, I plan to submit two different papers to be published in academic journals. The first will focus on the quantitative findings with respect to the factors contributing toward holistic health and well-being for breast cancer survivors. The second paper will report on the qualitative findings from the open-ended questions and sharing the participants' perspectives on what they feel is most important to improve life for breast cancer survivors. I have also presented the findings in a poster format at the Biennial Community Psychology conference that was held at Wilfrid Laurier University on May 12 – 14, 2006. Dissemination of results in the participating communities will involve distributing results to be posted at participating organizations should they choose to, including the regional cancer centre and other support organizations that helped to recruit participants in the area. In order to raise awareness within governmental organizations, a brief report outlining the key findings of the study may be distributed to regional health units and the new Local Health Integrated Networks.

Future Directions & Research

In addition to disseminating the results in the academic, breast cancer and healthcare communities, there are several directions for future research and interventions based on the current research findings. Some of the quantitative data may serve as a comparison for the Ontario Breast Cancer Dragon Boat Study to determine if there are holistic benefits for survivor dragon boaters that do not apply to breast cancer survivors in general. It would be interesting to look deeper qualitatively into the significant variables, such as exercise, volunteering and social and political involvement, to determine why these activities are especially beneficial for breast cancer survivors. There is also a need to further investigate the factors that decreased quality of life for the participants. For instance, how can research, services and support improve life for those suffering from lymphedema? What are the specific post-treatment needs of older breast cancer survivors that are not being met? Furthermore, why do women who live alone or without a significant other fare better psychologically and spiritually than other breast cancer survivors? The use of a variety of research traditions, such as surveys, qualitative interviews, focus groups, case studies and participatory research, in the study of breast cancer is important to advance a holistic understanding of women's experience (Wilkinson, 2000). Giving women a voice in the research can increase understanding of these socio-demographic variables and offer more in-depth explanations of their effect on the holistic health of survivors.

It is also important to translate the current findings into action through future interventions in terms of service, support and lifestyle for breast cancer survivors. For example, the finding that treatment by bilateral mastectomy contributes to post-traumatic distress should be an important consideration for doctors and women deciding on treatment for breast cancer and a priority for future research. The results reflect significant post-treatment needs for women, which continue throughout survivorship and over their lifetime. The medical community and service providers need to acknowledge these on-going needs and provide extra support for older women and those suffering from lymphedema. Breast cancer organizations may also encourage women to take an active role in improving their own quality of life by providing more opportunities for survivors to volunteer and participate in breast cancer support and advocacy. The findings of this study provide further evidence that breast cancer is a chronic disease and as such requires long-term studies and lifelong programs and support for survivors (Mitchell et al., in press). Future interventions may focus on increasing opportunities for breast cancer survivors to unite, create change and improve holistic well-being for women throughout the years of survivorship.

Conclusion

As a community psychology graduate student, this research has taught me so much about women, holistic health and well-being, and the experience of breast cancer. It seems counter-intuitive to study holistic health by breaking it down into smaller components. However, this study has confirmed that physical, psychological, social and spiritual aspects of well-being are not mutually exclusive. The individual elements of women's health are interconnected and affect each other in the years following diagnosis and treatment of breast cancer. It is specifically important to consider the holistic effects of the breast cancer experience with a consideration of the social and cultural contexts in our society. For example, losing a breast can be traumatic for women, not just in the physical sense, but concerning her femininity, her gender identity, and how she is viewed within society. Therefore, it is essential to study breast cancer holistically, and ecologically, determining the various impacts on a women's well-being including and beyond her physical functioning. With respect to women's typical role in society and social relationships, women are often focusing on the needs of others before their own, which can be detrimental for leading a healthy and balanced life and focusing on self care. It is important to consider the relationship between gender and health and the structural challenges women face post-treatment as we examine how the findings can be translated beyond individual level action to advances in treatment, after care, and public education.

Personally, I have learned that breast cancer can be an extremely traumatic experience. Although there are issues with pathologizing post-treatment experiences and needs and overemphasizing the lasting effects of a cancer diagnosis, there is a also an increasing danger in downplaying the severity of the breast cancer experience with a focus on the positive pink ribbon campaigns and the image of the courageous and 'happy' survivor. We need to advance the understanding of survivorship as complex and resist portraying breast cancer survivors as either victims or heroes, but rather as women who have been through a potentially life-threatening experience, and who are now re-learning to live beyond cancer diagnoses, treatment and the many changes and challenges this imposes. There needs to be discussion of both the positive strengths and resiliency of survivors and increased research into the continuing post-treatment concerns and issues associated with the experience of breast cancer as a chronic disease.

It has been a struggle to study breast cancer and women's experience from a community psychology perspective that values holism, social justice, diversity, and subjectivity, using a quantitative method, such as a survey, which has traditionally been portrayed and employed as an objective and value-free tool. Through this experience, I have grown as an academic and researcher to value diverse research methods, with the understanding that the context in which research instruments are developed and the dissemination and utility of the information within and to communities is important in pursuing knowledge for social change.

My findings tell a story about health and life for women after breast cancer that promotes understanding, choice, community and hope. This research may be seen as a tool for breast cancer survivors and communities, which can advance our knowledge about the chronicity of breast cancer and quality of life issues. It is my hope that these findings can be used in the advocacy work that is being done by a number of survivors to raise awareness, highlight the need for increased services and support, and contribute to changes for a better life for women after breast cancer.

APPENDIX I

Survey Instrument

Quality of Life Scale: BREAST CANCER

*Ferrell, Grant & Hassey-Dow, 1995

DIRECTIONS: We are interested in knowing how your experience of having cancer affects your Quality of Life. Please answer all of the following questions based on your life at this time.

Please circle the number from 0 – 10 that best describes your experiences:

Physical Well-Being

To what extent are the following a problem for you:

1. **Fatigue** No problem **0 1 2 3 4 5 6 7 8 9 10** Severe Problem

2. **Appetite changes** No problem **0 1 2 3 4 5 6 7 8 9 10** Severe Problem

3. **Aches or pain** No problem **0 1 2 3 4 5 6 7 8 9 10** Severe Problem

4. **Sleep changes** No problem **0 1 2 3 4 5 6 7 8 9 10** Severe Problem

5. **Weight Gain** No problem **0 1 2 3 4 5 6 7 8 9 10** Severe Problem

6. **Vaginal dryness / menopausal symptoms**
   No problem **0 1 2 3 4 5 6 7 8 9 10** Severe Problem

7. **Menstrual changes or fertility**
   No problem **0 1 2 3 4 5 6 7 8 9 10** Severe Problem

8. **Rate your overall physical health**
   Extremely Poor **0 1 2 3 4 5 6 7 8 9 10** Excellent

Psychological Well-Being

9. How difficult is it for you to cope today as a result of your disease?

Not at all difficult **0 1 2 3 4 5 6 7 8 9 10** Very difficult

10. How difficult is it for you to cope today as a result of your treatment?

Not at all difficult **0 1 2 3 4 5 6 7 8 9 10** Very difficult

11. How good is your quality of life?

Extremely Poor **0 1 2 3 4 5 6 7 8 9 10** Excellent

12. How much happiness do you feel?

None at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

13. To what degree do you feel like you are in control of things in your life?

Not at all **0 1 2 3 4 5 6 7 8 9 10** Completely

14. How satisfying is your life?

Not at all **0 1 2 3 4 5 6 7 8 9 10** Completely

15. How is your present ability to concentrate or to remember things?

Extremely Poor **0 1 2 3 4 5 6 7 8 9 10** Excellent

16. How useful do you feel?

Not at all **0 1 2 3 4 5 6 7 8 9 10** Extremely

17. Has your illness or treatment caused changes in your appearance?

Not at all **0 1 2 3 4 5 6 7 8 9 10** Extremely

18. Has your illness or treatment caused changes in your self concept (the way you see yourself)?

Not at all **0 1 2 3 4 5 6 7 8 9 10** Extremely

How distressing were the following aspects of your illness and treatment?

19. **Initial diagnosis**

Not at all distressing **0 1 2 3 4 5 6 7 8 9 10** Extremely distressing

20. **Cancer chemotherapy** (Complete only if you have had chemotherapy)

Not at all distressing **0 1 2 3 4 5 6 7 8 9 10** Extremely distressing

21. **Cancer radiation** (Complete only if you have had radiation)

Not at all distressing **0 1 2 3 4 5 6 7 8 9 10** Extremely distressing

22. **Cancer surgery**

Not at all distressing **0 1 2 3 4 5 6 7 8 9 10** Extremely distressing

23. **Hormone therapy (e.g. tamoxifen)** (Complete only if you have had hormone therapy)

Not at all distressing **0 1 2 3 4 5 6 7 8 9 10** Extremely distressing

24. **Completion of treatment**

Not at all distressing **0 1 2 3 4 5 6 7 8 9 10** Extremely distressing

25. How much **anxiety** do you have? (None at all 0, A great deal 10)

None at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

26. How much **depression** do you have?

None at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

To what extent are you <u>fearful</u> of:

27. **Future diagnostic tests**

No fear **0 1 2 3 4 5 6 7 8 9 10** Extreme fear

28. **A second cancer**

No fear **0 1 2 3 4 5 6 7 8 9 10** Extreme fear

29. **Recurrence of your cancer**

No fear **0 1 2 3 4 5 6 7 8 9 10** Extreme fear

30. **Spreading (metastasis) of your cancer**

No fear **0 1 2 3 4 5 6 7 8 9 10** Extreme fear

31. To what degree do you feel your life is back to **normal?**

None at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

Social Concerns

32. How distressing has your illness been for your **family?**

Not at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

33. Is the amount of support you receive from others sufficient to meet your needs?

Not at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

34. Is your continuing health care interfering with your **personal relationships?**

Not at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

35. Is your **sexuality** impacted by your illness?

Not at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

36. To what degree has your illness and treatment interfered with your **employment**?

Not at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

37. To what degree has your illness and treatment interfered with your **activities at home**?

Not at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

38. How much **isolation** do you feel is caused by your illness?

Not at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

39. How much **concern** do you have for your daughter(s) or other female relatives regarding breast cancer?

None at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

40. How much **financial burden** have you incurred as a result of your illness and treatment?

None at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

Spiritual Well-Being

41. How important to you is your participation in **religious activities** such as praying, going to church or temple?

Not at all important **0 1 2 3 4 5 6 7 8 9 10** Very important

42. How important to you are other **spiritual activities** such as meditation and praying?

Not at all important **0 1 2 3 4 5 6 7 8 9 10** Very important

43. How much has your **spiritual life** changed as a result of your cancer diagnosis?

Not at all important **0 1 2 3 4 5 6 7 8 9 10** Very important

44. How much **uncertainty** do you feel about your future? (Not at all uncertain 0, Very uncertain 10)

Not at all uncertain **0 1 2 3 4 5 6 7 8 9 10** Very uncertain

45. To what extent has your illness made **positive changes** in your life?

None at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

46. Do you sense a **purpose / mission** for your life or a reason for being alive?

None at all **0 1 2 3 4 5 6 7 8 9 10** A great deal

47. How **hopeful** do you feel? (Not at all hopeful 0, Very hopeful 10)

Not at all hopeful **0 1 2 3 4 5 6 7 8 9 10** Very hopeful

Mental Adjustment to Cancer Scale (MAC)

*Watson & Greer, 1986

INSTRUCTIONS: A number of statements are given below which describe people's reactions to having cancer. Please circle the appropriate number to the right of each statement, indication how far it applies to you at present. For example, if the statement definitely does not apply to you then you should circle 1 in the first column.

(Definitely does not apply to me **1**, Does not apply to me **2**, Applies to me **3**, Definitely applies to me **4**)

1. I have been doing things that I believe will improve my health e.g. changed my diet

1 2 3 4

2. I feel I can't do anything to cheer myself up **1**

2 3 4

3. I feel that problems with my health prevent me from planning ahead **1**

2 3 4

4. I believe that my positive attitude will benefit my health **1**

2 3 4

5. I don't dwell on my illness **1**

2 3 4

6. I firmly believe that I will get better **1**

2 3 4

7. I feel that nothing I can do will make any difference **1**

2 3 4

8. I've left it all to my doctors **1**

2 3 4

9. I feel that life is hopeless **1**

2 3 4

10. I have been doing things that I believe will improve my health, e.g. exercised **1**

2 3 4

11. Since my cancer diagnosis, I realize how precious life is, I'm making the most of it **1**

2 3 4

12. I've put myself in the hands of God **1**

2 3 4

13. I have plans for the future, e.g. holiday, jobs, housing **1**

2 **3** **4**

14. I worry about the cancer returning or getting worse **1**

2 **3** **4**

15. I've had a good life and what's left is a bonus **1**

2 **3** **4**

16. I think my state of mind can make a lot of difference to my health **1**

2 **3** **4**

17. I feel that there is nothing I can do to help myself **1**

2 **3** **4**

18. I try to carry on my life as I've always done **1**

2 **3** **4**

19. I would like to make contact with others in the same boat **1**

2 **3** **4**

20. I am determined to put it all behind me **1**

2 **3** **4**

21. I have difficulty in believing that this happened to me **1**

2 **3** **4**

22. I suffer great anxiety about it **1**

2 **3** **4**

23. I am not very hopeful about the future **1**

2 **3** **4**

24. At the moment I take one day at a time **1**

2 **3** **4**

25. I feel like giving up **1**

2 **3** **4**

26. I try to keep a sense of humour about it **1**

2 **3** **4**

27. Other people worry about me more than I do **1**

2 **3** **4**

28. I think of other people who are worse off **1**

2 **3** **4**

29. I am trying to get as much information as I can about cancer **1**

2 **3** **4**

30. I feel that I can't control what is happening **1**

2 **3** **4**

31. I try to have a very positive attitude **1**

2 **3** **4**

32. I keep quite busy, so I don't have time to think about it **1**

2 **3** **4**

33. I avoid finding out more about it **1**

2 **3** **4**

34. I see my illness as a challenge **1**

2 **3** **4**

35. I feel fatalistic about it **1**

2 **3** **4**

36. I feel completely at a loss about what to do **1**

2 **3** **4**

37. I feel very angry about what has happened to me **1**

2 **3** **4**

38. I don't really believe I had cancer **1**

2 **3** **4**

39. I count my blessings **1**

2 **3** **4**

40. I try to fight the illness **1**

2 **3** **4**

PCL-C (PTSD Checklist, Civilian Version) *Weathers, Litz, Huska & Keane, National Center for P

INSTRUCTIONS: Below is a list of problems and complaints that people sometimes have in response to stressful life experiences (such as breast cancer). Please read each one carefully, and then circle one of the numbers to the right to indicate how much you have been bothered by that problem <u>in the past month.</u>

(Not at all **1**, A little bit **2**, Moderately **3**, Quite a bit **4**, Extremely **5**)

1. Repeated, disturbing **memories, thoughts, or images** of a stressful experience from the past?

1 **2** **3** **4** **5**

2. Repeated, **disturbing dreams** of a stressful experience from the past?

1 **2** **3** **4** **5**

3. Suddenly **acting or feeling** as if a stressful experience **were happening again** (as if you were reliving it)? **1 2**
   3 4 5
4. Feeling **very upset** when **something reminded you** of a stressful experience from the past?
   1 2 3 4 5
5. Having **physical reactions** (e.g., heart pounding, trouble breathing, sweating) when **something reminded you** of a stressful experience from the past?
   1 2 3 4 5
6. Avoiding **thinking about** or **talking about** a stressful experience from the past or avoiding **having feelings** related to it?
   1 2 3 4 5
7. Avoiding **activities or situations** because **they reminded you** of a stressful experience from the past?
   1 2 3 4 5
8. Trouble **remembering important parts** of a stressful experience from the past?
   1 2 3 4 5
9. **Loss of interest** in activities that you used to enjoy?
   1 2 3 4 5
10. Feeling **distant or cut off** from other people?
    1 2 3 4 5
11. Feeling **emotionally numb** or being unable to have loving feelings for those close to you?
    1 2 3 4 5
12. Feeling as if your **future** will somehow be **cut short**?
    1 2 3 4 5
13. Trouble **falling or staying asleep**?
    1 2 3 4 5
14. Feeling **irritable** or having **angry outbursts**?
    1 2 3 4 5
15. Having **difficulty concentrating**?
    1 2 3 4 5
16. Being **"super-alert"** or watchful on guard?
    1 2 3 4 5
17. Feeling **jumpy** or easily startled?
    1 2 3 4 5

Self-Transcendence Scale

*Reed, Pamela, 1987

DIRECTIONS: Please indicate the extent to which each item below describes you. There are no right or wrong answers. I am interested in your frank opinion. As you respond to each item, think of how you see yourself <u>at this time of your life.</u> Circle the number that is the best response for you.

(Not at all **1**, Very little **2**, Somewhat **3**, Very much **4**)

At this time in my life, I see myself as:

1. Having hobbies or interests I can enjoy.

   1 2 3 4

2. Accepting myself as I grow older.

   1 2 3 4

3. Being involved with other people or my community when possible.

   1 2 3 4

4. Adjusting well to my present life situation.

   1 2 3 4

5. Adjusting to the changes in my physical abilities.

   1 2 3 4

6. Sharing my wisdom or experience with others.

   1 2 3 4

7. Finding meaning in my past experiences.

   1 2 3 4

8. Helping younger people or others in some way.

   1 2 3 4

9. Having an interest in continuing to learn about things.

   1 2 3 4

10. Putting aside some things that I once thought were so important.

1 2 3 4

11. Accepting death as a part of life.

1 2 3 4

12. Finding meaning in my spiritual beliefs.

1 2 3 4

13. Letting others help me when I may need it.

1 2 3 4

14. Enjoying my pace of life.

1 2 3 4

15. Dwelling on my past unmet dreams or goals.

1 2 3 4

Demographic Information Sheet

Basic Personal Information

1. Year of birth: ____________
2. In what country were you born? ______________________
3. If other than Canada, what is the year you came to Canada? ________
4. What is your first language? _________________________
5. What is your current relationship status:
    - ☐ I am single
    - ☐ I am married or in a committed relationship
    - ☐ I am separated or divorced
    - ☐ I am widowed
6. Living arrangements (Please check all that apply)
    - ☐ I live alone
    - ☐ I live with a partner / spouse / significant other
    - ☐ I live with dependants (children or parents), # of children / parents: ______
    - ☐ I live with other family or friends

7. Current Work Status (Please check all that apply)

   - ☐ Working full-time
   - ☐ Working part-time
   - ☐ Paid leave (e.g. receiving EI benefits, long-term disability)
   - ☐ Retired
   - ☐ Student
   - ☐ Homemaker
   - ☐ Seeking employment
   - ☐ Community volunteer

8. What is / was your occupation? ______________________________

9. Highest level of education you have completed:

   - ☐ No formal education
   - ☐ Up to high school
   - ☐ High school and / or some post-secondary
   - ☐ Trades certificate or diploma
   - ☐ College certificate or diploma
   - ☐ University certificate, diploma or degree

10. Household income per year:

    - ☐ Below 30,000
    - ☐ 30,000 – 45,000
    - ☐ 46,000 – 60,000
    - ☐ 61,000 – 70,000
    - ☐ Over 70,000

11. Do you currently participate in any physical activities? If so, how many times a week do you train in each activity in each time period as follows? ____________

Physical Activity	# Times / Week May - Sept	# Times / Week Oct - Jan	# Times / Week Feb - April
Running / Walking	☐ Do not train ☐ Once ☐ Twice ☐ Three or More	☐ Do not train ☐ Once ☐ Twice ☐ Three or More	☐ Do not train ☐ Once ☐ Twice ☐ Three or More
	☐ Do not train	☐ Do not train	☐ Do not train

Weight Training	☐ Once ☐ Twice ☐ Three or More	☐ Once ☐ Twice ☐ Three or More	☐ Once ☐ Twice ☐ Three or More
Yoga	☐ Do not train ☐ Once ☐ Twice ☐ Three or More	☐ Do not train ☐ Once ☐ Twice ☐ Three or More	☐ Do not train ☐ Once ☐ Twice ☐ Three or More
Swimming	☐ Do not train ☐ Once ☐ Twice ☐ Three or More	☐ Do not train ☐ Once ☐ Twice ☐ Three or More	☐ Do not train ☐ Once ☐ Twice ☐ Three or More
Other, Please Specify: ______________	☐ Do not train ☐ Once ☐ Twice ☐ Three or More	☐ Do not train ☐ Once ☐ Twice ☐ Three or More	☐ Do not train ☐ Once ☐ Twice ☐ Three or More

Breast Cancer History and Health

12. Year of Diagnosis: ______________

13. Stage at first diagnosis:

☐ Stage I
☐ Stage II
☐ Stage III
☐ Stage IV
☐ Don't know

14. Which of the following treatments have you received for your cancer? (Please check all that apply)

☐ Lumpectomy
☐ Mastectomy
☐ Bi-Lateral Mastectomy
☐ Radiation Therapy
☐ Chemotherapy
☐ Hormone Therapy (e.g. tamoxifen)
☐ Alternative / complementary therapies (e.g. acupuncture, naturopathy)
☐ Other, please specify:
☐ None of the above

15. Have you ever experienced lymphedema?

☐ Yes, if so please state year, and length of time experienced:

☐ No

16. Have you had a recurrence since your initial diagnosis?

☐ Yes, if so please state year:

☐ No

Social and/or Political Involvement

17. Are you involved in breast cancer support or advocacy (eg. volunteering with cancer organization, run or walk for the cure etc., lobbying for funding for research, increased (post) treatment options, health promotion and prevention, etc.)?

☐ Not at all

☐ Occasionally Involved

☐ Significantly Involved

Open-Ended Question:

a) What do you feel is the most important way to improve life for those affected by breast cancer?

b) If you have significantly been involved in breast cancer support or advocacy, please elaborate on your participation and how these activities can make a difference for people affected by breast cancer.

Thank you very much for participating!

APPENDIX II:

Creation of Scale & Subscale Scores

In order to analyze the scales in the survey, it was necessary to calculate scores for each subscale of the Quality of Life Scale, for the PCL-C Scale and the Self-Transcendence Scale. With respect to some questions, it was necessary to reverse the Likert Scale to interpret the score of the scale or subscale as reflecting a positive or negative outcome. For example, most questions on the Quality of Life Scale measure a negative outcome, such as "To what extent are the following a problem for you?" In this case, a higher number or score indicates a more severe problem. However, a few questions are phrased differently, in which a higher score indicates a positive outcome, such as "Rate your overall physical health". Therefore, the following sections indicated the methods for creating scores, indicating which questions were reversed in each scale or subscale.

Quality of Life Scale

Physical Quality of Life

The Physical Quality of Life subscale was calculated based on Questions 1-8 of the Quality of Life Scale (refer to Appendix I). Questions 1 – 7 were phrased to reflect a negative outcome. Question 8 was reversed in order to represent a negative outcome. Therefore, a higher the score on the physical subscale indicates poorer the physical quality of life.

Psychological Quality of Life

Questions 9 – 31 on the Quality of Life Scale measure psychological well-being. As was the case with physical quality of life, majority of these questions measure negative psychological functioning. Therefore, questions 11-16, and 31 have all been reversed in order to reflect negative outcomes. Higher scores on the psychological quality of life subscale indicate poorer psychological quality of life.

Social Quality of Life

Questions 32-40 of the Quality of Life Scale pertain to social concerns of breast cancer survivors. All questions on this subscale are phrased negatively, representing poorer social quality of life. Therefore, none of the questions were reversed.

Spiritual Quality of Life

The last 7 questions of the Quality of Life Scale, 41-47, are based on spiritual well-being. Most of these questions are phrased to indicate spiritual well-being. However, in order to be consistent with the previous scales, these positive questions (41-43, 45-47) were reversed to represent negative spiritual outcomes.

PCL-C

The questions on the PCL-C Scale are designed so that a higher scale on each question indicates a higher degree of trauma and post-traumatic stress. Participants that score 50 or higher on the PCL-C can be diagnosed with Post-Traumatic Stress Disorder. Therefore, it was not necessary to reverse any of the questions.

Self-Transcendence Scale

The Self-Transcendence Scale is the only tool in the survey in which a higher score indicates a positive outcome, a higher degree of self-transcendence. The first 14 out of 15 questions are phrased positively. Question 15 was reversed to be positive and consistent with the other questions.

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