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Adaptation to breast cancer following an autologous peripheral blood stem cell transplant: A prospective study.

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UMI
ADAPTATION TO BREAST CANCER FOLLOWING AN AUTOLOGOUS PERIPHERAL BLOOD STEM CELL TRANSPLANT: A PROSPECTIVE STUDY

by
Christina M. Dales

A Thesis
Submitted to the Faculty of Graduate Studies and Research through the School of Nursing in Partial Fulfillment of the requirements for the degree of Master of Science at the University of Windsor

Windsor, Ontario, Canada

2001

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ABSTRACT

This study examined how stressors and coping resources influenced quality of life in women with metastatic breast cancer who had received an autologous peripheral blood stem cell transplant as treatment for their disease. Lazarus and Folkman's (1984) stress/adaptation model was used to guide this prospective study. Perceived stress appraisal, symptom distress, optimism, and social support were measured to determine if they predicted the breast cancer patient's quality of life, prior to and following an autologous peripheral blood stem cell transplant. Twenty-seven women with metastatic breast cancer Stage II – IV participated in the study and completed questionnaires at three time periods.

The stressors and coping resources did not predict QOL when entered into a hierarchical regression model, probably due to the small sample size. However, there were significant correlations between stressors, coping resources and adaptation (QOL). Women with breast cancer reported low perceived stress appraisal, low symptom distress, more optimism and more social support when they reported higher levels of QOL prior to transplant. Following transplant the pattern continued for all variables except social support. It was also clearly evident that the one month post-transplant time period was most difficult for the women when they reported the highest stress appraisal and highest symptom distress, but by month three the women were reporting lower stress appraisal, less symptom distress, more optimism and improved quality of life. Implications for nursing practice are discussed.
DEDICATION

To my family, this would not have been possible without your support, my husband Christopher and my daughter Kennedy, my parents Roger and Patricia Toffolo and my parents-in-law James and Marilyn Dales.
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To my advisor, Dr. Sheila Cameron my sincere gratitude for her dedication and words of encouragement throughout the process of my thesis research. I would also like to extend a sincere thank you to my internal reader, Dr. Laurie Carty and my external reader, Dr. Kathryn Lafreniere for their assistance with my thesis research. I would also like to acknowledge Mrs. Robyn Nease for her assistance and expertise with the data analysis for my thesis research.

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CHAPTER ONE

Introduction

Statement of the Problem

It was estimated that almost 19,000 Canadian women would be diagnosed with breast cancer in 1999 and almost twenty-nine percent of those women would die from the disease (National Cancer Institute of Canada, 1999). It was also estimated that one out of every nine Canadian women would be diagnosed with breast cancer at some point in their lives and one out of every twenty-five women would die from the disease (National Cancer Institute of Canada, 1999).

Although cancer has been noted to be a disease of the elderly (National Cancer Institute of Canada, 1999), younger women who are diagnosed with breast cancer have a much poorer prognosis than older women. This is because breast cancer is thought to be a much more aggressive form in young women (Chung, Chang, Bland & Wanebo, 1996). The life expectancy of young women can be cut short dramatically by metastatic breast cancer (Chung et al., 1996; Schmidt, Tsangaris, Cheek, 1991). In breast cancer, the majority of Canadian women affected by the disease were diagnosed prior to their seventieth birthday (National Cancer Institute of Canada, 1999). In fact, twenty-two percent of the women diagnosed with breast cancer were diagnosed before age fifty and forty-five percent of all newly diagnosed breast cancer patients were diagnosed between the ages of fifty and sixty-nine years (National Cancer Institute of Canada, 1999).

Medical advances in breast cancer treatment have increased exponentially over the last two decades (Baynes et al., 1998; Cameron et al., 1996), but still, health care professionals believe that each woman who dies from conventional chemotherapy as the primary treatment for metastatic breast cancer represents a failure to the medical
community (Baynes et al., 1998). Women who face the devastating medical diagnosis of advanced metastatic breast cancer disease are left with few treatment alternatives. Advanced metastatic breast cancer with the use of conventional chemotherapy treatment has remained essentially an incurable disease; therefore early detection of the disease has become a priority (Crilley & Goldstein, 1995). Metastatic breast cancer generally has very poor outcomes, with the vast majority of women succumbing to the disease within five years of initial treatment (Crilley & Goldstein, 1995). Therefore, the need to utilize a more intensive form of high dose chemotherapy followed by hematopoietic stem cell rescue became apparent and a rather popular treatment (Baynes et al., 1998). This treatment modality is referred to as an autologous peripheral blood stem cell transplant (PBSCT). Researchers noted the survival rate of many women affected with metastatic breast cancer treated with an autologous PBSCT rose to approximately twenty percent after a five year period (Bitran et al., 1996; Crilley & Goldstein, 1995; Leonard, 1995). To date, treatment with an autologous PBSCT is the only treatment modality which offers these women hope for a possible cure for metastatic breast cancer (Baker, Vukelja, Lee, & Perry, 1998; Gisselbrecht et al., 1996).

An increasing number of breast cancer patients are choosing a transplant as treatment to fight their cancer (Lucey & Westphal, 1998). However as medical advances continue to take new strides, little attention has been devoted to the quality of life (QOL) or level of adaptation that these women experience after their transplant regardless of their disease status. After a period of five years (Baker et al., 1998), an increasing number of women with metastatic breast cancer who had an autologous PBSCT are alive but health care professionals need to evaluate the quality of women’s lives after treatment. Information regarding the QOL of breast cancer patients after specific
treatment modalities such as an autologous PBSCT, or adjuvant chemotherapy, may provide a better understanding about the patient's experience beyond the highly publicized disease-free interval. QOL has become a component of outcome evaluation and has also been considered as a measurement of the effectiveness of the proposed treatment (Hann et al., 1997a).

For the purposes of this study, quality of life will be defined as the breast cancer patient's perceived sense of well-being (Ferrell et al., 1992a). This perceived well-being encompasses six dimensions; physical well-being, emotional well-being, social well-being, functional well-being, relationship with doctor and additional concerns (McQuellon et al., 1997).

Measurements of QOL can be included in patient outcome evaluation to further assist health care professionals in individualizing the care of the patient. QOL measurements can enhance prospective treatment plans by viewing the trends of the patient's previous adaptation. The effect of a treatment regimen on the patient's lifestyle and her ability to return to normal functioning must also be included in patient outcomes and evaluation of treatment modalities. QOL measurements from patients with metastatic breast cancer will be helpful to nurses and other health care professionals as the measurements will enable the health care professionals to better understand the adaptation process of the breast cancer patients who undergo an autologous PBSCT. As more and more women are choosing this treatment modality in a desire for a cure for breast cancer it is hoped that this study will provide these women necessary knowledge regarding QOL after transplant to make an informed decision about treatment.

QOL measurements also have implications for nursing. QOL is considered to be a multidimensional concept that encompasses physical, psychological, social and spiritual
domains (Dow, Ferrell, Haberman, & Eaton, 1999). Nurses can assist patients and family members by helping them set realistic goals that are attainable for the patient. Health related concerns may be decreased by patient teaching and reinforcement of health promoting behaviours (Belec, 1992). The nurse can also act by providing helpful resources to the patient and family members such as counsellors, and social workers that may assist the patient to return to her prior level of functioning. For patients who experience physical limitations such as fatigue, the nurse can act by reviewing energy conservation activities for the patient (Belec, 1992).

Women who have the option of an autologous PBSCT for metastatic breast cancer are frequently quite young. Transplant centers involved with treating breast cancer patients note that these women fall between the ages of twenty-five and sixty-five years of age (McQuellon et al., 1996; Hann et al., 1997a). For many of these women it is a time in their lives when families are dependent upon them and their careers are a paramount part of their lives. After an autologous PBSCT many of these women may become dependent on family and friends and they may not be able to work for some time (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997). These factors and many others may affect the breast cancer patient’s QOL post-transplantation (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998b; Ferrell et al., 1997). Breast cancer affects women from all levels of socioeconomic class, educational background and culture. No one is immune.

Breast cancer patients face several other stressors in addition to their disease status. These stressors can have either a positive or a negative effect on the patient’s ability to cope. Various stressors that may inhibit the patient’s ability to adapt are the presence of physical symptoms, financial barriers, and the lack of social support (Ferrell et al., 1998b; Ferrell et al., 1997). The aid of support systems may help to alleviate the
stresors. Nurses can provide patients with referrals to financial counsellors, social workers and appropriate support groups. Both patients and family members may also have a better understanding of the physical symptoms after the nurse provides informational support and in-depth information on specific symptoms.

Autologous PBSCT has now become an effective treatment modality for approximately twenty percent of women with advanced metastatic breast cancer (Ayash et al., 1996). However, many of the women who undergo this treatment are left with feelings of uncertainty regarding their prospective treatment and their QOL post-transplantation (Ferrell et al., 1992a). They are unsure if they are making the correct treatment choice and fear relapse post-transplantation (Decker, 1995). During the pre-treatment and in-patient phase of the transplant process nurses can act to educate the patient on ways to cope more effectively and assist the patient in expanding her coping resources. Doing this may facilitate adaptation and improve QOL status post-transplantation. Patient adaptation or maladaptation post-transplantation presents nurses and family members new challenges.
Theoretical Framework

Adapted from Lazarus and Folkman, 1984

External Coping Resource
- Social Support: Tangible Support
- Informational/Emotional Support
- Social Interaction
- Affection
- Social Network

Stimulus
- Perceived Stress
- Appraisal
- Symptom Distress

Internal Coping Resource
- Optimism

 Adaptation Response to Stimulus QOL

To examine the impact of an autologous PBSCT on QOL in breast cancer patients, a theoretical framework was used to explore the adaptation process of these patients. Lazarus and Folkman's (1984) theory of stress and adaptation was used for this purpose. Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are
appraised as taxing or exceeding the resources of the person.” (p. 141). Throughout the treatment process for breast cancer, individuals attempt to overcome various stressors perceived as either threats or challenges. This process can be referred to as the coping process. Initially the patient appraises the situation. This appraisal may be derived as a result of many factors; physical symptoms, past experience, age, education, and social support. The reaction to the stressors may be related to prognosis of the disease or symptoms that the patient may be presenting at that time. Coping tasks of the individual act to reduce negative stressors, maintain positive self-esteem, and to continue satisfying relationships with others (Lazarus & Folkman, 1984). The end result of this process is either adaptation or maladaptation.

In this study, both internal and external coping resources were explored, over time, to view the relationship between coping resources and adaptation of a patient with breast cancer who has undergone an autologous PBSCT as treatment. The treatment of an autologous PBSCT is viewed as the stimulus and the outcome, patient adaptation, the response. Using Lazarus and Folkman’s (1984) model of adaptation, we examined the relationship between internal and external coping resources on adaptation. According to Lazarus and Folkman (1984), internal coping resources refer to one’s personality traits, and external coping resources refer to the individual’s social and material support availability. Internal and external coping resources, coupled with the stressful event, the PBSCT, will produce a response to the stimulus i.e., adaptation or maladaptation. For the purposes of this study the term adaptation involves the patient’s ability to accommodate or adjust to her level of well-being. Conversely maladaptation will be the individual’s inability to adjust to her level of well-being.
Significance of the Problem

The results of this study will be beneficial to breast cancer patients in various stages of disease and treatment by expanding the knowledge base regarding post-transplant recipients’ level of adaptation. It is hoped that this investigation will also provide knowledge to aid in the treatment decision-making process. Women considering transplantation, as a treatment option will be able to make an informed decision regarding transplantation by taking into account the experiences of women who have already undergone the transplant process. This study may also aid both the nursing staff and the significant others of breast cancer survivors to facilitate adaptation for the patients involved. Both the nursing staff and significant others would have an expanded knowledge base regarding the experiences of past patients and this knowledge could then benefit current and future patients. The results of this study will be useful in evaluating the outcome of an autologous PBSCT for metastatic breast cancer with respect to the QOL of these patients. This investigation may also assist nurses, and significant others, by increasing their knowledge base about stress appraisal, the role of optimism, and the importance of adequate social support and how these factors relate to the breast cancer patient’s ability to adapt to her circumstances.

The results of this study will be beneficial to nursing. When nurses evaluate all aspects of social support: tangible, affectional, social interaction, emotional/informational support, and social network, they may be able to better anticipate the needs of patients. This will aid clients in adaptation during the post-transplantation period. Nurses will provide patients with the necessary social support. Patients who are overwhelmed by physical symptoms will receive tangible support as well as informational support from the nursing staff. Nurses can also act to refer patients to
support groups so that they will receive the necessary emotional support. Investigation of
the quality and size of the client’s support network may also anticipate future needs of the
transplant recipient.

Aggressive forms of treatment such as an autologous bone marrow transplant
(BMT)/ PBSCT for breast cancer have been successful in terms of extending life (Ayash
et al., 1996). However, many of the side effects and sacrifices that patients endure in
order to increase their life expectancy have resulted in the need for health care
professionals to also consider on the quality of life of patients who have undergone such
an advanced form of treatment (Haas, 1999). Nurses who have an understanding of the
adaptation process can provide their clients optimal care by offering additional coping
resources for the patient and family members.

When using Lazarus and Folkman’s (1984) model of adaptation, coping resources
may play an important role in adaptation. Nurses who become familiar with Lazarus and
Folkman’s (1984) adaptation model may use it to anticipate the needs of breast cancer
patients who undergo an autologous PBSCT for treatment. The nurse and client may
work together to set mutual goals that promote adaptation. For the purpose of this study
the medical treatment of an autologous PBSCT was referred to as the stimulus and the
patient’s adaptation, the response to the stimulus. Factors that influence the response
were the patient’s appraisal of the stressful event, physical symptoms as well as their
coping resources. Both internal and external resources were investigated to determine
their relationship to the outcome, QOL.
CHAPTER TWO

Review of the Literature and Related Theory

Breast Cancer and Transplantation

Metastatic breast cancer can be defined as cancer of the breast tissue with any size of tumor that has metastasized to the lymph nodes. Metastatic breast cancer also has a distant metastasis site, i.e. lungs, liver, bone. (American Joint Committee on Cancer, 1998).

Patients who receive either an autologous bone marrow transplant (ABMT) or an autologous PBSCT for breast cancer are given combinations of high-dose chemotherapy followed by the reinfusion of the patient’s bone marrow or peripheral blood stem cells. The use of the high-dose chemotherapeutic agents may cause complications to multiple organs, the liver, lungs, heart, kidneys, skin and bone marrow. These physical functioning stressors can pose a severe threat to the patient’s QOL (Crilley & Goldstein, 1995). Although most of these complications occur early in the transplant process, some of the complications may become evident later following transplant. Follow-up of transplant patients over an extended period of time would enable the investigators to view any possible changes in their perceived QOL related to delayed complications (Molassiotis et al., 1995).

QOL studies in women with breast cancer who have undergone an ABMT have presented varying results from impaired functioning to improved functioning post-transplantation (Hann et al., 1997a; McQuellon et al., 1996). Further investigations are required to provide clarity regarding QOL issues in this population. In two recent comparative studies (Hann et al., 1997a; McQuellon et al., 1996), the QOL of breast cancer patients who had received an ABMT was measured. Both of these studies used
different instruments. In the first study the instruments used were the SF-36 Health Survey, Performance Status Rating (PSR), and Memorial Symptom Assessment Scale (MSAS). Hann et al., (1997) compared the QOL of forty-three breast cancer patients who received an ABMT with forty-three women who had no history of malignant disease. The results of this study indicated that the women who had received an ABMT reported “significantly impaired physical functioning, general health, vitality and social functioning” (p. 257) compared to women who had no prior history of cancer. In a similar study by Hann et al., (1997b), women treated with an ABMT were compared to women who had no history of cancer. This investigation found that fatigue was found to impair a breast cancer patient’s QOL post-transplantation.

McQuellon et al., (1996) looked at the QOL of breast cancer patients before and after an ABMT using the Functional Assessment Cancer Therapy - Bone Marrow Transplant (FACT-BMT) Scale, the Profile of Mood States, the Total Mood Disturbance Scale (POMS-TMDS) and the Medical Outcome Study-Social Support Survey (MOS-SSS). The sample consisted of twenty-four patients with breast cancer varying from high-risk Stage II through Stage IV metastatic disease. The results of this study indicated that all three measures showed “improved post-transplant functioning” concerning functional well-being, total FACT score, and Total Mood Disturbance Score (McQuellon et al., 1996, p. 581). Social support did not change significantly from pre to post-transplant status.

After an autologous PBSCT for breast cancer was completed, patients expressed several psychological impacts once their physical complications had become manageable (Ferrell et al., 1998b). Patients expressed feelings of depression, uncertainty towards the future (Hann et al., 1997a) and anxiety (Ferrell et al., 1998b).
Transplant Related

In the late 1980s physicians began to investigate the role of high dose chemotherapy followed by an autologous bone marrow transplant for metastatic breast cancer. This treatment modality received attention almost immediately from both the medical community and the media. Those who pioneered the treatment were excited to see an increase in women with advanced breast cancer who were relapse free after three years post-transplant (Frei, Antman, Teicher, Eder & Schnipper, 1989; Peters et al., 1988). Medical technology was expanding to what is now a very broad knowledge base. The focus of treatment was to increase the life expectancy of women treated with metastatic breast cancer. Little attention was devoted to these women returning to their normal functioning or QOL post-transplantation.

An autologous peripheral blood stem cell transplant consists of the collection of the patient’s peripheral blood stem cells, an intensive course of high dose chemotherapy followed by the reinfusion or transplantation of the patient’s own peripheral blood stem cells. The word autologous is used to describe the transplant because the patient’s own cells are used instead of cells from a donor. An autologous PBSCT can result in several life threatening complications, complications which occur less frequently with conventional chemotherapy regimens (Kalaycioglu, Lichtin, Andresen, Tauson, & Bolwell, 1995). Compared to standard chemotherapy treatment, the incidence of complications such as severe mouth sores, renal failure, infection, and severe nausea and vomiting are much more frequent with an autologous PBSCT (Cameron et al., 1996). Long term follow-up has also noted the development of leukemia possibly from the administration of the high dose chemotherapy (Lucey & Westphal, 1998).
Several studies described patients who were continually overwhelmed with physical ailments as a result of the transplant. Transplant patients reported that fatigue was the greatest problem related to QOL (Andrykowski et al., 1997; Hann et al., 1997b; Ferrell et al., 1998a; McQuellon et al., 1998). Breast cancer patients also reported depressive symptoms post-transplantation (McQuellon et al., 1996).

**Quality of Life**

In 1993, The World Health Organization, (WHO) defined quality of life as how an individual perceives his/her life. The concept of QOL encompasses cultural beliefs and the individual’s value system. Haas (1999) conducted a study to clarify the concept of QOL. She reported that QOL is made up of several subjective and objective indicators. Her findings reported that subjective indicators were comprised of well-being and life satisfaction. An individual’s performance status or functional status was referred to as an objective indicator. Throughout the literature, there is a range of definitions concerning QOL. Molassiotis & Morris (1998) stated that QOL is a “subjective concept, and only the individual himself is the proper judge of his well-being” (p.206). Dibble, Padilla, Dodd, & Miaskowski (1998) defined QOL as a “multidimensional concept that includes physical functioning and psychological well-being” (p. 577). A common theme regarding QOL appears to be the individual’s perceived life satisfaction (Young & Longman, 1983; Meeberg, 1993; Zhan 1991). Ferrell et al., (1992a) devised a QOL model that encompassed four dimensions of quality of life: physical well-being and symptoms, psychological well-being, social well-being and spiritual well-being.

A recent study regarding QOL in women with metastatic breast cancer reported that women with an oncology related diagnosis were concerned with both physical and psychosocial aspects of their QOL whereas men being treated for cancer were more
concerned with vitality and personal resources (Dibble et al., 1998). An individual’s QOL is influenced by current life situations, past experiences, and the anticipation of future events (Belec, 1992). Past research on QOL noted that fatigue, uncertainty, depression, impaired physical functioning and financial difficulties affected breast cancer patients’ ability to adapt to their own level of quality of life post autologous BMT as well as their ability to adapt to their QOL (Hann et al., 1997b; McQuillon et al., 1996; Ferrell et al., 1992a).

Social Support

The types of social support examined in this study are tangible support, social interaction, affection, emotional / informational support and social network. Tangible support involves providing services for someone who is ill. Social interaction is the amount that an individual interacts with others. Affection refers to the amount of affection that an individual is receiving from others. Emotional support refers to the support received from being able to confide in another person. Informational support requires that a professional provide the client with information, advice or feedback. Social network refers to the quality and number of relationships that the client has available to them (Sherbourne & Stewart, 1991)

Several studies have been done regarding the social support of oncology patients. These studies reported that patients with strong social support networks do much better when faced with a life threatening illness (Goodwin, Hunt, Key, & Samet, 1987; Halstead & Fernsler, 1994). In a large retrospective study by Goodwin et al., (1987) marital status and disease survival rate were examined. Subjects who were married had much higher survival rates than those with advanced cancer who were single. It was further noted that BMT patients receive more social support than breast cancer patients who are receiving
conventional chemotherapy. BMT patients reported that the support that nurses gave them was important (Molassiotis, Van den Akker, Boughton, 1997). Ferrell et al., (1992b) also found that BMT patients valued their family relationships but were stressed with the financial burdens caused by not returning to work. Patients also added, in this study, that providing emotional support groups for them have been beneficial. Bone marrow transplant recipients also reported that sexual difficulties post-transplantation had a negative impact on their relationships with partners (McQuellon et al., 1996).

**Perceived Stress Appraisal**

Lazarus & Folkman (1984) define stress appraisal to include potential harm/loss, threat or challenge. In 1999, a study by Northouse et al., investigated the quality of life of African-American women with breast cancer. Ninety-eight women with breast cancer were examined in a cross-sectional study. The authors found that promoting a positive appraisal of the women's illness was of paramount importance and indirectly affected the women's quality of life. In a comparison study by Northouse, Templin, Mood, & Oberst, (1998), women with benign breast disease were compared to women with metastatic breast cancer. The study concluded that those who were highly distressed at the time of diagnosis remained distressed at sixty days and one year following diagnosis.

Fridfinnsdottir, (1997), used a descriptive study to explore the nature of stressors among twelve Icelandic women diagnosed with breast cancer. The study reported that the Icelandic women all viewed the diagnosis of breast cancer as a threat. The women in the study identified social support as a critical coping resource.

**Optimism**

Scheier and Carver (1985) have defined optimism as the ability to generalize outcomes to positive expectancies. Scheier and Carver (1985) further found that
optimism can result in an individual coping more effectively with stress and illness. In a study of seventy women with breast cancer by Carver et al., (1994) it was concluded that optimism correlated strongly with subjective well-being during the assessment periods. Optimism was also found to predict shifts in well-being over time. Optimism was significantly associated with well-being at three and six month intervals for breast cancer patients following surgery. In a similar study by Lauver and Tak (1995), findings supported that optimism had an indirect effect on anxiety seeking behaviours for patients with breast cancer symptoms. In a study that involved 139 undergraduate students Scheier and Carver (1985) indicated that those subjects who initially reported being highly optimistic were less likely to be bothered by physical symptoms than other participants who reported being less optimistic. Further investigation is warranted with individuals with life threatening illnesses.

Theoretical Model

According to Lazarus and Folkman (1984), stress is defined as either a stimulus or a response. For the purposes of this study the treatment of an autologous PBSCT for patients with metastatic breast cancer was referred to as the stimulus, the stressful event. The patient then appraises the stress, Lazarus and Folkman (1984) describe three kinds of cognitive appraisal: primary appraisal, secondary appraisal, and reappraisal. In primary appraisal the patient needs to judge the situation to determine if the event is irrelevant, stressful or positive.

In the case of a metastatic breast cancer patient faced with the option of an autologous PBSCT, she would likely appraise the situation as a stressful one. According to Lazarus and Folkman, (1984), stressful events are appraised as harmful, as a threat, or as a challenge. How the breast cancer patient appraises her situation will vary based on
her current and past experiences. For example, a breast cancer patient about to undergo an autologous PBSCT may view the up-coming treatment as a threat and potentially harmful. Although the transplant has not occurred she anticipates what may happen (Lazarus & Folkman, 1984). Secondary appraisal of a situation “includes an evaluation about whether a given coping option will accomplish what it is supposed to” (Lazarus & Folkman, 1984). Reappraisal refers to a change in original appraisal because of new information from the environment (Lazarus & Folkman, 1984). Reappraisal may occur in this situation after the nurse acts to educate the patient about the proposed treatment plan. The patient would then view the situation differently based on the knowledge gained from the education session with the nurse about the treatment plan.

A breast cancer patient’s coping resources determine how she adapts to this situation. Lazarus and Folkman (1984) identified both internal and external coping resources. Internal resources refer to the individual’s personality traits. An example of an internal resource is optimism. Optimism refers to an individual’s ability to generalize positive outcomes (Scheier & Carver, 1985). External resources refer to the resources in the patient’s environment. An example of an external resource is social support. As mentioned previously, social support may be considered to have different components: tangible support, social interaction affection, emotional / informational support and social network.

For breast cancer patients receiving an autologous PBSCT as treatment, the individual’s coping resources may be used to promote adaptation. The patient’s external resources reflect her environment and her internal resources encompass her personality traits. The response is determined as either adaptation or maladaptation.
Upon admission to the transplant unit, the nurse is able to assess how the prospective transplant patient views the up-coming treatment plan. Does the patient view the stressful event as a potential threat, or perhaps a combination of both a threat and a challenge? Staff nurses who are able to communicate with their patients regarding feelings of the anticipated course of therapy can assist the patients and support their coping efforts.

Nurses need to evaluate the patient’s coping strategies and whether or not they have had a positive effect on the patient’s QOL. The outcome analysis includes the patient’s return to normal functioning, including both physical and psychological functioning (Lazarus & Folkman, 1984).

Staff nurses on a bone marrow transplant unit who are able to assess a patient’s coping abilities prior to the patient becoming gravely ill are better able to assist the patient in her time of need. This is done because the nurse knows in advance how the patient reacts to a stimulus. The nurse then acts to assist the patient by having coping resources such as family, or a support network of other patients, with similar experiences available to both the patient and her social support system. The nurse can also assist both the patient and family by providing current literature to them regarding daily living after an autologous PBSCT.

**QOL & Transplant**

To date the majority of the literature concerning QOL and bone marrow transplantation / peripheral blood stem cell transplantation has been cross-sectional in design and has not permitted the evaluation of the transplant recipients over a period of time (Andrykowski et al., 1997; Hann et al., 1997a; Sutherland et al., 1997). It would be beneficial to analyze patients over a period of time to view any trends in QOL and the
impact that the medical treatment PBSCT has on a patient’s adaptation throughout the transplant process. Several studies have investigated the QOL of transplant patients. These studies, however, have not investigated the transplant recipient’s response in the context of an adaptation model (Andrykowski et al., 1997; Hann et al., 1997a; Sutherland et al., 1997). Measures that specifically analyze the adaptation process for transplant patients would aid in assessing the unique issues that transplant recipients face. An adaptation model would explore stress appraisal, symptom distress, and coping resources that promote adaptation. As mentioned previously, coping resources include both external and internal resources that act to promote optimal QOL across all dimensions: physical well-being, functional well-being, emotional well-being, and social well-being.

The majority of the studies that measured QOL in transplant recipients did not use a homogeneous group. Instead, these studies used a heterogeneous group that consisted of a variety of different malignant diseases that are routinely treated with an autologous bone marrow transplant/autologous peripheral blood stem cell transplant. These studies also included samples that consisted of both males and females. (McQuellon et al., 1998; McQuellon et al., 1997; Molassiotis, Boughton, Burgoyne, & Van den Akker, 1995; Wettergren, Languis, Bjorkholm, & Bjorvell, 1997). Gender, disease and type of transplant could influence QOL after transplant. Most studies did not evaluate these factors (Sutherland et al., 1997; McQuellon et al., 1998; McQuellon et al., 1997). Different diseases and protocols can result in varying degrees of complications (Frei et al., 1989; Molassiotis et al., 1995).

In a retrospective study of 123 patients by Larsson, Bjorkstand, & Ljungman, (1998), it was revealed that patients who received an autologous PBSCT had a faster engraftment period than those patients who received an ABMT. Engraftment refers to
the time period required for hematopoietic recovery. Furthermore, it was also noted that patients from the PBSC group required fewer transfusions of red blood cells and platelets. Results of this study also noted that patients who received an autologous PBSC were discharged from the hospital prior to those who had received an ABMT. Another advantage to PBSC is that it is associated with less transplant-related toxicity such as a shorter period of myelo-suppression (Crlilley & Goldstein, 1995). The majority of the literature revealed QOL studies in bone marrow transplant recipients as opposed to peripheral blood stem cell recipients (Hann et al., 1997a; McQuellon et al., 1996; Sutherland et al., 1997; Wettergren et al., 1997). The effect of earlier hematopoietic recovery on QOL has yet to be determined.

A variety of studies have been conducted concerning QOL and bone marrow transplant recipients. In some studies, patients reported to have improved QOL post-transplantation (McQuellon et al., 1998; McQuellon et al., 1997; McQuellon et al., 1996; Molassiotis et al., 1995). Other studies found fatigue and energy level to have the greatest impact on the transplant recipient's QOL (Andrykowski et al., 1997; Hann et al., 1997b). Sutherland et al., (1997) compared QOL of bone marrow transplants patients to that of population norms. These findings reported that less than three years post-transplantation QOL was considerably impaired for transplant patients, but at three years and beyond QOL was indistinguishable from population norms.

Ferrell et al., (1992a) investigated the QOL of 119 bone marrow transplant recipients in a qualitative study. Eight themes were derived from the study. They were family and relationships, independence, health, ability to work/financial status, appreciation for life, being alive, life satisfaction and being normal. This study consisted of survivors who had undergone an allogeneic bone marrow transplant as opposed to an
autologous transplant. An allogeneic bone marrow transplant involves the transplantation of a donor's bone marrow. This is important to note because allogeneic bone marrow transplant recipients frequently have more chronic complications after transplant than do autologous transplant recipients (Molassiotis et al., 1995). In the second part of the study by Ferrell et al., (1992b), patients were asked what health care professionals could do to enhance their QOL. The themes that emerged were; accessible health care providers, support groups, discovery of a cure, reinforcement of current education, provision of additional coping strategies and finally increased patient participation in treatment decision making.

In 1997, a prospective study involving a sample of twenty patients evaluated the physical and psychosocial functioning of patients and their coping strategies after undergoing an ABMT. The study used three standard questionnaires; the EORTC Quality of Life questionnaire, the Hospital Anxiety and Depression (HAD) Scale, and the Sense of Coherence Scale. It was found that a decrease in coping capacity led to an overall decrease in physical and psychosocial functioning, and overall QOL was impaired. Functional limitations were reported to be related to deficient coping strategy. Coping with life threatening situations is an important aspect to consider in illustrating the differences in the patients’ perceived illnesses (Wettergren et al., 1997). It was also reported that coping and adaptation to one’s illness may influence the QOL of patients with life threatening illnesses (Molassiotis, 1997; Wettergren et al., 1997).

This study provided information on the noted gaps in the literature. It focused specifically on women who underwent an autologous PBSCT for breast cancer. Therefore, disease, gender, and type of transplant were held constant as the trends in QOL were examined. Another noted gap in the literature was the lack of focus regarding
the transplant recipients’ ability or inability to cope with their own level of illness throughout the transplant process. This was explored using Lazarus and Folkman’s (1984) Adaptation Model. The social support networks of the breast cancer patients, as well as an assessment of the patient’s level of optimism, increased understanding of the breast cancer patient’s ability to cope and then adapt to stressors.

Purpose

The purpose of this study was to examine prospectively the influences that perceived stress appraisal, symptom distress and internal and external coping resources have on the quality of life of women with metastatic breast cancer treated with an autologous PBSCT. Measures of stress included perceived stress appraisal and symptom distress. Internal coping resources were evaluated through the personality trait optimism. External coping resources were evaluated through measures of the patient’s social support system: tangible support, social interaction, affection, emotional/informational support, and an evaluation of the patient’s social network system. The outcome measurement, QOL, measured six subscales (physical well-being, emotional well-being, social/family well-being, functional well-being, and the patient’s relationship with her physician). Measurements were taken at three different stages during the transplant process: pre-transplant, one month post-transplantation and three months post-transplant. This study observed and described the adaptational response of breast cancer patients who received an autologous peripheral blood stem cell transplant for treatment. As mentioned earlier the treatment of the autologous peripheral blood stem cell transplant was the stimulus. This study described the relationship between the patient’s perceived stress appraisal, symptom distress and internal and external resources and the patient’s adaptational response to the stimulus according to Lazarus and Folkman’s (1984) model.
The primary goal of this research project was to explore QOL in women with metastatic breast cancer who have received an autologous PBSCT using the theoretical model of adaptation (Lazarus & Folkman, 1984). This study described the relationship that existed between an individual’s perception of stress, symptom distress and coping resources, both internal and external, and the patient’s response to a specific treatment regimen.

**Research Questions**

1. What are the demographic characteristics of women with metastatic breast cancer who received an autologous PBSCT as treatment for their disease?
2. What changes occurred in perceived stress appraisal, symptom distress, optimism, social support, and QOL between pre-transplantation, one month post-transplantation, and three months post-transplantation in women with breast cancer who received an autologous PBSCT as treatment?
3. How did perceived stress appraisal, symptom distress, optimism, and social support influence the QOL of women with breast cancer who received an autologous PBSCT as treatment before transplant, one month post-transplant and three months post-transplantation?
CHAPTER THREE

Methology

Research Design

This research design is a prospective correlational study. The primary goal of
correlational research is to explain the relationship and not to determine cause or effect
(Burns & Grove, 1993). Correlational studies act to guide quasi-experimental and
experimental research by generating hypotheses that focus on cause-effect relationships
(Polit & Hungler, 1999).

Subjects

The participants for this study consisted of a homogeneous group of women with
a medical diagnosis of metastatic breast cancer. All of the participants had documented
responsive disease. Responsive disease means that the disease has responded to prior
treatment of chemotherapy / radiation. Disease status is important to note since
responsive disease has a higher cure rate (McQuellon et al., 1996). All of the participants
included in this study had chosen to be treated with an autologous PBSCT. The sample
size for this study was estimated at thirty-three participants (Burns & Grove, 1993). An
approximate sample size of thirty-three subjects is estimated to achieve a power of 0.80
at the significance level of 0.05 for a medium effect size (Aron & Aron, 1999).

Selection Criteria

The type of sampling plan was that of a convenience sample. The participants for
this study were recruited from one metropolitan Detroit area cancer center. In order to be
eligible for this study, the subjects had to meet the following criteria: eighteen years of
age or older, diagnosed with responsive metastatic breast cancer, and be literate and
fluent in the English language. The exclusion criteria included those who had been
diagnosed with major psychiatric or neurological disorders, or metastatic brain disease that would have interfered with the completion of the self-reports.

**Procedure and Data Collection**

Prior to the administration of the questionnaires the researcher coded the questionnaires. The codes were also on the envelopes provided to the participants. Only the researcher and a member of the Clinical Trials office had access to the master list.

All of the patients who were scheduled to receive an autologous PBSCT for metastatic breast cancer at a cancer center were invited to participate in the study. The BMT coordinator had initial contact with the subjects. The BMT coordinator then presented the prospective study participants with an envelope containing a letter explaining the purpose of the study, consent for the study, and the first set of questionnaires. The subjects were then asked by the BMT coordinator to seal the envelope prior to returning it. In doing this, members of the BMT team were not aware whether or not the breast cancer patient was participating in the study, therefore ensuring that the patient’s participation would not affect the care that she received. Once the questionnaires were returned to the BMT coordinator, the BMT coordinator transferred the sealed envelopes to the Clinical Trials office where the sealed envelopes were kept in a locked file. The first set of questionnaires was given to the participant by the BMT coordinator prior to the initiation of the PBSCT treatment and hospital admission. The second set of questionnaires was given to the participant by the BMT coordinator one month post-transplantation during a regular scheduled outpatient clinic appointment. The third set of questionnaires was given to the participant by the BMT coordinator three months post-transplantation during a scheduled visit to the outpatient clinic. Throughout the study, members of the BMT team were not aware which breast cancer patients were
participating in the study. For the duration of the study, the BMT coordinator delivered the questionnaires to the prospective subjects and the breast cancer patients returned the questionnaires to the BMT coordinator in a sealed envelope. The five questionnaires took approximately twenty to thirty minutes to complete. Participants were asked to complete the questionnaires while they were at the BMT clinic. In the event that participants were unable to complete the surveys while they are at the Cancer Center, they were given a stamped envelope so they could complete the survey at home and return it to the researcher. Follow up phone calls were made by the researcher to the participants who did not return their questionnaires within two weeks by mail to their BMT coordinator at the hospital where they received care.

The questionnaires were returned to the researcher and kept in a locked file for the duration of the study. Only coded data that did not identify patients by name were saved. The questionnaires were destroyed after the coded data was entered into the computer program and analysis was completed. Confidentiality of participants was maintained by coding the subject’s responses and not using names in the data analysis phase of the study. The time frame of three months post-transplantation was chosen because it is typically a date that is described as a milestone for transplant survivors. At the three month time point, post-transplantation initial complications have usually resolved and the patient is beginning to resume previous roles Baker et al., 1998; Bitran et al., 1996). At this time patients are often re-staged for the status of their disease. The administration of self-report measures at pre-treatment, one month post-transplantation, and three months post-transplantation allowed for the assessment of adaptation over time.
Demographics

Data on patient characteristics were collected. Information included disease stage, age, marital status, and number of dependents, level of education, race, and income level.

Measures

Five questionnaires were given to each participant. Each participant was given the Perceived Stress Scale (PSS) (Cohen, Kamarck, & Mermelstein, 1983), the Symptom Distress Scale (SDS) (McCorkle, Cooley & Shea, 1997), the Life Orientation Test (LOT) (Scheier & Carver, 1985), the Medical Outcome Study – Social Support Survey (MOS-SSS) (Sherbourne, Stewart, 1991), and the Functional Assessment of Cancer Therapy - Bone Marrow Transplant (FACT-BMT) Scale (McQuellon et al., 1997).

PSS

The Perceived Stress Scale (PSS) was developed to measure the degree to which an individual appraises a stressful event (Cohen, Kamarck, & Mermelstein, 1983). The PSS consists of fourteen items on a five point Likert type scale (0 = never, 1 = almost never, 2 = sometimes, 3 = fairly often, 4 = very often). In order to score the PSS, scores must be reversed for the seven positively stated items and then the sum of all fourteen items on the PSS must be calculated.

The PSS has reported reliability and validity (Cohen, Kamarck, & Mermelstein, 1983). Alpha coefficients were recorded at .84, .85 and .86 in three samples. Test-retest reliability was reported as .85 after two intervals, two days and six weeks (Cohen, Kamarck, & Mermelstein, 1983).
**SDS**

The purpose of the SDS scale is to measure symptoms associated with cancer (McCorkle, Cooley, & Shea, 1997). The SDS was developed as a self-administered, self-report questionnaire. The questionnaire consists of thirteen items on a Likert type scale. The symptoms are listed and the participant rates the symptom on a scale of one to five. A score of one represents no distress and a score of five represents extreme distress for the specific symptom. The scores two, three and four represent intermediate levels of distress for the symptom (McCorkle, Cooley, & Shea, 1997). The scoring of the SDS can be obtained by adding the participant’s total score. The score ranges from thirteen to sixty-five with a higher score indicating more symptom distress.

The SDS has reported both reliability and validity. Internal reliability reported an alpha coefficient of 0.83 for adults with lung cancer (McCorkle & Benoliel, 1983). The test-retest reliability after one month was reported to be 0.78 in both lung cancer patients and patients with myocardial infarction (McCorkle & Benoliel, 1983). Field testing was also done to ensure that the SDS was measuring symptom distress.

**LOT**

The LOT scale was devised to measure an individual’s optimism. The LOT measurement is an eight-item true/false questionnaire. Four of the questions are optimistically worded and four of the questions are pessimistically worded. The questionnaire also contains four filler items. Prior to scoring, the pessimistic questions should be reversed since they are phrased pessimistically. Once the scores are totaled, a low score reflects optimism.

The LOT has reported internal consistency, test-retest reliability, and validity (Scheier & Carver, 1985). Lauver & Tak (1995) reported a Cronbach’s alpha of .68
whereas Carver et al., (1994) reported an alpha coefficient of .87 and the test-retest reliability was reported to be .74 after a twelve month interval.

**MOS-SSS**

The Medical Outcomes Study Social Support Survey (MOS-SSS) involves a nineteen-item scale that considers five dimensions of social support. The five dimensions of social support in this scale are emotional support, informational support, tangible support, positive social interaction and affection (Sherbourne & Stewart, 1991). The dimensions emotional support and informational support are scored as one dimension in the survey. Each question pertains to how often each form of support is available to the participant. The questionnaire also contains one structural support item that asks the participant about the quantity of close friends or relatives (McDowell & Newell, 1996). The main purpose of this scale is to provide an indication of the participant’s social support over all of the dimensions (McDowell & Newell, 1996). The questionnaire consists of a five point likert response scale (1= none of the time, 2= a little of the time, 3= some of the time, 4= most of the time, 5= all of the time).

The internal consistency for the complete scale was high (alpha coefficient = 0.97) and the values for the subscales ranged from alpha = 0.91 to 0.96 (McDowell & Newell, 1996). In addition the one year test re-test was also high at 0.78 and the individual subscales ranged from 0.72 to 0.76 (McDowell & Newell, 1996). Factor analyses demonstrated validity of the questionnaire (McDowell & Newell, 1996). Correlations between the four subscales ranged from 0.69 to 0.82 (McDowell & Newell, 1996).
FACT-BMT

QOL was measured with the Functional Assessment of Cancer Therapy - Bone Marrow Transplant (FACT-BMT) Scale (McQuellon et al., 1997). The FACT-BMT scale was developed from the Functional Assessment of Cancer Therapy - General (FACT-G) Scale (Cella et al., 1993). The primary goal of the FACT measuring system is to assess QOL in patients who have received cancer therapy, on four dimensions: physical well-being, social/family well-being, emotional well-being, and functional well-being. An additional subscale is included that measures the quality of the doctor-patient relationship (Cella et al., 1993). A second additional subscale focuses on areas of specific concern to BMT patients (McQuellon et al., 1997) e.g. concerns about ability to return to work and fear of relapse.

According to McQuellon et al., 1997, the FACT-BMT assessment tool was “developed with the emphasis on patient values and sensitivity to change over time” (p. 358). The BMT subscale was designed with the specific needs of the BMT patient in mind, the BMT subscale was intended to complement the FACT-G (Cella et al., 1993) scale and was never intended to be given alone (McQuellon et al., 1997).

The FACT-BMT scale consists of a five point likert scale ranging from 0-4 (0= not at all; 1= a little bit; 2= somewhat; 3= quite a bit; and 4= very much). There are a total of 41 questions. The FACT-BMT scale is scored by totaling the six subscales, which yield a score for each individual subscale (Physical Well-Being 0-28, Social/Family Well-Being 0-28, Emotional Well-Being 0-24. Functional Well-Being 0-28, Relationship with physician 0-8, and Additional Concerns 0-48). The range of scores on the FACT-BMT is 0-164 (McQuellon et al., 1997). The higher the score, the better the QOL (Cella et al., 1993; McQuellon et al., 1997).
The FACT-BMT scale has demonstrated both reliability and validity. The alpha coefficient for the total FACT-BMT scale (FACT-G +BMT subscale) ranged from 0.85 to 0.92 (McQuellon et al., 1997). The BMT subscale recorded a Cronbach's Alpha score of 0.52 to 0.60 (McQuellon et al., 1997). The developers of the FACT-G (Cella et al., 1993) established alpha coefficients for each subscale: physical well-being 0.82, functional well-being 0.80, social/family well-being 0.60, emotional well-being 0.74 and relationship with physician 0.65. The total scale recorded an alpha coefficient of 0.89 (Cella et al., 1993). The developers of the BMT subscale never intended for the BMT subscale to be given without accompanying the FACT-G (McQuellon et al., 1997).

In terms of construct validity both physical and functional well-being subscales were highly correlated with performance status (McQuellon et al., 1997). The subscale emotional well-being also correlated highly with Brief Profile of Mood States (POMS) and Center for Epidemiological Scale-Depression (CES-D). Finally the correlation between social/family well-being with MOS-SS was 0.50. (McQuellon et al., 1996). Test-retest reliability demonstrated high correlation coefficients for the subscales: physical well-being 0.88, functional well-being 0.84, social well-being, emotional well-being 0.82, relationship with physician 0.83 and total score 0.92 (Cella et al., 1993).

Data Analysis

**Research Questions**

1. What are the demographic characteristics of the women with metastatic breast cancer who received an autologous PBSCT as treatment for their disease?

Demographics were recorded from all of the participants in the study. Analysis included percentages and frequencies for some of the variables, i.e. marital status and race. Other analyses included means, standard deviations, and range of scores for all data.
2. What changes occurred in perceived stress appraisal, symptom distress, optimism, social support, and QOL between pre-transplantation, one month post-transplantation, and three months post-transplantation in women with breast cancer who had received an autologous PBSCT as treatment?

In order to analyze question 2 separate repeated measures of analysis of variance (ANOVA) were used to examine the changes in perceived stress appraisal, symptom distress, optimism, and social support and QOL over time. Measures were analyzed pre-transplant, one-month post-transplant, and three months post-transplant.

3. How did perceived stress appraisal, symptom distress, optimism, and social support influence the QOL of women with breast cancer who received an autologous PBSCT as treatment before transplant, one month post-transplant and three months post-transplant?

Correlational analysis followed by multiple regression were used to answer question 3. The predictor variables were stress appraisal, symptom distress, optimism, and social support. The statistical test of multiple regression was used to determine the relationship between predictor variables and the criterion variable QOL.

After the completion of the study, group results were made available to the Cancer Center through the BMT coordinator. Participants were able to contact their BMT coordinator for group results, no individual results were analyzed.

**Ethical Considerations**

This research was presented to the Investigational Review Boards, (IRB), at the hospital included in the study for external review and approval (Polit & Hungler, 1999) and to the University of Windsor, School of Nursing, Research Ethics Committee. Prior to the initiation of the study all participants were given a letter informing them of the
study. Participants in the study signed an informed consent form prior to the administration of any of the self-report tools. The BMT coordinator at the hospital fully described to all prospective participants the complete nature of the study. Patients were not exposed to any harmful material or equipment during the study. There were no anticipated risks for the participants of the study. All of the information was confidential and patient names were not used in the reporting of data. All of the patients had the right to withdraw from the study at any time during the investigation.

Limitations of the Study

Randomization in this study was not feasible. However, the risk of sampling bias was minimal because the investigation group was fairly homogenous (Polit & Hungler, 1999). In addition, the nurse researcher was unable to assign a control group to this study. The treatment of an autologous PBSCT was an informed treatment decision made by the physician and the patient. The nurse researcher was aware that this was one of the weaknesses of the proposed design. The use of self-report measures was a limitation of this investigation. Self-report data have disadvantages, according to Lazarus & Folkman (1984), the disadvantages with self-reports are “problems with memory, the desire of the subjects to present themselves in a positive light, language ambiguity, and the use of verbal reports as an ego defense” (p. 321). Once again, replication of the study would increase the external validity of the findings.

Assumptions

It was assumed that perceived stress appraisal, symptom distress and internal and external coping resources influence the adaptation of women with breast cancer who receive an autologous PBSCT as treatment. The investigator further assumed that the internal coping resource, optimism and the external coping resource, social support
promote the adaptation of quality of life in women with breast cancer who received an autologous PBSCT.
CHAPTER FOUR

Results

The data were coded and analyzed using SPSS. All of the data analysis focused on the three research questions previously stated and the results are reported according to the specific research questions.

1. What are the demographic characteristics of the women with metastatic breast cancer who received an autologous PBSCT as treatment for their disease?

Twenty-eight women with metastatic breast cancer completed the surveys. One of the participants dropped out of the study as a result of disease progression prior to treatment. All of the women received an autologous PBSCT at a metropolitan Detroit cancer center. The subjects ranged in age from 27 to 60 years of age with a mean of 44.5 years of age.

This study focused on women with breast cancer who received an autologous PBSCT. The women who participated in this study ranged from Stage II breast cancer to Stage IV breast cancer. The majority of the women had Stage IV breast cancer. As mentioned the sample size included twenty-eight women who completed the surveys. All of the women involved in the study had documented responsive disease, that is, all of the women who were involved in the study had responded to prior treatment documented by the oncologist.

The number of dependents reported by each participant ranged from zero to four. Fifty-four percent (n = 15) of the respondents reported having no dependents under the age of eighteen years. Twenty-one percent (n = 6) of the participants reported having only one dependent and 14.3% (n = 4) and 7.1% (n = 2) of the study participants recorded
having two and three dependents at home respectively. One participant reported having four dependents at home under the age of eighteen.

Thirty-nine percent ($n = 11$) of the participants reported that they had a female relative with breast cancer. The majority of the respondents reported that they were Caucasian, 71.4% ($n = 20$) and 17.9% ($n = 5$) of the participants reported that they were African-American. Two of the respondents classified their race in the “other” category and one of the participants declined to answer the question.

Most of the women who completed the survey were married, 64.3% ($n = 18$). Fourteen percent ($n = 4$) of the respondents reported their marital status as single, 17.9% ($n = 5$) reported they were divorced and one participant (3.6%) reported that she was widowed.

All of the participants were also asked what their highest level of education was. Their levels of education ranged from partial high school to a graduate degree. Three of the participants, 10.7% reported completing partial high school and 32.1% ($n = 9$) of the women surveyed reported completing high school. Twenty-five percent ($n = 7$) of the participants had a partial college education and 21.4% ($n = 6$) stated that they completed college. Eleven percent ($n = 3$) of the participants replied that they had university degrees.

The level of income for the participants ranged from less than $10,000 to greater than $71,000 annually. Five respondents declined to report their family income (See Table 1).
Table 1

Yearly Household Income

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<th>Income</th>
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<th>Percentage</th>
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<td>14.3%</td>
</tr>
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<td>3.6%</td>
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<td>3</td>
<td>10.7%</td>
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<td>$41,000-$50,000</td>
<td>5</td>
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<td>$51,000-$60,000</td>
<td>3</td>
<td>10.7%</td>
</tr>
<tr>
<td>$61,000-$70,000</td>
<td>2</td>
<td>7.1%</td>
</tr>
<tr>
<td>$71,000+</td>
<td>5</td>
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</tbody>
</table>
2. What changes occur in perceived stress appraisal, symptom distress, optimism, social support, and QOL between pre-transplantation, one month post-transplantation, and three months post-transplantation in women with breast cancer who have received an autologous PBSCT as treatment?

MANOVAs were conducted on Social Support subscales and QOL total score and QOL subscales, but were not significant. This may be a result of the small sample size and the number of variables included in the MANOVAs. Because of these limitations we examined the ANOVAs in order to see if there were any significant differences over time. Means, standard deviations, and ANOVAs are presented in Table 2 for perceived stress appraisal, symptom distress, optimism and each subscale of social support and QOL as well as the QOL total score over the three time periods, pre-transplant, one month post-transplant and three months post-transplant.

Perceived Stress Appraisal

There was no statistically significant overall effect of time for perceived stress appraisal, nor differences between Times 1 and 2 or between Times 2 and 3.

Symptom distress

For the variable, symptom distress, a lower measurement indicated fewer complaints of symptom distress. The women surveyed did not report statistically significant change in their symptom distress between the pre-transplant level and the measurement at one month post-transplant. However, women did report statistically significant differences between one month post-transplant and three months post-transplant based on post hoc analysis of paired t-tests $t(26) = 1.80 \ p = 0.083$. That is, the women stated that they experienced fewer treatment related side effects three months
Table 2

ANOVA Comparisons of Variables Over Time

<table>
<thead>
<tr>
<th>Variables</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
<th>F(2, 25)</th>
</tr>
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<td></td>
<td>(N = 28)</td>
<td>(N = 27)</td>
<td>(N = 27)</td>
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<tr>
<td>Perceived Stress Appraisal</td>
<td>24.32 (6.25)</td>
<td>24.59 (7.18)</td>
<td>24.07 (6.20)</td>
<td>0.26</td>
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<tr>
<td>Symptom distress</td>
<td>25.80 (8.81)</td>
<td>26.30 (6.26)</td>
<td>22.92 (4.98)</td>
<td>4.76*</td>
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<tr>
<td>Optimism</td>
<td>8.64 (1.19)</td>
<td>9.30 (1.98)</td>
<td>9.26 (2.30)</td>
<td>2.21</td>
</tr>
<tr>
<td>Social Support Survey Subscales:</td>
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<td></td>
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<tr>
<td>Tangible Support</td>
<td>17.18 (3.56)</td>
<td>17.85 (3.20)</td>
<td>17.22 (3.71)</td>
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</tr>
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<td>Social Interaction</td>
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<td>17.82 (3.27)</td>
<td>18.19 (2.56)</td>
<td>3.08†</td>
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<tr>
<td>Affection</td>
<td>13.14 (2.77)</td>
<td>13.89 (1.72)</td>
<td>13.70 (1.94)</td>
<td>3.40*</td>
</tr>
<tr>
<td>Emotional / Informational Support</td>
<td>34.64 (6.52)</td>
<td>35.11 (7.10)</td>
<td>36.19 (4.91)</td>
<td>1.59</td>
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<tr>
<td>Quality of Life</td>
<td>106.07 (26.78)</td>
<td>106.04 (21.34)</td>
<td>110.15 (21.36)</td>
<td>1.08</td>
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<tr>
<td>Quality of Life Subscales:</td>
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<td></td>
</tr>
<tr>
<td>Physical Well-Being</td>
<td>21.11 (5.87)</td>
<td>18.70 (4.66)</td>
<td>20.81 (4.96)</td>
<td>4.22*</td>
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<tr>
<td>Social Well-Being</td>
<td>18.96 (7.19)</td>
<td>20.81 (5.54)</td>
<td>20.63 (6.01)</td>
<td>1.59</td>
</tr>
<tr>
<td>Relationship with Doctor</td>
<td>6.21 (2.52)</td>
<td>7.19 (1.80)</td>
<td>7.00 (2.15)</td>
<td>3.25†</td>
</tr>
<tr>
<td>Emotional Well-Being</td>
<td>15.41 (4.32)</td>
<td>16.14 (5.74)</td>
<td>17.17 (4.97)</td>
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<tr>
<td>Functional Well-Being</td>
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<td>14.48 (6.26)</td>
<td>15.70 (6.09)</td>
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<tr>
<td>Additional Concerns</td>
<td>29.19 (6.17)</td>
<td>28.70 (6.84)</td>
<td>28.85 (5.64)</td>
<td>0.94</td>
</tr>
</tbody>
</table>

† p < 0.06
* p < 0.05
** p < 0.01

A low level of optimism, indicates more optimism

A low level of perceived stress appraisal, indicates low perceived stress

High levels of symptom distress, social support and QOL indicates more symptom distress, more social support and higher levels of QOL.
post-transplant compared to one month post-transplant when they reported most symptom distress (See Figure 1).

**Figure 1.** Means for symptom distress, over three time periods

![Symptom Distress Graph]

**Optimism**

There was no statistically significant overall effect of time for optimism using the Life Orientation Scale. However, there was a statistically significant difference between level of optimism at Time 1 and the level of optimism at Time 2, \( t (26) = -2.14 \ p = 0.04 \) (See Figure 2).

**Figure 2.** Means for optimism over the three time periods.

![Optimism Graph]
Social Support

The Social Support Scale has four subscales, tangible support, social interaction, affection and emotional/informational support as well as a social network score. From these subscales only social interaction and affection demonstrated statistically significant changes over time. Tangible support and emotional/informational support did not show any effects of time. The women who participated in the study did not consistently answer the question concerning the size of their social network at any time period. The range in social network size was 1 to 40 with a mean value of 12.9 for the number of people in the participants’ social network at all three time periods.

Social Interaction

Social interaction demonstrated a marginal statistically significant change between Time 1 and Time 2. After one month post-transplantation, respondents reported a higher level of social interaction compared to their pre-transplantation level of social interaction based on the post hoc analysis of a paired t-test, $t(26) = -2.20$ $p = 0.037$. Although the level of social interaction continued to rise at the time of three months post-transplantation, this change was not statistically significant (See Figure 3).

Figure 3. Means for social interaction over the three time periods
Affection

Participants reported statistically significant higher affection at Time 2 compared to their report at Time 1 based on the post hoc analysis of a paired t-test $t(26) = -2.62$, $p = 0.015$. There was no statistically significant change in affection between Time 2 and Time 3 (See Figure 4).

**Figure 4.** Means for affection over the three time periods.

Quality of Life

The FACT-BMT scale was used to measure QOL. This scale provides a total score as well as subscales of: physical well-being, social well-being, emotional well-being, functional well-being, relationship with doctor and additional concerns. The total QOL of the breast cancer participants did not demonstrate a statistically significant overall effect of time. The variables physical well-being, emotional well-being and relationship with doctor showed statistically significant changes over time. Social well-being, functional well-being, and additional concerns subscales of the QOL measure did not demonstrate a statistically significant overall effect of time (See Table 2).
Physical Well-Being

The women surveyed reported that their physical well-being was highest for Time 1. There were statistically significant differences in physical well-being between Time 1 and Time 2 ($t(26) = -2.51 \ p = 0.019$) and between Time 2 and Time 3 ($t(26) = -2.17 \ p = 0.039$) based on post hoc analysis of paired t-tests. The women who participated in the surveys reported that their physical well-being was at lowest one month post-transplant. In other words, the women stated that they were experiencing more physical side effects related to the transplant one month post-transplant compared to the other two time periods.

**Figure 5.** Means for physical well-being over the three time periods.

![Physical Well-Being Graph]

Relationship with Doctor

Patient reports of their relationship with their doctor also showed a statistically significant effect of time between Time 1 and Time 2 based on the post hoc analysis of a paired t-test $t(26) = -2.31 \ p = 0.029$. After one month post-transplant, respondents indicated a closer relationship with their physician. Time did not have a statistically significant overall effect between Time 2 and Time 3 although the relationship at Time 3 continued to be higher than at Time 1 (See Figure 6).
Figure 6. Means for relationship with doctor over the three time periods.

Emotional Well-Being

The women surveyed reported a statistically significant difference in emotional well-being between Time 1 and Time 3 based on the post hoc analysis of a paired t-test $t(26) = -2.47$, $p = 0.020$. The women reported that their emotional well-being was highest at Time 3, three months post-transplant. Time did not have a statistically significant effect between Time 1 and Time 2 (See Figure 7).

Figure 7. Means for emotional well-being over the three time periods.
3. How do perceived stress appraisal, symptom distress, optimism, and social support influence the QOL of women with breast cancer who receive an autologous PBSCT as treatment before transplant, one month post-transplantation, and three months post-transplantation?

To determine if perceived stress appraisal, symptom distress, optimism and social support influence QOL a hierarchical multiple regression was conducted. A two step model was used, at step 1 perceived stress appraisal and symptom distress were entered first then optimism and social interaction were entered in the second block. In the hierarchical regression model although the stress variables collectively accounted for 47% in variance in the QOL score, the coping variables did not add significantly to the prediction of QOL and no individual predictors emerged. This is likely due to the lack of statistical power (27/28 subjects). Therefore, Pearson's \( r \) correlations were examined to see if the stressors and coping resources influenced adaptation (QOL) in accordance with Lazarus & Folkman’s (1984) adaptation model.

The degree of association between each pair of variables was analyzed using the Pearson Product Moment Coefficient (Pearson’s \( r \)) for the three time periods (See Tables 3, 4 & 5). There were no statistically significant correlations between the demographics age, level of education, or income and perceived stress appraisal, symptom distress, optimism, social support subscales, or QOL. However, age correlated negatively with the number of dependents, that is the older the participant the fewer the number of dependents. Age was also statistically significantly correlated with level of income, the older the participant, the higher her level of income. These relationships were as expected.
### Table 3

**Correlation Matrix for Measured Variables in Breast Cancer Patients who Received an Autologous PBSCT Time 1 (N = 28)**

<table>
<thead>
<tr>
<th>Variables</th>
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<th>4</th>
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<td>1. Perceived Stress Appraisal</td>
<td>1.00</td>
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<tr>
<td>2. Symptom distress</td>
<td>0.59**</td>
<td>1.00</td>
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<tr>
<td>3. Optimism</td>
<td>0.48*</td>
<td>0.57**</td>
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<td>4. Tangible Support</td>
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<tr>
<td>5. Affection</td>
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<td>-0.14</td>
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<tr>
<td>6. Social Interaction</td>
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<td>-0.39*</td>
<td>0.60**</td>
<td>0.87**</td>
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<tr>
<td>7. Emotional/Informational Support</td>
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<td>-0.24</td>
<td>-0.22</td>
<td>0.78**</td>
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<td>8. Quality of Life</td>
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<td>-0.39*</td>
<td>0.32*</td>
<td>0.37*</td>
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<tr>
<td>9. Physical Well-Being</td>
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<td>10. Social Well-Being</td>
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<td>0.51</td>
<td>0.54*</td>
<td>0.84**</td>
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<td>0.07</td>
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<td>-0.49</td>
<td>-0.43*</td>
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<td>0.55**</td>
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* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).
Table 4

**Correlation Matrix for Measured Variables in Breast Cancer Patients who Received an Autologous PBSCT Time 2 (N = 27)**

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<tr>
<td>2. Symptom distress</td>
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<td>4. Tangible Support</td>
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<tr>
<td>6. Social Interaction</td>
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<td>0.87**</td>
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<tr>
<td>8. Quality of Life</td>
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<td>-0.58**</td>
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<tr>
<td>9. Physical Well-Being</td>
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<td>-0.51**</td>
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<td>0.21</td>
<td>0.14</td>
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<tr>
<td>10. Social Well-Being</td>
<td>-0.43</td>
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<td>-0.22</td>
<td>0.44*</td>
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<td>0.37</td>
<td>0.64**</td>
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<tr>
<td>11. Relationship with Doctor</td>
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<td>-0.09</td>
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<td>-0.16</td>
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<td>0.65**</td>
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<tr>
<td>12. Emotional Well-Being</td>
<td>-0.67**</td>
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<td>-0.75**</td>
<td>-0.23</td>
<td>0.02</td>
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<td>0.72**</td>
<td>0.50**</td>
<td>0.20</td>
<td>0.18</td>
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<tr>
<td>13. Functional Well-Being</td>
<td>-0.18</td>
<td>-0.19</td>
<td>-0.25</td>
<td>0.05</td>
<td>0.22</td>
<td>0.21</td>
<td>0.27</td>
<td>0.70**</td>
<td>0.09</td>
<td>0.48*</td>
<td>0.37</td>
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<tr>
<td>14. Additional Concerns</td>
<td>-0.50**</td>
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<td>0.02</td>
<td>0.01</td>
<td>0.02</td>
<td>0.87**</td>
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<td>0.22</td>
<td>0.62**</td>
<td>0.49**</td>
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</tbody>
</table>

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).
Table 5

Correlation Matrix for Measured Variables in Breast Cancer Patients who Received an Autologous PBSCT Time 3 (N = 27)

<table>
<thead>
<tr>
<th>Variables</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Perceived Stress Appraisal</td>
<td>1.00</td>
<td></td>
<td></td>
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<tr>
<td>2. Symptom distress</td>
<td>0.48*</td>
<td>1.00</td>
<td></td>
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</tr>
<tr>
<td>3. Optimism</td>
<td>0.65**</td>
<td>0.36</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Social Support Subscales</td>
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</tr>
<tr>
<td>4. Tangible Support</td>
<td>-0.18</td>
<td>0.03</td>
<td>0.12</td>
<td>1.00</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5. Affection</td>
<td>-0.17</td>
<td>-0.04</td>
<td>0.13</td>
<td>0.82**</td>
<td>1.00</td>
<td></td>
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</tr>
<tr>
<td>6. Social Interaction</td>
<td>-0.10</td>
<td>-0.14</td>
<td>0.06</td>
<td>0.55**</td>
<td>0.74**</td>
<td>1.00</td>
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</tr>
<tr>
<td>7. Emotional/Informational Support</td>
<td>-0.10</td>
<td>-0.13</td>
<td>0.02</td>
<td>0.64**</td>
<td>0.78**</td>
<td>0.96**</td>
<td>1.00</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>8. Quality of Life</td>
<td>-0.65**</td>
<td>-0.55**</td>
<td>-0.61**</td>
<td>0.08</td>
<td>0.13</td>
<td>0.25</td>
<td>0.25</td>
<td>1.00</td>
<td></td>
<td></td>
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<tr>
<td>Quality of Life Subscales</td>
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</tr>
<tr>
<td>9. Physical Well-Being</td>
<td>-0.37</td>
<td>-0.56**</td>
<td>-0.49**</td>
<td>-0.23</td>
<td>-0.13</td>
<td>-0.07</td>
<td>-0.06</td>
<td>0.48*</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Social Well-Being</td>
<td>-0.43*</td>
<td>-0.28</td>
<td>-0.16</td>
<td>0.52**</td>
<td>0.44*</td>
<td>0.34</td>
<td>0.37</td>
<td>0.68**</td>
<td>-0.11</td>
<td>1.00</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>11. Relationship with Doctor</td>
<td>-0.05</td>
<td>-0.13</td>
<td>-0.05</td>
<td>-0.04</td>
<td>-0.06</td>
<td>-0.04</td>
<td>-0.03</td>
<td>0.44*</td>
<td>-0.27</td>
<td>0.59**</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Emotional Well-Being</td>
<td>-0.71**</td>
<td>-0.54**</td>
<td>-0.80**</td>
<td>-0.11</td>
<td>-0.06</td>
<td>0.06</td>
<td>0.06</td>
<td>0.78**</td>
<td>0.44*</td>
<td>0.38</td>
<td>0.22</td>
<td>1.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Functional Well-Being</td>
<td>-0.48*</td>
<td>-0.31</td>
<td>-0.40*</td>
<td>0.14</td>
<td>0.21</td>
<td>0.43*</td>
<td>0.38*</td>
<td>0.84**</td>
<td>0.32</td>
<td>0.54**</td>
<td>0.32</td>
<td>0.51**</td>
<td>1.00</td>
<td></td>
</tr>
<tr>
<td>14. Additional Concerns</td>
<td>-0.53**</td>
<td>-0.42*</td>
<td>-0.58**</td>
<td>-0.08</td>
<td>-0.01</td>
<td>0.13</td>
<td>0.12</td>
<td>0.87**</td>
<td>0.42*</td>
<td>0.47**</td>
<td>0.37</td>
<td>0.65**</td>
<td>0.66**</td>
<td>1.00</td>
</tr>
</tbody>
</table>

* Correlation is significant at the 0.05 level (2-tailed).
** Correlation is significant at the 0.01 level (2-tailed).
Quality of Life Total Score

QOL correlated with perceived stress appraisal, symptom distress, optimism and all social support subscales. QOL was found to be negatively correlated with perceived stress appraisal and symptom distress at all three time periods. High levels of QOL were associated with low levels of stress and low symptom distress. QOL and optimism correlated negatively at all three time periods. An optimistic outlook was associated with a higher level of QOL. QOL positively correlated with all the subscales from the Social Support Survey for the first time period only. At Time 1 a high level of QOL was associated with higher levels of tangible, affection, social interaction and emotional/informational supports.

Perceived Stress Appraisal

Perceived stress appraisal was positively correlated with symptom distress for all three time periods. A high level of perceived stress was associated with a high level of symptom distress. Perceived stress appraisal correlated with optimism at each time period, meaning that high perceived stress correlated with low levels of optimism. Perceived stress appraisal also had a significant negative correlation at Time 1 with emotional/informational support. Breast cancer patients experiencing high levels of stress reported lower levels of emotional/informational support.

Perceived stress appraisal also negatively correlated with QOL subscales physical well-being, emotional well-being, social well-being, functional well-being, and additional concerns. A negative relationship between perceived stress appraisal and physical well-being was reported for Time 1 and Time 2. Low stress was associated with the participant feeling physically well. Perceived stress appraisal was negatively correlated with emotional well-being for all three time periods, low stress was related to the
participants feeling emotionally well. For Time 2 and Time 3 there is a negative relationship between perceived stress appraisal and social well-being and additional concerns. Low levels of stress were associated with a high level of social well-being and the transplant recipient expressing fewer additional concerns related to their transplant. Perceived stress appraisal also correlated negatively with functional well-being at Time 3. Low levels of stress were related to a high functional ability (See Tables 3, 4, & 5).

**Symptom distress**

Symptom distress significantly correlated with perceived stress appraisal for all three time periods. More symptom distress was associated with a higher level of stress. Symptom distress was positively correlated with optimism at Time 1. Low levels of symptom distress were associated with an optimistic outlook. Symptom distress correlated negatively with the QOL subscales of physical well-being and emotional well-being for all three time periods. Low symptom distress was associated with high levels of both physical well-being and emotional well-being. Symptom distress was also negatively correlated with additional concerns at Time 2 and 3. Low symptom distress was associated with fewer additional concerns related to transplant.

**Optimism**

Optimism was positively correlated with perceived stress appraisal at all three time periods, patients reporting more optimism were also reporting less stress. Optimism correlated positively with symptom distress at Time 1. Participants were reporting more optimism when they were reporting less symptom distress. Optimism was negatively correlated with social interaction at Time 1, indicating that patients reporting more social interaction reported being more optimistic. Optimism correlated negatively with QOL subscales of physical well-being and emotional well-being for all three time periods. A
low score on the optimism scale implied an optimistic outlook, when women reported
they were feeling physically and emotionally well, they were more optimistic. At Times 2
and 3 optimism scores negatively correlated with additional concerns, the more optimistic
the breast cancer patient, the fewer transplant related concerns. Optimism was also
negatively correlated with functional well-being at Time 3, when patients reported more
optimism they also reported high levels of functional ability.

Social Support Survey

As expected social support subscales correlated significantly with each other,
correlations ranged from 0.55 to 0.97 for all subscales. The variables, social interaction
and emotional/informational support were highly correlated across the three time periods
(0.94 to 0.97) indicating that these subscales appear to be measuring the same construct.

Tangible Support

Tangible support correlated positively with social well-being at Times 2 and 3.
When patients received more tangible support it was related to a high level of social well-
being.

Affection

At Time 1, affection was positively correlated with functional well-being.
Patients reporting receiving high levels of affection also reported high levels of functional
ability. Affection positively correlated with social well-being at Time 1 and Time 3. A
high level of affection was associated with a high level of social well-being.

Social Interaction

Social interaction was correlated positively with physical well-being and
functional well-being at Time 1. When breast cancer patients reported a high level of
social interaction it was associated with a high level of physical well-being and functional
well-being. Social interaction also correlated positively with functional well-being at Time 3.

**Emotional/Informational Support**

Emotional/informational support scores indicated a significant positive correlation with functional well-being for the first and third time periods. High levels of emotional/informational support were associated with high functional abilities of the breast cancer patients. Emotional/informational support correlated positively with social well-being at Time 1. High levels of emotional/informational support were associated with high levels of social well-being. Emotional/informational support did not correlate with any other variables at Time 2.

**QOL Subscales**

Correlations between QOL subscales demonstrated the following relationships.

**Physical Well-Being**

Physical well-being was positively correlated with emotional well-being and additional concerns for all three time periods. When the breast cancer patient reported feeling physically well, she also reported feeling emotionally well and expressed fewer complaints related to transplant. Physical well-being was also positively correlated with functional well-being. High levels of physical well-being were associated with high levels of functional ability.

**Social Well-Being**

At Time 1 social well-being positively correlated with all subscales of the QOL scale except the variable physical well-being. At Time 2 and 3 social well-being positively correlated with relationship with doctor, functional well-being and additional concerns. Social well-being also correlated with emotional well-being at Time 3.
Relationship with Doctor

Relationship with doctor correlated with the subscale social well-being for all three time periods. A good relationship with the physician was associated with high levels of social well-being. No other correlations were noted for the variable.

Emotional Well-Being

Emotional well-being, correlated positively with physical well-being and additional concerns at all three time periods. Emotional well-being was positively correlated with social well-being at Time 1 and Time 3. Emotional well-being also correlated with functional well-being at Time 3.

Functional Well-Being

Functional well-being was positively correlated with physical well-being, social well-being, relationship with doctor, and additional concerns at Time 1. At Time 2 functional well-being was only correlated positively with social well-being and additional concerns. At Time 3 functional well-being correlated positively with social well-being, emotional well-being, and additional concerns.

Additional Concerns

Additional concerns correlated with all subscales of the QOL Survey except for relationship with doctor for Time 2. No other significant relationships were noted for any of the three time periods.

It appears that the most difficult time period for the women in the study was at Time 2. During the second time period the women complained of higher perceived stress, higher symptom distress, less optimism and lower QOL. It should also be noted that at this time period the women reported receiving the most social support. At three
months post-transplant the women in the study reported the lowest amount of perceived stress appraisal, lowest symptom distress and the highest QOL.
CHAPTER FIVE

Discussion

This study examined how stress and coping resources influence QOL in women with metastatic breast cancer who received an autologous PBSCT as treatment for their disease at three time periods, prior to transplant, and at one and three months post-transplant. Perceived stress appraisal, symptom distress, optimism and social support were measured to determine if they predicted the breast cancer patient’s QOL following an autologous PBSCT. This discussion summarizes the main findings and examines the clinical significance and implications of the results as well as the need for future research and application of a theoretical model.

Considering Lazarus and Folkman’s (1984) adaptation model, it was proposed that the breast cancer patient’s appraisal of the stressful event and her own symptom distress (individual stressors) as well as her use of coping resources (optimism and social support) would influence the QOL of women with breast cancer following an autologous PBSCT. These relationships were measured at three points in time, pre-transplant, one month post-transplant and three months post-transplant.

This study involved twenty-eight women with metastatic breast cancer, Stage II – Stage IV. The majority of the women who participated in the study had Stage IV breast cancer and ranged in age from 27 – 60 years. Most of the women reported having no dependents under eighteen at home and responded that they did not have a female relative with breast cancer. The sample of participants was predominantly Caucasian and the majority of the women were married. Level of education ranged from partial high school to a university degree; however, the majority of the women surveyed reported that they had completed college. Level of household income ranged from less than $10,000 to
greater than $71,000, with the majority of the participants reporting an annual income of greater than $41,000.

Initially we examined how stressors, coping resources and adaptation variables changed over time. Two measures were used to evaluate stress. A perceived stress appraisal scale and a symptom distress scale. Perceived stress appraisal did not change significantly over time. It is likely that the level of perceived stress appraisal did not change as a result of the participant continuing to appraise the treatment modality and her condition as a threat (Lazarus & Folkman, 1984). Symptom distress did demonstrate a statistically significant change between one month post-transplant and three months post-transplant. At one month post-transplant recipients reported that they were experiencing common side effects like nausea and fatigue. The participants reported that their “symptom distress” significantly decreased three months post-transplantation. That is, the women stated that they were feeling at their best three months post-transplant compared to the other two time periods. This finding is consistent with other clinical studies (Baker et al., 1998; Bitran et al., 1996) that have found that transplant related side effects had resolved by three months post-transplant.

Coping resources in this study were measured using an optimism scale to evaluate “internal” coping resources and a social support scale to evaluate “external” coping resources. The women who participated in the study reported more optimism prior to transplant than at any other time period. The level of optimism decreased significantly one month post-transplant. Interestingly this is when the women reported greater perceived stress, more symptom distress and lower QOL. However, at Time 3 although it was not significant, optimism did increase slightly.
Social interaction and affection, two of the social support subscales, increased significantly at Time 2. This difference may have been evident at Time 2 as a result of the attention received by the participants from family members and caregivers during the immediate period following their transplant procedure. The subscales tangible support and emotional/informational support did not change significantly over time.

The QOL total score did not change significantly over time but was higher at Time 3. Three variables from the QOL survey; physical well-being, relationship with doctor, and emotional well-being did show significant effects over time. Physical well-being decreased one month post-transplant and increased at the third time period. The breast cancer patients reported a lower level of physical well-being and were complaining of transplant related side effects like nausea and fatigue at Time 2. As symptoms decreased women reported higher levels of physical well-being that had almost returned to the pre-transplant level. This finding is supported by clinical studies in which breast cancer patients who had received an autologous PBSCT returned to their pre-transplant level of wellness three months post-transplant (Cameron et al., 1996). A further study reported QOL of transplant recipients was impaired until three years post-transplantation when the level of QOL of the transplant recipients was indistinguishable from population norms (Sutherland et al., 1997). However, in this investigation no normal controls were used to measure QOL.

The breast cancer patient’s relationship with doctor was highest one month post-transplant. It is likely that the participants reported that they had a close relationship with their physician as a direct result of the daily patient-doctor contact immediately post-transplantation. The participants reported their emotional well-being was higher at three
months post-transplant when they experienced a decrease in perceived stress, less symptom distress and more optimism.

In order to examine how QOL was influenced by stressors and coping resources over time we used hierarchical multiple regression. Although these results were not significant, probably due to the small sample size, there were significant correlations between stressors, coping resources and adaptation (QOL). Considering the stress measures used relationships were reported between perceived stress appraisal, symptom distress and optimism for all three time periods as expected. When perceived stress appraisal and symptom distress were lower the women reported more optimism and improved QOL. These results further support a previous study by Northouse et al., (1999) which found that a decreased level of stress was related to reduced symptom distress. A low level of perceived stress was also associated with higher levels of social interaction. One would expect that women experiencing less stress would be more inclined to social contact.

The internal coping resource of optimism was also associated with patient reports of higher social interaction as well as higher levels of QOL. These findings were expected by the researcher, an optimistic outlook by the participant correlated with higher levels of physical well-being and emotional well-being as measured by the QOL subscales. Lauver & Tak (1995) also noted that breast cancer patients were particularly optimistic at the time of diagnosis prior to receiving treatment. The internal coping resource of optimism and the external coping resource social interaction were associated with an improved level of physical and emotional well-being at Time 1 but not at other time periods. All social support subscales correlated positively with QOL at Time 1, but
not at Times 2 or 3. At Time 1 women who reported receiving more tangible support, affection, social interaction, emotional/informational support reported better QOL.

Lazarus and Folkman’s Adaptation Model of Stress and Coping

In this study support was found for relationships between stressors, coping resources and adaptation in women who received an autologous PBSCT. These relationships indicated that women with breast cancer reported low perceived stress appraisal, low symptom distress, more optimism and more social support when they reported higher levels of QOL. However, the coping resource social support only correlated with QOL prior to transplant and not following the procedure. The breast cancer participants may have found they required more social support such as informational support prior to transplant. Patient appraisal of stress and reports of symptom distress and optimism continued to relate to the QOL of breast cancer patients throughout the investigation. Although these findings were not significant when multiple regression analysis was used to examine how stressors and coping resources influenced adaptation it appears likely that findings could be different with a larger sample size.

Recommendations for Future Research

This QOL study made a contribution to the advancement of nursing knowledge with regards to the adaptation of breast cancer patients who undergo an autologous PBSCT. Further research is necessary to determine if the trends in perceived stress appraisal, symptom distress, optimism, social support, and QOL continue in a longitudinal study or if the variables return back to the pre-transplant levels after a prolonged period of time.

Strengths of this study were that the study was a prospective investigation that examined the impact of stressors and coping mechanisms on QOL over three time
periods. In addition, the study involved a relatively homogeneous group of women with metastatic breast cancer.

One of the limitations of this study was that the sample size was quite small. This may be related to the fact that treatment of an autologous PBSCT for breast cancer patients is highly controversial, and as a result not all insurance companies cover the treatment, and not all physicians recommend their patients for this treatment modality. Consequently, the small sample size may have been influenced by patients' ability to select the treatment.

A further limitation is that this study relied on self-report measures. The use of objective measures on replication of the study would increase the external validity of the findings. Future studies that involve breast cancer patients could also focus on the use of objective measures such as laboratory values and radiology results as well as nurse and physician reports.

Future research is required concerning the relationship that breast cancer patients have with their nurses and how this relationship may influence the breast cancer patient's ability to adapt. The survey in this investigation contained one question that inquired if the patient had confidence in their nurses. Overwhelmingly, the participants replied that they did have confidence in their nurses (85%) at all three time periods. However, the addition of a short questionnaire about caregivers could provide further information about which caring behaviours were most helpful to patients, and inspired patient confidence.

Implications for Nursing Practice

The findings in this study provide support for the use of an adaptation model to guide nursing practice. Nursing assessment of symptom distress, patient's appraisal of
stress and the coping resources available to them can enable the nurse to plan for care to maximize adaptation during time of illness.

In addition to the stress of a treatment such as an autologous PBSCT, it is important for nurses to recognize there are differences in how patients experience and appraise their stress. In this study the patient’s perceived stress appraisal was strongly correlated with her symptom distress. This suggests that nurses need to provide patients with an opportunity to express their feelings about their condition in addition to providing symptom relief. This could include asking how they were feeling about their situation and dealing with it. Nurses could also provide comfort measures to help alleviate symptom distress.

In this study, the variable optimism was found to correlate with both perceived stress appraisal and symptom distress. Findings suggest a need for nursing interventions to encourage or maintain an optimistic approach on the part of the breast cancer patient. This may be possible, first by screening patients to determine their level of optimism and then working with both the patient and family members to encourage their expression of optimistic/pessimistic feelings so that where possible encouragement can be given to support optimism.

Findings further suggest that nurses need to be able to evaluate the social support available to patients considering it’s multiple dimensions when caring for patients with a life threatening illness. Informational support prior to transplant can provide the patient with information regarding the proposed treatment enabling them to make an informed decision about treatment. Emotional support can be provided to patients through the presence of caring staff and or family support. Tangible support is support that is given to an individual when she is ill, the nurse needs to be aware if the patient has anyone who
could provide tangible support for family at home, when the patient is hospitalized, and also for the patient herself at the time of discharge. Nurses can also evaluate the patient’s social network to determine whether or not adequate family/friend support is available to each individual. The different dimensions of social support can act to influence adaptation and nurses need to recognize that informational support is not the only type of social support that they can offer to patients and family members.

There is a growing population of women with breast cancer who have received an autologous PBSCT as treatment for their disease. This treatment remains highly controversial as physicians debate whether or not PBSCT is an effective treatment for breast cancer patients. Although this study did not end the controversy it did provide nurses with some guidance when providing care for these patients. It is hope that as a result of this investigation nurses may consider the importance of stressors, and internal and external coping resources, and how these variables can impact on an individual’s ability to adapt over time. The results of this study address the importance of providing nursing care to breast cancer patients receiving an autologous peripheral blood stem cell transplant, that is effective in promoting their adaptation and improving their quality of life. In situations of life threatening illness, a patient’s quality of life is clearly important to consider when providing care and planning for optimal patient outcomes.
References


**Perceived Stress Scale (Appendix A)**

The questions in this scale ask you about your feelings and thoughts during the past month. In each case, you will be asked to indicate how often you thought or felt a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is do not try and count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate by checking the appropriate box.

In the last month, how often have you...

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>almost never</th>
<th>sometimes</th>
<th>fairly often</th>
<th>very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Been upset because of something that happened unexpectedly?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Felt that you were unable to control the important things in your life?</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>Felt nervous and “stressed”</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>Dealt successfully with irritating life hassles</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>5.</td>
<td>Felt you were effectively coping with important changes that were occurring in your life</td>
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<td></td>
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<tr>
<td>6.</td>
<td>Felt confident about your ability to handle your personal problems</td>
<td></td>
<td></td>
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<tr>
<td>7.</td>
<td>Felt things were going your way</td>
<td></td>
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<tr>
<td>8.</td>
<td>Found that you could not cope with all the things that you had to</td>
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<tr>
<td>9.</td>
<td>Felt you were on top of things</td>
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<tr>
<td>10.</td>
<td>Been angered because of things that happened that were outside of your control</td>
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<tr>
<td>11.</td>
<td>Felt yourself thinking about things that you have to accomplish</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>12.</td>
<td>Been able to control the way you spend your time</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the last month, have you...

<table>
<thead>
<tr>
<th></th>
<th>never</th>
<th>almost never</th>
<th>sometimes</th>
<th>fairly often</th>
<th>very often</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.</td>
<td>Been able to control irritations in your life</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Felt difficulties were piling up so high that you could not overcome them</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Symptom Distress Scale (Appendix B)

**Instructions**
Below are 5 different numbered statements. Think about what each statement says, then place a circle around the one statement that most closely indicates how you have been feeling lately. The statements are ranked from 1 to 5, where number 1 indicates no problems and number 5 indicates the maximum amount of problems. Numbers two through four indicate you feel somewhere between these two extremes. Please circle one number for each symptom.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nausea (1)</strong></td>
<td>I seldom feel any nausea at all</td>
<td>I am nauseous once in a while</td>
<td>I am often nauseous</td>
<td>I am usually nauseous</td>
<td>I suffer from nausea almost continually</td>
</tr>
<tr>
<td><strong>Nausea (2)</strong></td>
<td>When I do have nausea, it is very mild</td>
<td>When I do have nausea, it is mildly distressing</td>
<td>When I have nausea, I feel pretty sick</td>
<td>When I have nausea, I feel very sick</td>
<td>When I have nausea, I am as sick as I could be</td>
</tr>
<tr>
<td><strong>Appetite</strong></td>
<td>I have my normal appetite</td>
<td>My appetite is usually, but not always pretty good</td>
<td>I don’t really enjoy my food like I used to</td>
<td>I have to force myself to eat my food</td>
<td>I cannot stand the thought of food</td>
</tr>
<tr>
<td><strong>Insomnia</strong></td>
<td>I sleep as well as I always have</td>
<td>I have occasional spells of sleeplessness</td>
<td>I frequently have trouble getting to sleep and staying asleep</td>
<td>I have difficulty sleeping almost every night</td>
<td>It is almost impossible for me to get a decent night’s sleep</td>
</tr>
<tr>
<td><strong>Pain (1)</strong></td>
<td>I almost never have pain</td>
<td>I have pain once in a while</td>
<td>I frequently have pain – several times a week</td>
<td>I am usually in some degree of pain</td>
<td>I am in some degree on pain almost constantly</td>
</tr>
<tr>
<td><strong>Pain (2)</strong></td>
<td>When I do have pain, it is very mild</td>
<td>When I do have pain it is mildly distressing</td>
<td>The pain I do have is usually fairly intense</td>
<td>The pain I have is usually very intense</td>
<td>The pain I have is almost unbearable</td>
</tr>
<tr>
<td>Fatigue</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>---------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>I am usually not tired at all</td>
<td>I am occasionally rather tired</td>
<td>I frequently have periods when I am quite tired</td>
<td>I am usually very tired</td>
<td>Most of the time, I feel exhausted</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Bowel</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a normal bowel pattern</td>
<td>My bowel pattern occasionally causes me some discomfort</td>
<td>I frequently have discomfort from my present bowel pattern</td>
<td>I am usually in discomfort because of my present bowel pattern</td>
<td>My present bowel pattern has changed drastically from what was normal for me</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Concentration</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have my normal ability to concentrate</td>
<td>I occasionally have trouble concentrating</td>
<td>I often have trouble concentrating</td>
<td>I usually have at least some difficulty concentrating</td>
<td>I just can't seem to concentrate at all</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Appearance</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>My appearance has basically not changed</td>
<td>My appearance has gotten a little worse</td>
<td>My appearance is definitely worse than it used to be, but I am not greatly concerned about it</td>
<td>My appearance is definitely worse than it used to be, I am concerned about it</td>
<td>My appearance has changed drastically from what it was</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Breathing</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I usually breathe normally</td>
<td>I occasionally have trouble breathing</td>
<td>I often have trouble breathing</td>
<td>I can hardly ever breathe as easily as I want</td>
<td>I almost always have severe trouble with my breathing</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outlook</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am not fearful or worried</td>
<td>I am a little worried about things</td>
<td>I am quite worried, but not afraid</td>
<td>I am worried and a little frightened about things</td>
<td>I am worried and scared about things</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cough</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>I seldom cough</td>
<td>I have an occasional cough</td>
<td>I often cough</td>
<td>I often cough, and occasionally have severe coughing spells</td>
<td>I often have persistent and severe coughing spells</td>
<td></td>
</tr>
</tbody>
</table>
**Life Orientation Scale** (Appendix C)

Below are 12 statements, please respond by circling either TRUE or FALSE to each statement.

| 1. In uncertain times, I usually expect the best. | TRUE | FALSE |
| 2. It is easy for me to relax. | TRUE | FALSE |
| 3. If something can go wrong with me, it will. | TRUE | FALSE |
| 4. I always look on the bright side of things. | TRUE | FALSE |
| 5. I am always optimistic about the future. | TRUE | FALSE |
| 6. I enjoy my friends a lot. | TRUE | FALSE |
| 7. It is important for me to keep busy. | TRUE | FALSE |
| 8. I hardly ever expect things to go my way. | TRUE | FALSE |
| 9. Things never work out the way that I want them to. | TRUE | FALSE |
| 10. I don’t get upset too easily. | TRUE | FALSE |
| 11. I am a believer in the idea that “every cloud has a silver lining.” | TRUE | FALSE |
| 12. I rarely count on good things happening to me. | TRUE | FALSE |
Social Support Survey (Appendix D)

1. About how many close friends and relatives do you have, people you feel at ease with and can talk to about what is on your mind? Write in number of close friends and relatives: ________

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

<table>
<thead>
<tr>
<th></th>
<th>None of the time</th>
<th>A little of the time</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Someone to help you if you were confined to bed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. Someone you can count on to listen to you when you need to talk</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. Someone to give you good advice about a crisis</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. Someone to take you to the doctor if you need it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>6. Someone who shows you love and affection</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. Someone to have a good time with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8. Someone to give you information to help you understand a situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9. Someone to confide in or talk to about yourself or your problems</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10. Someone who hugs you</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11. Someone to get together with for relaxation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12. Someone to prepare your meals if you were unable to do it yourself</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13. Someone whose advice you really want</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14. Someone to do things with to help you get your mind off things</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15. Someone to help with daily chores if you were sick</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Question</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>16. Someone to share your most private worries and fears with</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Someone to turn to for suggestions about how to deal with a personal problem</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Someone to do something enjoyable with</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Someone who understands your problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Someone to love and make you feel wanted</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Quality of Life Scale (Appendix E)**

Below are several statements, circle the response that best describes how you feel today. The statements are ranked from 0 to 4, where 0 indicates no problems and 4 indicates the maximum amount of problems. Numbers 1, 2, and 3 indicate that you feel somewhere in between these two extremes.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I have a lack of energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I have nausea</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Because of my physical condition, I have trouble meeting the needs of my family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I have pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. I am bothered by side-effects of treatment</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I feel sick</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I am forced to spend time in bed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. I feel distant from my friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I get emotional support from my family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I get support from my friends and neighbors</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. My family has accepted my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. My family communication about my illness is poor</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. I feel close to my partner (the person who is my main support)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. Have you been sexually active during the past year? No__ Yes__ if yes: I am satisfied with my sex life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. I have confidence in my doctor</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. My doctor is available to answer my questions</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. I feel sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. I am proud of how I am coping with my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. I am losing hope in the fight against my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I feel nervous</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. I worry about dying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. I worry that my condition will get worse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. I am able to work (include work in home)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. My work (include work in home) is fulfilling</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>---</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td>25. I am able to enjoy life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. I have accepted my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. I am sleeping well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28. I am enjoying things I usually do for fun</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29. I am content with the quality of my life right now</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>30. I am concerned about keeping my job (include work in the home)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>31. I feel distant from other people</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>32. I worry that the transplant will not work</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>33. The effects of the treatment are worse than I had imagined</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>34. I have a good appetite</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>35. I like the appearance of my body</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>36. I am able to get around by myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>37. I get tired easily</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>38. I am interested in having sex</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>39. I have concerns about my ability to have children</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>40. I have confidence in my nurse(s)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>41. I regret having the bone marrow transplant</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

***Other concerns/symptoms/changes I have specifically noticed in myself compared to health before or the last time filling out this questionnaire:
**Demographics (Appendix F)**

For the questions below please fill in the blanks

What is your age? ____________

How many dependents (children under 18 years)? _________

Age(s) of Dependent(s) ________________________________

Sex of Dependent(s) _________________________________

Do you have any female relatives with breast cancer? ____________ Relationship ____________

**Please circle the correct response for the questions listed below.**

<table>
<thead>
<tr>
<th>Race</th>
<th>Caucasian</th>
<th>African American</th>
<th>Asian</th>
<th>Hispanic</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td>Married / Common Law Partner</td>
<td>Single</td>
<td>Divorced</td>
<td>Widowed</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of Education</th>
<th>Less than 7th grade</th>
<th>Junior High School (9th grade)</th>
<th>Partial High School</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>High School Graduate</td>
<td>Partial College (at least 1 year)</td>
<td>College Graduate</td>
</tr>
<tr>
<td></td>
<td>Graduate Degree</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Yearly household Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>71,000 +</td>
</tr>
<tr>
<td>61,000 - 70,000</td>
</tr>
<tr>
<td>51,000 - 60,000</td>
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Appendix G

Informed Consent

Title: A Prospective Study of Adaptation to Breast Cancer Following an Autologous Peripheral Blood Stem Cell Transplant

Principal Investigator: Christina M. Dales, RN, MSc Candidate, University of Windsor, School of Nursing
Supervisor: Sheila Cameron, RN, Ed.D, Dean of Graduate Studies and Research, University of Windsor

Introduction: You are invited to take part in this study because you have breast cancer and are being treated with an Autologous Peripheral Blood Stem Cell Transplant.

Purpose: The purpose of this study is to examine the quality of life of women with breast cancer treated with an Autologous Peripheral Blood Stem Cell Transplant.

Description of the Study Procedure: All patients with breast cancer who are scheduled to receive an Autologous Peripheral Blood Stem Cell Transplant will be invited to participate in this study. A member of the Bone marrow transplant (BMT) team will ask you to complete questionnaires at three different time periods during your transplant. The first set of questionnaires will be given to you prior to your transplant. The second set of questionnaires will be given to you one month after your transplant and the third set of questionnaires three months after your transplant.

It is important if you agree to participate in the study that you complete all five of the questionnaires at the three specified time periods.

Risks: There are few risks associated with participation in this study and they are minimal. You may become fatigued or have additional stress as a result of your participation. You may call the nurse practitioner at any time to discuss your condition. If you find any questions offensive or objectionable you may refuse to answer them. There are no known additional risks to you or your family by your participation in this study.

Benefits: Although this study has no direct benefits to you, it may help to improve the understanding that health care professionals have regarding quality of life for women with breast cancer who receive an autologous peripheral blood stem cell transplant. Your contribution will assist us greatly.

Compensation: You will not receive any compensation for your participation in this study. In the unlikely event of an injury resulting from your participation in the research study you will not receive any reimbursement, compensation or free medical care from your hospital or Cancer Center.

Voluntary Participation: Your participation in this study is completely voluntary. You are free to withdraw your consent to participate in the study at any time without prejudice.
to your subsequent care. Refusing to participate will not affect your future relations with your physician or your hospital.

Confidentiality: Your completed questionnaires will be kept in a locked file at your hospital. Questionnaires that are completed will be coded to maintain your confidentiality. All results will be considered strictly confidential. There will be no way to identify you in the data analysis phase of the study. Only the results from the total group of breast cancer patients will be used. If you are interested in the results of this study they will be available to you after the analysis phase through your physician or BMT Coordinator.

Questions: This study has received ethical clearance from the University of Windsor School of Nursing Research Committee, and from your hospital’s Investigational Review Board. Any questions or concerns that you have about the conduct of the study should be referred to Dr. Cheri Hernandez, Chair of the Nursing Department Ethics Committee, University of Windsor at (519) 253-3000 ext. 2258.

Consent to Participant in a Research Study: I have read all of the above information about this research study, including the procedure, possible risks and the likelihood of any benefits to me. The content and meaning of this information has been explained to me and I understand it. All my questions have been answered. I hereby consent and voluntarily offer to follow the study requirements and take part in this study. I will receive a signed copy of this consent form.

_____________________________  __________________________
Patient’s Signature                      Date

_____________________________  __________________________
Witness                      Date

I have explained the study to the above named individual and have answered all his/her questions. To the best of my knowledge, this individual understands the content of this form and has voluntarily given informed consent.

_____________________________  __________________________
Signature of Investigator (or designee’s)  Date
Letter of Information (Appendix H)

INVESTIGATOR: Christina M. Dales, RN, MSc Candidate, University of Windsor, School of Nursing
SUPERVISOR: Dr. Sheila Cameron, RN, Ed.D, Dean of Graduate Studies and Research, University of Windsor, School of Nursing

Dear Participant:

I am conducting a study on the quality of life of women with breast cancer who are currently choosing to undergo an autologous peripheral blood stem cell transplant for treatment. The results of this study will help to determine ways nurses and other health care professionals can assist women with breast cancer who have an autologous peripheral blood stem cell transplant. Your contribution will be helpful.

This letter has been given to you from the clinic in order to preserve confidentiality. Surveys will be coded to maintain your confidentiality. All results will be considered strictly confidential. There will be no way to identify you in the data analysis phase of the study. Only the results from the total group of breast cancer patients will be used.

You, the patient, are asked to complete surveys. Your decision to participate, or not to participate will in no way affect any of the services you are receiving. Participation in the study involves filling out surveys and returning them to your Bone Marrow Transplant (BMT) Coordinator. You will be asked to complete the surveys at three different times, prior to transplant, one month after transplant, and three months after your transplant. It is expected that surveys will take approximately twenty to thirty minutes to complete and you are to fill out the surveys independently. Please try to respond to each question, however if the question is offensive to you, do not complete the question. Group results of this study will be made available to you through your BMT coordinator and or physician.

Questions: This study has received ethical clearance from the University of Windsor School of Nursing Research Committee, and from your hospital’s Investigational Review Board. Any questions or concerns that you have about the conduct of the study should be referred to Cheri Hernandez, Chair of the Nursing Department Ethics Committee at (519) 253-3000 ext. 2258.

Thank you in advance if you choose to participate in this study.

Sincerely,

Christina M. Dales, RN, MSc Candidate
VITA AUCTORIS

NAME               Christina Michelle Dales

BIRTH DATE         August 13, 1970

PLACE OF BIRTH     Iroquois Falls, Ontario

EDUCATION          Iroquois Falls Secondary School, Iroquois Falls, Ontario
                   1984-1988
                   University of Windsor, Windsor, Ontario
                   1988-1992 B.Sc.N.
                   University of Windsor, Windsor, Ontario