# OPTIMISM, HEALTH LOCUS OF CONTROL, AND QUALITY OF LIFE WOMEN WITH INITIAL VERSUS RECURRENT BREAST CANCER Gina Graci, B.A., B.S., M.S.

Dissertation Prepared for the Degree of DOCTOR OF PHILOSOPHY

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Health Locus of Control (HLOC) and other predictors of Quality of Life (QL) were examined for women with an initial versus recurrent breast cancer diagnosis. Twenty-eight women with an initial breast cancer (IBC) diagnoses and twenty-eight women with recurrent breast cancer (RBC) diagnoses were recruited from doctors' offices and cancer support groups. Correlational analyses were used to assess the relationships between variables. No significant differences were found between women with IBC and RBC on Psychological QL. Doctor HLOC and Psychological QL were related for women with RBC (r = .481, p = .01) and marginally so for women with IBC (r = .481, p = .01) and marginally so for women with IBC (r = .481, p = .01) = .329, p = .09). A positive correlation was also found between Doctor HLOC and Functional QL for both women with IBC (r = .464, p = .01) and women with RBC (r = .464, p = .01) .390, p = .04). After controlling for stage of cancer, women with RBC reported higher Functional QL than did women with IBC. Advanced (stages III or IV) versus early (stages I or II) cancer stage related to lower Functional QL, controlling for initial versus recurrent diagnosis (r = -.283, p = .01). A marginally significant relationship was also found for cancer stage, regardless of initial versus recurrent diagnosis, with higher Overall QL for women with early stages of breast cancer (r = -.157, p = .09). No significant differences in Optimism or Overall QL were found between women with IBC versus RBC. No differences were found between married and single women. This

research begins to explore differences in Quality of Life for women with a new versus a recurrent breast cancer diagnosis.

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#### **CHAPTER I**

#### INTRODUCTION

## Reasons for the Study of Quality of Life (QL) in Breast Cancer (BC) Patients

Cancer is a general term used to describe over 100 diseases that are characterized by the malignant spread of abnormal cells in the body (American Cancer Society, 1993). Breast cancer (BC) is the most common cancer in women, accounting for one out of every three cancer diagnoses (American Cancer Society, 1999). Breast cancer mortality rates are highest amongst women aged 30-to-50 (Ganz, Hirji, Sim, Schag, Fred, & Polinsky, 1993; Royak-Schaler, 1992) and the leading cause of death in women aged 15-to-54 years (American Cancer Society, 1999). Women aged 50 and older are more likely than younger women to receive a cancer diagnosis. However, women less than 45 years who are diagnosed with breast cancer have a 79% five-year survival rate, whereas this rate increases to 84% for women aged 45 to 64 and to 87% for those women 65 years and over (American Cancer Society, 1993).

In addition to age, ethnicity has become a significant factor in mortality rates because Caucasian women are more likely to develop breast cancer than other ethnicities. However, African American and Hispanic women are more likely to die of breast cancer than Caucasian women due to unavailability of treatment and stage of cancer at diagnosis (American Cancer Society, 1999).

Recurrence is defined as the reappearance of the disease that was thought to be cured or in remission (National Cancer Institute, 1992). Recurrent cancers are classified

by location, that is local (cancer came back in same place), regional (growth of a new tumor in lymph nodes or in tissue near the original site of cancer), or metastatic (cancer spread to organs or tissue far from the initial cancer site). If a patient is diagnosed with a breast cancer recurrence, this diagnosis does not necessarily mean a "death sentence." Many recurrences are localized to the original cancer site and not indicative of metastatic cancer. This type of recurrence diagnosis yields high survival rates.

Exact estimates of BC recurrence are not available; however, many women with a history of BC experience a recurrence (Mahon & Casperson, 1995). Reactions to a recurrent diagnosis vary according to several factors: location and stage of cancer, treatment options, and prognosis of the disease (Christ, 1993). There is general consensus in the cancer literature that a recurrent diagnosis is threatening at all levels (Mahon et al., 1995) and that a recurrent diagnosis causes patients to re-experience feelings of psychological distress that were present at the initial diagnosis with loss of optimism and hope of a future (Christ, 1993; Holland, 1998; National Institutes of Health, 1992). Not only does the disease threaten the life of the patient, but a cancer diagnosis also holds further implications for psychological, physical, and functional well-being in addition to the changes in social experience. However, reactions to recurrence may not be as devastating as the initial diagnosis because many patients may have learned certain skills, knowledge and supports that have aided them in working through the prior cancer experience (Christ, 1993; Holland, 1998; Mahon, et al. 1995).

To date no studies have been conducted comparing women with an initial versus a recurrent BC diagnosis. It is hypothesized that both types of diagnoses (initial or recurrent) and treatment of cancer initiates a period of turmoil, uncertainty, and

psychological distress for the patient. However research has not been conducted on how both types of patients experience cancer, so one can only speculate how women with an initial versus a recurrent diagnosis will react to the cancer experience. For instance, once treatment ends, women with either an initial or recurrent diagnosis may be apprehensive about the future because of the fear of a (another) cancer recurrence. This fear may diminish over time as long as the individual remains in remission, however, the consensus is that it never completely disappears (Christ, 1993).

Advances in medical treatments during the last two decades have not only increased survival time but also improved the quality of life for BC patients. More than 50% of BC patients are in remission for at least five years after a primary treatment with surgery and chemotherapy, radiation therapy, or hormonal therapy. These treatments are often quite toxic and many compromise a patient's physical, psychological, and social well-being. Side effects of these treatments can also increase pain as well as debilitation, limiting an individual's ability to function at work, regulate mood, sleep and participate in physical activities and social relationships (Cleeland, 1990 as cited in Ahles, 1993). Recurrent patients may experience even more debilitation and reduction in quality of life than a patient experiencing cancer for the first time because recurrent cancer therapies utilize more aggressive treatment methods. Nonetheless, both types of patients, in addition to the psychological and physical distress, have to confront serious issues related, but not limited to: health insurance, finances, employment, and interpersonal relationships.

Neither the needs, perceptions, nor psychosocial concerns of patients with recurrent BC have received adequate exploration (Mahon et al., 1995). Many BC patients

have to revise their initial optimism and hope for a cure after a recurrence diagnosis since the average length of survival decreases significantly with repeated episodes of the disease (Holland, 1998; Worden, 1989). Patients having been in remission for a long (e.g., ten years), as compared to a short length of time (e.g., two years), may be especially susceptible to the stress associated with a BC recurrence diagnosis (Holland, 1998; Mahon et al., 1995; Worden, 1989), as these long-term survivors may again view themselves as being healthy.

Although progress in cancer treatment continues, recurrence of BC is still considered to be a poor prognostic sign (Worden, 1989). Treatment goals for recurrent BC may differ from treatment goals for an initial diagnosis of BC. The goal, from a medical and psychological perspective, in treating recurrent BC cancer may be to increase patient's quality of life by helping patients adjust and cope with the disease, increase compliance and treatment, and to detoxify death by helping patients to face their potential loss(es) (Mahon et al., 1995). These losses include long-term cure and long-term survival being less likely for recurrent BC patients.

Since there is a paucity of recurrent cancer research, one can only speculate about how women with an initial versus recurrent BC diagnosis will react to their cancer experience. The goal of this study is to determine if differences exist between these groups of women and to gain a greater understanding of the cancer experience from these two different perspectives.

## Conceptualization of QL

Quality of life research (QL) has been of interest to researchers for several decades dating back to the early 1960's. However, this research focused on length of survival, treatment

toxicity (Cella, 1992), and progression/severity of the disease/illness. These were not considered to be adequate measures of psychological, social, functional, and physical domains of a patient's life. Although current research has concerned itself with improving not only "quantity" but also the "quality of life of a person" (Cella, 1989) by focusing on the physical, emotional, and social dimensions of well-being (Aaronson, 1990; Ganz & Coscarelli, 1995; Ringdal, 1996), many cancer treatment clinical trials do not include QL measures. Gotay & Wilson (1998) reviewed 1,504 articles on cancer treatment clinical trials from 1992 to 1996 and less than 5% of these articles focused on patient ratings of QL. While cancer research has broadened to incorporate QL issues, there is a scarcity of empirical QL research, possibly preventing clinical interventions from improving QL in cancer patients.

Cella (1989), and Nanda and Andresen (1998) stress the importance of associating QL to changes in health status. They suggest that QL is a dynamic construct that changes over the course of an individual's life, especially when illness strikes. Self-reported measures of QL domains provide a measure of health from the patient's perspective. Factor analytic studies have suggested that there are essentially four QL domains: functional, psychological, social, and physical status (Aasonson, 1986; Schipper et al, 1984; Stewart et al, 1981, as cited in Cella, 1983; Gotay, et al., 1998; Rummans et al., 1998). However, QL research has been problematic because the domains have been difficult to operationalize and repeatedly undergo conceptual revision. As a result, QL has become a difficult construct to measure. Furthermore, QL may mean many different things to various professionals within multiple settings (Lindley, 1992). Wellisch (1983) reviewed approximately 100 articles and found that few authors agreed on a working

definition of the QL construct. Using factor analytic studies could potentially aid researchers in determining the underlying dimensions of QL; however, these measures are rarely reported because many of the QL measures were developed and validated on an insufficient number of participants.

Two key aspects of QL are often employed in defining the construct; subjectivity and multidimensionality (Aaronson, 1989; Cella, 1992; 1994 Ganz et al., 1995; Ringdal, 1996; Rummans et al, 1998). Subjectivity refers to understanding QL from the patient's own perspective (Cella, 1992; 1994) rather than being based on objective medical, physiological, or functional measures. This information may include perception of illness, perception of treatment, expectations of self, and appraisal of risk/harm.

Measurements of overt behavior fail to account for the patients' perceptions of QL because cognitive processes that mediate these perceptions of QL are often neglected (Cella, 1989; 1994) and provide an incomplete assessment of the QL construct.

The second component of the QL concept, multidimensionality, assesses multiple domains of patient functioning (Aaronson, 1988;1989; Barofsky, 1984; Cella, 1994; de Haes, 1985; Ganz et al., 1995; Gotay et al., 1998; Lindley, 1992; Rummans et al., 1998; Ware, 1984). These domains have been partitioned into four quality of life domains as illustrated in Figure 1. The areas include: (a) Functional Status, including ratings of mobility, self care, physical activities, and role activities, such as employment or household responsibilities (Aaronson, 1988; 1989; Ganz et al., 1995; Holland, 1998); (b) Psychological status, including levels of anxiety, depression or other nonspecific forms of distress that may be secondary to the disease itself or its progression and/or treatment (Aaronson, 1988; 1989; Ganz et al., 1995; Greer & Silberfarb, 1982; Holland, 1998;

Worden & Weisman, 1984); (c) Physical Functioning, also referred to as Disease and Treatment-Related Symptoms, involving specific symptoms from the disease such as pain or shortness of breath, or side effects of drug therapy such as nausea, hair loss, impotence, or sedation (de Haes & Van Knippenberg, 1985; Ganz et al., 1995;); and (d) Social Functioning, including the ability to maintain social interactions (Ganz et al., 1995).

These four domains of QL affect all aspects of an individual's life. QL must take into account these domains because each one has an unique influence in how a person interacts with others and life and copes with adversity. The importance of the QL construct becomes apparent because the four domains have significant influence on how satisfied an individual is with their life from a psychological, functional, social, and disease-treatment related perspective.

The theoretical relationship of these indicators of QL is shown together in Figure 2, with the original model being adapted from Tchekmedyian, Hickman, Siau, Greco, and Aisner (1990). This model was initially revised by deleting health care related, life satisfaction variables, and adding more relevant life satisfaction variables as indicators of psychological well-being. Psychological and functional status variables have also been retitled Psychological QL and Functional QL and will be referred to as such from this point on. Quality of life is modeled as the construct of interest and is causally determined by Psychological QL, Social QL, Functional QL, and Disease-Treatment-Related Symptoms. These four influential constructs are composites of the variables shown.

Additional considerations that are important in the evaluation of QL include: spirituality (Cella, 1989; Ganz et al., 1995; Holland; 1998; Ringdal, 1996), leisure, work,

family functioning, sexuality and body-image, and treatment satisfaction (Aaronson, 1988; 1989; Cella, 1989; 1994; Ganz et al., 1995; Ganz et al., 1993; Ware, 1993). Several researchers suggest that these additional factors are important to assess but are not adequately captured by a linear four-dimensional model as shown in Figure 1 (Aaronson, 1990; Cella, 1989; 1992).

Aaronson and Cella also argue that these areas are important to cancer patients; however, they appear to be separate, independent dimensions of QL. Since factor analytic studies have not been conducted on sufficient sample sizes, it is hypothesized that these factors only affect overall QL under specific circumstances and are illustrated as such subordinate dimensions in Figure 2. Nonetheless, these subordinate domains are suggested to be associated with several of the QL domains (Cella, 1989). For instance, both physical and functional statuses, as well as psychological status, mediate sexual functioning.

The concept of QL involves more than individual components such as physical well-being, disease progression, and/or pain at any given point. A patient's response to disease and treatment should not be an acceptable QL measure, rather measures of QL are most effective when they address the related domains of functional, psychological, and social status. Each of these factors contributes to the general sense of well-being and help constitute quality of life. QL, therefore, refers to patients' appraisal of, and satisfaction with, their current level of functioning when compared to what they perceive is possible or ideal (Cella & Cherin, 1988). This value-based rating has utility because it provides a patient's subjective opinion about the stress related to treatment and disease. Only a multidimensional assessment of quality of life can capture both subjective and

objective perceptions of patient illness and pinpoint the actual level of disability experienced within multiple domains.

Cella (1992) poignantly illustrates this "level of actual disability" experienced. He proposes that, although two patients may experience the same degree of nausea, they may experience very distinct disruptions in social or daily living. This difference could be due to differences in the emotional reaction to the nausea, or to differences in patient role. One patient may be able to function adaptively with the nausea, while the other's adaptive capacity is severely weakened. Thus, both patients may have comparable survival rates; however, one patient significantly experiences a reduced QL (Gotay et al., 1998).

Lastly, it is important to realize that components of QL overlap with each other; they are interdependent as opposed to independent (Cella, 1992, 1994). For instance, a patient's experience of depression may affect their rating within both psychological and physical domains of QL. Thus, a valid measurement of QL must account for the interdependence of these variables and the influence of contextual factors such as phase of treatment and frequency of remission. The QL construct is becoming more valued as an indicator of life satisfaction across multiple life domains and during all phases of the cancer treatment cycle, from initial diagnosis through cure, extended remission, or death (Cella, 1992). Empirically, the use of a dialectical perspective, accounting for multiple factors seems most appropriate.

To date, selected researchers (Aaronson, 1988; 1989; 1990; Cella, 1992, 1994, 1996; Cella et al., 1987) have gathered information from each of the individual component domains, quantified these reports, and then used statistical procedures to

develop a composite measurement of the QL construct. This operationalized, dialectical approach is believed to be useful because it incorporates a patient's overall experiences across different phases of the cancer process. A major concern regarding the use of this operationalized definition has been raised by several researchers (Aaronson, 1990; Cella, 1989; 1992, 1994, 1996; Rummans et al., 1998). They posit that the use of a composite index to assess broad, often subjective experience can result in inaccurate, unreliable, and incomplete data.

The general findings in the literature do not provide much information on the separate components of QL, such as functional and psychological QL, because composite scores are typically used. In terms of functional QL, it appears plausible that BC patients with higher functional abilities will be more protected from fatalistic and hopelessness perceptions than individuals with lesser functional abilities. Furthermore, it is difficult to determine if symptoms are related to psychological disturbance or are directly related to the disease and treatment. When assessing QL, physical and psychological QL may have overlapping constructs, which can confound measurement of reported QL domains. While composite scores may be useful for a global QL assessment, they do not provide insight into areas of an individual's experience, which influence their QL scores. For instance, a person may report good social and functional QL, while their physical or psychological health is poor, resulting in an average QL score. It is apparent that composite scores do not provide information that is helpful in improving the areas of a patient's health that is unsatisfactory.

Additionally, Aaronson (1989) cautions the researcher from using instruments that rely heavily on physical symptoms (i.e., tiredness, loss of appetite) to identify

psychological QL. This cautionary especially relates to patients with late stage cancers because in addition, the physical effects of illness may have psychological effects (Burgess, Morris, & Pettingale, 1988). QL assessment of late stage cancers has been problematic because of the cognitive deficits, severity of physical symptoms, and psychological disability of patients, preventing them from providing much needed QL information (Grassi et al., 1996).

Lastly, Cella (1996) suggests that assessing the psychological, physical, functional, and social domains of QL may be difficult to cover in a single brief questionnaire. Since QL research has important implications for cancer patients, and since measurement issues pose problems, investigating a couple of QL domains and applying it to a cancer population holds significant clinical importance. Although combining measures of QL domains to approximate a single index of QL has been suggested (Stewart, Ware, & Brook, 1981), Cella (1989; 1996) cautions the researcher, because not many validity studies have been performed on many of the existing QL measures and measurement issues must be taken into consideration.

The diversity of the different components of QL is essential when discussing overall satisfaction with life or general sense of patient well-being. This discussion of QL domains will be limited to psychological and functional components. Psychological and functional QL are used interchangeably with psychological and functional quality of life.

Psychological/emotional well-being and the ability to function in everyday life have not been thoroughly investigated in the literature, and research into these separate QL components can promote a greater understanding of how women with an initial

versus a recurrent diagnosis evaluate and manage life. The theoretical formulations of factors having most significance for clinical intervention are functional and psychological QL. Since the physical dimension may overlap considerably with the psychological and functional QL domains, it is difficult to isolate the factors involved in the latter 2 domains. Additionally, medical treatment can be provided to alleviate many of the physical symptoms associated with cancer disease, but treatment may not be appropriate for someone who has lost functional abilities. Research suggests that lose of role functioning, for instance, can produce psychological symptoms such as depression. Therefore, investigating these two domains will bring about greater insight in understanding how cancer affects a person's life both from a psychological perspective, as well as a functional one, and promote useful interventions.

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<u>Functional QL.</u> The functional dimension of quality of life is correlated with but sufficiently different from the physical dimension because many of the physical symptoms (i.e., treatment side-effects, bodily function/dysfunction or weight loss) overlap with psychological QL (i.e., loss of appetite, fatigue, or weight loss)(Aaronson, 1988; 1989; Cella, 1992; Cordoba, Fobair, & Callan, 1993; Hays & Stewart, 1990;

Stewart et al., 1981). Functional QL incorporates an individual's personal needs, ambitions, and social role. At the most basic level, these abilities include instrumental activities of daily living (IADLs), which are walking, feeding, bathing, and dressing oneself. Additionally, it also incorporates an individual's ability to carry out responsibilities not only inside the home but those with family, friends, and colleagues (Cella, 1989; 1992). Physical and functional components of QL can be independent of one another, especially when an individual is able to continue to function in his/her work environment effectively despite physical discomfort and/or weakness caused by treatment (Cella, 1989; Rummans et al. 1998).

Ditto, Druley, Moore, Danks and Smucker (1996) evaluated the importance of valued life activities in health-state evaluations. Valued life activities were defined as any activity or activities that an individual perceives as pleasurable or meaningful, ranging from simple daily tasks (e.g., reading or listening to music) to interactions with family and friends and ability to care for oneself. The authors suggest that cognitive, functional, and physical dysfunctions, as well as pain only affect QL ratings when individuals perceive these dysfunctions to prevent them from engaging in their valued life activity. If receiving a cancer diagnosis or living with cancer interferes with an individual's ability to engage in their valued life activities, then a decrease in QL ratings occurs. For example, a cancer patient who enjoys reading is likely to have higher QL ratings than someone who is not able to hike or golf (if these were valued life activities) due to side effects of cancer treatment. These authors further suggest that given a particular health state, individuals will calculate their perceived QL based on the amount of interference with their valued life activity and not on the level of physical, functional,

or psychological dysfunctions. The theoretical relationship of valued life activities and QL domains is illustrated in Figure 3.

Cancer tends to limit both functional ability and role performance and these limitations can affect patients' expectations of themselves as the disease progresses. Pain becomes relevant to discuss because not only can it be a component of disease symptoms, it can also affect an individual's functional QL (Cella, 1989; Holland, 1998; Rummans et al. 1998). For instance, many studies have found pain to significantly influence a patient's ability to function, which, in turn, affects overall QL. Rummans et al. suggests that pain involves cognitive, motivational, behavioral, psychological, and physical components, which all greatly contribute to QL. In Rummans' study, half of their female participants with either recurrent breast or gynecologic cancers experienced mild-to-moderate pain. This mild-to-moderate pain level correlated with the physical QL domain; however, many of the items related to the functional and social dimensions. These correlations were also not as strong between pain and psychological and spiritual dimensions.

Besides recovery, the primary goal for patients is to maximize their function in everyday life and to achieve the highest level of psychological well-being. Both functional and psychological QL are highly valued by patients and these are essential outcomes of medical care (Rummans et al., 1998; Stewart et al., 1989; Ware, 1989). The goal of maximum functioning may hold even greater importance for recurrent cancer patients. Silberfarb, Mauer, and Crouthomel (1980) compared functional QL of BC patients undergoing either primary treatment, recurrent treatment, or palliative care (therapy aimed at relieving discomfort, not curing illness). Review of the results from

this 1980 study will center on its comparisons between palliative and recurrent treatment. Silberfarb et al. found recurrent BC patients in active treatment needed more help with functioning than did the terminally ill patients in the palliative care group. The recurrent BC patients also had more reported difficulties with daily routine issues and with depression than did the palliative care patients.

Osoba et al. (1996) compared functional status of recently diagnosed brain cancer patients to those with a brain cancer recurrence. The authors reported that recently diagnosed patients had fewer functional problems than patients with recurrent brain cancer. It is plausible that a diagnosis of recurrence lowers one's optimism and increases both psychological distress and fatalism. The decrease in functional abilities may also be related to more aggressive therapies that may be used to treat a cancer recurrence.

Employment status, as the proportion of patients who are working, is also affected by type of cancer and treatment. Barofsky (1984) reported that blue-collar workers are less able to sustain their previous level of activity than are higher paid white-collar workers. Thus, the burden of cancer and its treatment can differentially impact the functional domain of an individual's life independent of disease severity. These differences may involve a patient's cancer status or their role functioning. For example, physical limitations may not affect role performance (employment status), and there may be occasions of role dysfunction in the absence of physical limitations (Grassi et al., 1996; Rummans et al., 1998; Stewart et al., 1981).

Few studies have examined the relationship between age and QL in women with BC (Ganz, Lee, Sim, Polinsky, & Schag, 1992; Vinokur, Threatt, Vinokur-Kaplan, & Satarino, 1990). The general literature for mental health and aging research indicates a

positive relationship between age and better QL in women newly diagnosed with BC.

Ganz et al. (1992) found that age did not predict QL in newly diagnosed BC patients.

Ganz et al. did report a weak relationship between age for elderly, newly diagnosed BC patients and QL, indicating evidence for better QL with advancing age. However, Graci (1998) in a QL study investigating, health locus of control beliefs, optimism, and psychological and functional QL in women with recurrent BC found a significant positive correlation between restriction of activities and psychological distress for women aged 65 years and older. Age also did not relate to a lower functional QL. It seems plausible that the relationship between age and QL may be a complex multivariate relationship.

Problems in QL research rest on the notion that if a disease does not cause behavioral dysfunction than it does not have personal/social implications. Ware (1983) reported that role functioning is only very weakly related to emotional functioning (mental health). However, psychological distress has been found to impact functional QL, specifically at the level of personal and role functioning. A BC patient may not be experiencing significant psychological distress but may have limitations on her functional ability. Grassi et al. (1996) investigated QL ratings of homebound patients with advanced cancer patients, as well as ratings by family members and oncologists. The researchers reported that reduction in role performance or onset of treatment side-effects did not necessarily result in low ratings of psychological or social QL.

<u>Psychological QL</u>. The psychological dimension of QL is also correlated to, but distinct from, the physical and functional dimensions (Cella, 1989; 1992; Hays & Stewart, 1990; Rummans et al., 1998). Psychological QL refers to the mental health status or feeling states of an individual reflecting the impact of the cancer diagnosis,

disease progression, or side-effects of treatment (Greer & Silberfarb, 1982; Worden & Weisman, 1984). Common psychological feelings include volatility of emotion, guilt, depression, fatigue, resurfacing of unresolved issues, negativity, and strong attempts to remain in control (Christ, 1993; Holland, 1998; Mahon et al., 1995). Cella (1989) argues that the psychological domain is bipolar in that its spectrum goes from positive affect (well-being) to negative affect (distress). Ideally, researchers should assess a patient's psychological functioning at the onset of cancer and treatment, as well as during disease stability. Cella hypothesizes that during the onset of cancer and treatment, a reduction in psychological QL may occur due to blunting of positive affect experienced by the patient.

The diagnosis, course, and treatment of cancer have extensive psychosocial consequences for the BC patient and her family. There is considerable evidence that early stages of BC and its treatment are associated with psychological distress, sexual dysfunctioning, and social morbidity (Christ, 1993; Fallowfield, Baum, & Maguire, 1986; Morris, Greer, & White, 1977; Holland, 1998; Morris & Ingham, 1988). De Vita, Hellman and Rosenberg (1993 as cited in Gotay et al., 1998) suggest that diagnosis and treatment of cancer affects psychological functioning and disrupts family and employment activities.

Unfortunately, less research has focused on the psychosocial aspects of recurrent cancer. Graci (1998) utilized a composite score for the functional and psychological QL domains when investigating whether advancement in cancer stage would related to lower functional and psychological QL. This research did not find significant mean differences between cancer stages and QL ratings, a surprising result because the majority of cancer studies suggest that advancement in cancer stage relate to lower functional and

psychological QL. It is plausible that many of these individuals relied on social support systems, which buffered the stress associated with advancement of the disease and the functional impairment experienced. It is also likely that many of the participants retained their valued life activities so they were still able to enjoy some of their valued activities such as reading, playing cards, listening to music, or watching television.

There is general support for the relationship between disease progression and severity of treatment and psychological well-being (Anderson, 1992). Cella et al. (1987) examined psychological distress in lung cancer patients and found that the extent of disease and physical impairment from treatment based on composite scores was a predictor of magnitude of mood disturbance. DeHaes, Van Oostrom, and Welvaart (1986) reported overall QL was related to extent of treatment for BC: radical surgery or breast conserving surgery. Patients undergoing breast-conserving surgery reported higher QL than patients receiving radical treatment. However, patients receiving breast-conserving surgery reported more fears of cancer recurrence. However, Cella et al. (1987, as cited in Grassi et al., 1996) found that reduction in functional status did not necessarily cause a reduction in psychological or social functioning.

Few studies have examined the relationship between age, psychosocial adaptation, and QL in women with BC (Ganz et al., 1992; Ganz, Schag, & Heinrich, 1985; Vinokur, Threatt, Vinokur-Kaplan, & Satarino, 1990). Several researchers have found that groups of older individuals with chronic medical conditions and cancer report better mental health than younger individuals (Cassileth et al., 1984; Feinson, 1985; Ganz et al., 1992; Ganz et al., 1985). Ganz et al. (1992) investigated the relationship between age and psychological and social status in newly diagnosed BC patients and reported a

weak, negative relationship with younger women fairing slightly better. However, post hoc analyses revealed a positive relationship between age and better psychological and social status in married women. Married women were also found to have less mood disturbance with increasing age as annual household income declined. The authors offered no explanation for these possible chance findings. However, Graci (1998) in her recurrent BC study did not find a significant relationship between having a significant other and higher functional and psychological QL. The findings suggest that the cancer experience is distressing at all levels and may be just as distressing for a woman in a marriage or significant relationship as it is to someone who is single.

Research studies show that many cancer patients suffer considerable distress from the implications of their recurrent diagnosis as well as from the progression and treatment of their disease. deHaes and Welvaart (1985) reported older BC patients, after primary treatment, reported less fear of recurrence and death than younger patients. Additionally, Worden (1989) assessed the emotional and psychological QL of patients with recurrent cancer. Younger recurrent patients were found to be more distressed than older patients. These younger patients were also more likely to blame themselves for their disease recurrence. The time from initial diagnosis to recurrence and the time from last treatment to recurrence was not found to be significantly correlated with distress levels. This finding is somewhat contrary to the research of Mahon et al. (1995) and Worden (1989). Weisman and Worden (1986) in a study of 102 patients diagnosed with recurrent cancer, found a relationship between the degree of distress experienced at time of recurrence and degree of expectation of recurrence. Those individuals who were surprised by their recurrence reported the highest level of distress compared to those that had never

believed their disease to be cured, experienced the least amount of distress. Surprisingly, these researchers also found no evidence that a recurrent cancer diagnosis is more distressing than the initial diagnosis. Holland (1998) suggests that when a patient is diagnosed with a recurrence, the experience is similar to that experienced at the initial diagnosis. She proposes that the emotional turmoil (sadness, depression, etc.) is intensified because a patient has to cope with the idea that treatment (the greatest hope for cure) has failed and their mortality is threatened. Holland reports that physicians who educate the recurrent BC patient about what constitutes a cancer recurrence and outline a revised treatment plan help alleviate the anxiety and depression experienced.

Graci (1998) investigated whether age impacted the relationship between psychological and functional QL in recurrent BC patients. The initial hypothesis was that for individuals at 65 years of age and older will report more restriction of activities and distress. These hypothesis was not supported. Women in both age groups did not report a decrease in functional or psychological QL. It is plausible that both groups of women receive adequate emotional support and assistance to buffer the deleterious effects of the diagnosis, treatment, and cancer progression. Younger women tend to be in physically better health than older women; they may not have the functional role loss that older women experience from treatment and/or cancer progression. If functional abilities become compromised, younger women may be more willing to engage help from others. For example, younger women may need help with care-taking for their children.

Assistance from others, not only helps them cope better because they are not forsaking their responsibilities, but it lessens the functional/physical burden (e.g., side-effects from treatment) associated with the cancer experience. This assistance may enhance their

psychological well-being. If a person is able to self-care (regardless of their age or if assistance was necessary), psychological well-being may not be compromised.

Additionally, adaptive coping methods may be employed by both age groups to enhance psychological QL. In this sample, younger women were less likely to have advanced cancers, suggesting a better prognosis. Younger women diagnosed with earlier stages may also be more optimistic about their prognosis, reflecting higher QL ratings. Younger women may also engage in more problem-focused coping, which preserves their psychological QL. It is plausible to suggest that the psychological and functional dimensions of QL can both independently and jointly buffer the deleterious affects of the cancer process. Based on this statement, one may see how a positive relationship between these variables would exist.

Since the majority of studies on cancer are conducted on patients with early-staged disease, QL research does not have adequate information on QL ratings of advanced-staged cancer patients. While the focus of this study is not on pain and its relationship to QL, one must take into consideration the role that pain has on psychological functioning. Rummans et al. (1998) reported that as patients' pain experience increases due to advancement of disease, their psychological ratings decline. He hypothesizes that as pain increases, that is goes from mild to severe, anxiety and depression increase. Glover et al. (1997) as cited in Rummans et al., 1998) found that as pain intensified, psychological distress increased and total mood disturbance rose. These findings are important for BC patients experiencing side-effects of cancer treatment. As pain or discomfort increase, psychological QL ratings may decline. This statement may hold even greater significance for the recurrent BC patient in treatment because many

treatment modalities used are aggressive and may produce significant pain and discomfort.

Tross and Holland (1998) and Christ (1993) discuss extended psychological responses to cancer. These responses include fears of recurrence, continued preoccupation with cancer, increased fears of death, greater uncertainty about the future, increased feelings of anxiety and depression, loss of sense of control, fear of social rejection, increased sense of personal inadequacy, and job insecurity. This extended psychological morbidity is hypothesized to affect long-term survivors. Longitudinal studies are currently investigating this phenomenon.

Christ (1993) reported that 104 cancer survivors having been out-of-treatment for at least one year had a significantly lower sense of self-control and more general health worries than a healthy control group. It is important to emphasize that psychological functioning primarily depends upon the stage of BC identified at time of diagnosis, treatment plan, and prognosis (Tross et al, 1998), as well as the age and coping strategies available to women diagnosed with initial or recurrent BC diagnoses.

Holland (1998) suggests that patients, either receiving an initial or recurrent diagnosis, tend to search for the cause of their disease. Some BC patients blame themselves, the doctor, or fate as having caused their disease. These patients have to struggle with trying to control their emotions as well as plan the best treatment modality. Health Locus of Control

The meaning of health can be an ambiguous term because health can refer to an individual's predisease state, or it may refer to a person's current experience with disease (Dahnke, Garlick, & Kazoleas, 1994). In addition, individuals may also believe that they

can influence their health through either personal factors, such as willpower to cure a cold, or by using external resources, such as visiting a doctor to alleviate symptoms of a cold. In this sense, health may be perceived as a variable that is controllable. The belief that an individual's health is or is not determined by behavior is a health locus of control belief (Wallston & Wallston, 1978). Health locus of control is defined as the beliefs an individual has over the control of their health (Wallston, Greer, Pruyn, & Van Den Borne, 1990; Wallston, Stein, & Smith, 1994). A person can believe that personal, internal, factors or situational, external, factors control health. Wallston et al. (1994) reported health locus of control orientation is not only mediated by an individual's behavior but it is an "indirect determinant of health status" (p. 535). These researchers assert that health beliefs are learned over the course of an individual's lifetime and become the function of prior health status and health-related experiences.

The health locus of control belief system was adapted from Rotter's (1966) locus of control theory. Locus of control is defined as the belief that an individual has personal control over a variety of life circumstances (Danke et al., 1994; Lewis, 1982). Locus of control is a personality variable derived from Rotter's (1966) social learning theory. He cites that individuals have various psychological resources and among these resources are certain beliefs in either an internal or external locus of control playing an active role in an individual's appraisal of an event. Locus of control is commonly referred to as being an expectancy belief because it involves dealing with the source of the control over an outcome (Smith, Wallston, & Smith, 1995; Wallston, 1991). This belief of control can determine how a person will react to social, physical, and emotional stressors and can serve as a coping strategy for an individual in a life crisis (Folkman, 1984). Coping

becomes an important strategy for a woman afflicted with cancer. Her coping strategies may be influenced by her beliefs regarding the personal control she has over her health/cancer.

Both the locus of control and health locus of control construct are composed of an internal or external orientation. For example, a BC patient may actively search for a causal explanation of her disease. Depending on her control beliefs, she may believe her state of health is internally or externally controlled. An individual with an internal view regarding health believes that if she remains in good health or if her disease progresses, it is the result of her behavior. In comparison, an individual with an external health locus of control orientation believes that other factors, such as luck, chance, or fate determine the state of health. Additionally, individuals may feel that their health is influenced by other powerful factors (e.g., health professionals) over which they have little control (Smith et al., 1995; Wallston et al., 1978; Wallston et al, 1994).

Unlike the locus of control construct, the health locus of control construct is viewed as a multidimensional construct (Wallston, 1991; Wallston, et al., 1994; Wallston et al, 1978). While both constructs are composed of internal and external superordinate poles, the health locus of control orientation is composed of internal, powerful others, and chance factors. The saliency of the health locus of control belief system (i.e., health controlled by self, powerful others, or chance factors such as fate) becomes apparent because it invariably plays an integral role in contributing to cancer patients' perception of QL.

Wallston et al. (1994) theorizes that people with varying health conditions may hold different locus of control beliefs about their health condition than about their general health status. For instance, a cancer patient may hold an external orientation regarding her cancer while at the same time believe that she can influence other aspects of her health. She may believe that a "powerful other" is in control of the fate of her disease, yet maintain that she can control her arthritis by resting often, eating properly, and limiting stressful activities.

Dahnke et al. (1994) and Graci (1998) challenge the stability of the health locus of control construct, suggesting that the construct might fluctuate at different points/stages in an individual's disease. They also suggest that an individual's perception of disease control in earlier stages may be different from perception of disease control in later stages. For example, a BC patient diagnosed with Stage I cancer might have an internal orientation regarding her health; whereas, a BC patient diagnosed with a Stage IV (late/terminal stage) cancer may perceive her health as being controlled by external factors (powerful others, God).

Little is known about the meaning of experienced personal control or its relationship to QL in cancer patients, especially late-stage patients (Lewis, 1982; Weisman, 1979). The literature presents contradictory findings regarding cancer and control beliefs. Lewis (1982) reported that patients who take an active, decisive role in their cancer treatment and disease are believed to maximize their sense of control and experience higher levels of psychological QL. This higher level of QL reported appears to be a function of a generalized sense of control over an individual's life and not necessarily control over their health. Christ (1993) further supports the importance of self-control beliefs. She found that cancer patients who had developed a sense of competence, mastery, and control reported higher QL ratings. However, Lewis (1982)

also suggests that patients may relinquish concern over maintaining control of their health in late stages of cancer. Relinquishing of control maybe perceived as a coping strategy because the cancer patient does not bear the burden of failing to control her disease.

Additionally, relinquish of control may also enhance/preserve her quality of life and facilitate coping with the course of cancer (e.g., acceptance of death).

Individuals who believe they can control their environment or their health often attempt to do so (Dabbs & Kirscht, 1971). Lewis, Haberman, and Wallhagen (1987) reported cancer patients with an internal health locus of control orientation tended to believe that the following domains were under their control: adjustment to treatment, cancer, daily activities, ownership-responsibility for disease, pain, and externalizing control. Caplan (1981) found individuals who attempted to cognitively control their health by imparting meaning or purpose to it, also created a world that was in their control. Taylor, Lichtman, and Wood (1984, as cited in Taylor & Armor, 1996) reported that asymptomatic BC patients often perceive having control over their cancer and believe they can prevent it from coming back. Taylor et al. (1984, as cited in Taylor et al., 1996) also reported that many BC patients asserted having a high degree of personal control over their cancer (i.e., an individual can change their health status or prevent recurrence), despite the fact that their medical records revealed a poor prognosis. This belief in personal control over cancer was positively associated with psychological adjustment. These perceptions of personal control over the cancer may have served as a coping strategy. Furthermore, Newsom, Schultz, and Kapp (1996) posit that beliefs in control over the course of illness may produce better adjustment and psychological QL in patients. However, these authors state that research findings have been inconclusive regarding the benefits of beliefs control over the course of an illness.

Watson, Greer, Pruyn, and Ven Den Borne (1990) reported cancer patients with high internal control beliefs over the course of their illness were associated with a positive, "fighting" attitude toward the disease. This finding was largely confined to those patients with relatively good prognosis whose disease was either in remission or at an early stage. Additionally, Pruyn et al. (1988, as cited in Watson et al., 1990) examined head and neck cancer patient's internal control over the cause of their illness and internal control over the course of their illness, (i.e., how their cancer will progress). Patients with high internal locus of control regarding the course of their illness experienced less loss of control and were more likely to show health-related behavior, received more social support, showed higher self-esteem, experienced less physical complaints, had less anxiety, less depression, and less psychological and physical complaints. In comparison, cancer patients with high internal locus of control regarding the cause of their illness reported more loss of control, suggesting that patients attributing personality characteristics for the cause of their cancer may have heightened levels of anxiety and may be preoccupied with their disease. Furthermore, individuals with early-staged cancers and who believe that the course of their disease is under their control may have a more optimistic, fighting attitude toward the disease. However, if the cancer progresses and the prognosis becomes poor, psychological well-being may become compromised for these same patients.

If psychological well-being should become compromised, it is postulated that individuals may switch their health locus of control orientation (Dahnke, 1994; Graci,

1998; Ringdal, 1996). Lewis et al. (1987) examined late-stage cancer patients who relinquished control of their disease and reported that patients were satisfied with their decision. These patients were hopeful that their "powerful others" (i.e., physicians) would help them gain their health back. Similarly, Surla (1984, as cited in Lewis et al., 1987) discovered that late-stage cancer patients, who relied on their physician's management of their cancer treatment and prognosis, did not want to assume or participate in trying to establish control over their treatment protocol (as cited in Lewis et al., 1987). Thompson and Spacapan (as cited in Taylor et al., 1996), in their study of men with advanced stages of AIDS reported a high degree of control over their day-to-day medical care and treatment, but only a mild degree of control over the course of their illness. Stage of disease, whether a patient is symptomatic, disease prognosis, and cognitive coping strategies appear to be some of the mediating factors which may account for differences found in cancer patients regarding health locus of control orientation.

Wagner, Armstrong, and Laughlin (1995) report contradictory findings regarding an internal health locus of control orientation. They investigated coping styles and quality of life ratings after onset of cancer in a sample of men diagnosed with different types of cancer. Their findings revealed that at the time of the cancer diagnosis, the stronger a person's motivation to control the effects of cancer, the poorer was the patient's quality of life perception. Also, the more motivated the patients were to control their cancer, the lower was their quality of life rating. The researchers suggest that patients with greater levels of motivations to preserve their quality of life became more dissatisfied with setbacks, such as cancer progression. Additionally, Dahnke et al. (1994) also suggest that

patients who suffer a loss of personal control (i.e., cancer progresses) also may experience a decrement in quality of life.

Graci (1998) investigated whether greater beliefs in internal health locus of control would related to lower Psychological QL in a sample of recurrent BC patients. For early staged and over all cancer stages, non-significant relationships were reported. Although, for later stages, a marginally significant negative association was found, possibly suggesting that as disease progresses, women with higher beliefs in internal locus of control will report lower Psychological QL. Additionally, Graci reported a nonsignificant relationship between greater internal control beliefs and higher Functional QL ratings for early stages and over all stages of cancer. Surprisingly, a positive significant correlation was found for greater beliefs in internal control and Functional QL in late stages of cancer. It is hypothesized that having a high internal locus of control in advanced cancer stages may cause a woman to experience less loss of control, be more likely to show health-related behavior (attend treatments or doctor appointments), receive more social support, and have higher self-esteem. Additionally, internal orientations may cause women to experience less physical complaints, anxiety, and depression as well as other psychological complaints. Lastly, if psychological well-being is being compromised, switching health locus of control orientations may enhance Psychological QL. It may be more advantageous psychologically for a recurrent BC patient, with a late stage cancer, to have an internal health locus of control orientation because it may increase her optimism and promote a "fighting" attitude toward the cancer. These patients are able to maximize their sense of control and experience higher

levels of Psychological QL. It is plausible that the more control a patient perceives over her health regardless of disease stage, psychological adjustment will be enhanced.

Although the research reports contradictory findings regarding quality of life and health locus of control beliefs, one cannot ignore the fact that control does appear to be an important predictor of quality of life. Control also appears to serve as a coping strategy and may buffer against the deleterious effects (e.g., psychological/functional disability) of cancer (Friedman et al., 1992, Friedman et al., 1994; Taylor et al., 1996). Relinquish of disease control may be an important factor for late-stage cancer patients in trying to improve/restore quality of life.

Newsom et al. (1996) conducted a longitudinal analysis of specific domains of internal control and depressive symptoms in patients with recurrent cancers. The researchers reported that high internal control beliefs were related to depressive symptomatology. For these individuals with perceived control over cancer onset, despite actions to prevent progression, had greater negative affect. However, the researchers found a significant decline in illness course control. The authors postulated that in the early-disease stages, a sense of control over the course of cancer is associated with depression levels, but as the illness and symptoms progress, patients lose their sense of control over their illness. The theory that health locus of control beliefs fluctuate as cancer progresses, is an area worthy of investigation.

### **Optimism**

Many individuals believe that positive thinking leads to a more enriched life and can aid individuals in adverse situations. When individuals are faced with adversity, they can either continue to strive or give up and turn away (Scheier & Carver, 1992; Scheier et

al., 1989). Optimistic behavior is regarded as the continued striving of an individual who perceives an outcome as being attainable. This type of individual will additionally strive toward achieving the desired outcome even when obstacles arise (Friedman et al., 1992; Friedman et al., 1994; Scheier & Carver, 1992). Conversely, pessimistic behavior is regarded as giving up and turning away, occurring when individuals perceive outcomes as unattainable. These individuals will withdraw their effort and disengage themselves from pursuit of the established goal/outcome. Carver et al. (1993) postulate that individuals who believe that their goals are attainable experience positive affect and those who view their goals as unattainable experience negative affect. Positive affect often includes enhanced psychological well-being of an individual whose emotions can range from pride to gratitude to simple relief. In contrast, negative affect can encompass feelings of shame, anger, resentment, depression, and mood disturbance.

Optimism is defined as the tendency to believe or the expectation that things will work out positively (Scheier & Carver, 1985; 1986; 1992). A fundamental disposition toward generally positive or negative outcomes constitutes an individual's life orientation. This life orientation construct allows for the observation of whether an individual's expectation of an outcome will be good or bad, rather than internally or externally controlled (Knapp, 1993). Carver et al. (1993) suggest that by defining optimism in this mannerism, predictions can be made about an individual's overt action because expectancies become a major determinant of behavior. Carver and Scheier (1992) have labeled Dispositional Optimism as the personality variable that affects how individuals cope with stressors/adversity. Dispositional Optimism is defined as the tendency to believe that an individual will generally experience good vs. bad outcomes in

life (Scheier et al., 1985). Additionally, Dispositional Optimism is perceived as a stable personality trait that exists across time and context (Scheier & Carver, 1985; 1992; Scheier et al., 1989; Scheier, Weintraub, & Carver, 1986).

Reker and Wong (1985) have suggested that Hope and Optimism be used as interchangeable constructs. In terms of Psychological and Functional aspects of QL, Hope and Optimism may be of significant benefit to illness. The general literature suggests that Optimism, or Dispositional Optimism, may be influential in adaptation to illness because it may provide some protection against illness and disease. This protection is hypothesized to be influenced by Dispositional Optimism, which is perceived as being a determinant/mediator of a person's ability to cope with or respond to stress (Carver et al., 1993; Scheier & Carver, 1986). Dispositional Optimism may act as a buffer against adversity and lower the psychological distress associated with the adversity.

The effect of Optimism on Psychological Well-Being and over-all reported QL has been a topic of research interest. Taylor et al. (1996) suggest that unrealistic Optimism may aid an individual in coping with a traumatic event or health-related event because it provides an individual with a sense of mastery over their life. However, Taylor and Armor assert that once unrealistic Optimism is disconfirmed, an individual may experience severe psychological distress. Stanton and Snider's study (as cited in Lauver & Tak, 1995) of coping and emotional outcomes of women undergoing breast biopsies reported that Optimism was associated with less avoidance strategies (e.g., wishing it would go away) and less emotional distress. Additionally, Graci (1998) reported in a sample of recurrent BC patients, a significant positive association between

Optimism and higher Psychological and Functional QL ratings in a sample of recurrent BC patients.

Similarly, Carver et al. (1993) studied the relationship of optimism to coping and emotional adjustment in a sample of BC patients undergoing cancer treatment. Carver et al. interviewed these patients at different time periods: one day prior to surgery, ten days, three months, six months, and a year postsurgery. They found optimism to be associated with greater levels of active planning and acceptance, and lower levels of psychological disengagement (e.g., denial) during initial treatment. Acceptance of breast cancer in early treatment was associated with less psychological distress (e.g., anxiety, depression, and anger) than in later treatment. Psychological and behavioral disengagement in early treatment was associated with greater levels of psychological distress. Additionally, Scheier, Carver, & Bridges (1994) investigated the relationship of optimism to emotional and functional outcomes of coping in BC patients undergoing cancer treatment at three time periods: one day prior to surgery, six-to-eight days, and six months postsurgically. Optimism was associated with higher ratings of quality of life prior to surgery, and at the six-month follow-up period.

Scheier et al. (1989) interviewed male coronary artery bypass surgery patients regarding optimism, coping tactics, mood, and quality of life at three points in time: one day prior to surgery, six-to-eight days, and six months postsurgery. Presurgical optimists reported lower levels of depression and hostility than did pessimists. This same group also reported making plans for their future and setting goals for their recovery more often than did pessimists. Optimists also reported being less focused on the negative aspects of the surgery (i.e., emotional distress and physical symptoms) than pessimists. At the one-

week postsurgery time period, optimists reported greater feelings of relief and happiness, greater satisfaction with the level of medicare received and more emotional support from friends than pessimists. They also were more likely to report seeking out and requesting information from their physician regarding the recovery process and were less likely to suppress thoughts about their physical symptoms than pessimists. At the six-month follow-up, optimists reported higher quality of life ratings than did pessimists. The researchers suggest that the differences found in quality of life ratings at the six-month follow-up were due to the different coping strategies utilized by the patients.

Scheier, Matthews, Owens, Magovern, and Carver (1990) in a five-year follow-up study from the same group of male patients in the Scheier et al. (1989) study, found that optimists felt more rested following sleep and were less likely to waken in the early morning. Optimists also rated their lives as more interesting and diverse, and free from pressures and annoyances when compared to pessimists. Lastly, optimists reported greater employment satisfaction and reported higher quality of life ratings than pessimists.

To date, no research has been conducted on comparing the effects of optimism on quality of life ratings of patients with an initial versus recurrent BC diagnosis. While optimism has been shown to positively influence psychological QL, the prognosis of the disease, severity of pain, duration of the disease, and a patient's dispositional orientation must be taken into account when discussing quality of life. Most researchers would agree that a diagnosis of breast cancer is threatening and reduces one's hope and optimism about the future. Christ (1993) suggests that a recurrent diagnosis may greatly reduce optimism because a person is confronted with their mortality. However, it is possible that

a recurrent BC patient may develop an overly optimistic outlook on her disease, which may yield psychological distress if her beliefs are shattered.

It is plausible that with an initial BC diagnosis, psychological distress increases and optimism decreases. However, with a recurrent diagnosis, psychological distress may increase or decrease depending on what skills, supports, knowledge, expectancies regarding recurrence, and coping strategies a patient has developed since the initial diagnosis. Psychological distress may not be as severe as during an initial diagnosis because the patient has been through it once and it has become a day to day reality. Additionally, an increase in optimism for a recurrent patient may activate a fighting attitude because the patient fought the cancer the first time, they can fight it again.

Silberfarb et al. (1980) suggest that psychological turmoil is predictable if a disease should progress, generally yielding a poor prognosis. However, employing active coping strategies may act as a buffer against experiencing psychological turmoil (Friedman et al., 1992, Friedman et al., 1994; Taylor et al. 1996). The relationship of optimism to coping and quality of life appears to play a pivotal role in patients with chronic or terminal illness (Carver et al., 1994; Carver et al., 1993; Friedman et al., 1992; Lauver et al., 1995; Sheier et al., 1989; 1992; Scheier et al., 1994; Scheier et al., 1986). Although coping style may be a salient factor in reported quality of life, it is beyond the scope of this study.

The literature presents conflicting findings regarding the effect of optimism on chronic and terminally ill patients. Unrealistic optimism is theorized to encourage coping disadvantages (Scheier et al., 1992). For example, a person may believe that through divine intervention their cancer will go into remission (a positive outcome). In this

example, an individual may simply sit and wait for something to happen without putting forth any effort to achieve the goal. If the positive outcome does not occur, the person may experience emotional/psychological distress.

The contradictory findings regarding optimism and quality of life appear to revolve around issues of controllability. Optimism has been reported to be harmful in situations when the outcome is not achievable or alterable (Carver, 1986; Scheier et al., 1992). For example, if an optimist holds positive expectations or assumptions regarding something that is perceived as being controllable or alterable, and if these expectations are disconfirmed, psychological distress might result (Taylor et al., 1996). When optimistic beliefs are shattered, lower quality of life may occur. If a BC cancer patient believes that her cancer is getting better or does not believe she has a poor prognosis, she may experience severe psychological distress if the cancer spreads. In comparison, if an optimist views a stressor as being controllable, changeable, or alterable, then higher ratings of quality of life are reported.

In order to compensate for the psychological distress associated with the shattering of beliefs, a BC patient may cognitively restructure her belief system. This restructuring of beliefs may take on the form of acceptance, viewing the cancer in a more realistic light, or positively reframing the situation (i.e., the cancer has caused me to grow closer to my family) (Scheier, 1994). Lastly, Taylor et al. (1996) assert that individuals, who experience personal tragedies or setbacks and respond with adaptive coping methods, report higher levels of psychological QL.

Thompson and Pitts (1993) suggest that positively reframing a traumatic event, such as a cancer diagnosis, may aid optimists in viewing the consequences of traumatic

events in a positive light. By concentrating on the positive side of a cancer experience, individuals may reduce the negativity associated with cancer or the pain encountered from the disease, producing feelings that life is still meaningful (Thompson et al., 1993). Thus, restructuring of beliefs may be perceived as an adaptive coping strategy, promoting higher ratings of quality of life.

### Conclusion

Health is generally reported to be a central factor in an individual's perception of QL. Although some aspects of QL may be significantly impaired during cancer treatment, an optimistic outlook can enhance psychological and functional quality of life. More specifically, optimism may act as a psychological resource that promotes health and lessens the effects of illness. Additionally, the general literature suggests functional QL may be a causal participant to optimism. However, the literature suggests a bidirectional relationship between optimism and psychological QL. That is, optimism and psychological QL of a BC patient are mutually independent.

Cancer patients have been found to be better adjusted if they perceive themselves to have some personal control over their life (Lewis, 1982; Taylor, 1982). Chronic illness may even produce a shift toward an external locus of control over one's life (Reid, 1989). Every form of cancer treatment carries with it some degree of physical and emotional morbidity and issues of QL become critical. QL becomes even more important in late stages of cancer because psychological and functional QL, as well as physical and social functioning, become more impaired. The more impaired an individual becomes, the more QL has an impact in the way an individual copes with everyday life events. QL

can act as a buffer against the pain and discomfort caused by the disease, thereby enhancing a woman's satisfaction with her well-being or current level of functioning.

Since research on recurrent cancer is still in its early exploratory stages, one can only speculate about the differences reported for women with an initial versus recurrent diagnosis in the area of QL, optimism, and health locus of control beliefs. The present study was designed to examine the relationship of these variables and how these variables affect the quality of life of patients with initial versus recurrent BC patients.

There were three main goals of this comparison study of women with an initial BC (IBC) versus recurrent BC (RBC) diagnosis. The first goal addressed how health locus of control beliefs and disease stage relate to QL. The second goal examined the relationship between optimism and QL. The third goal examined the relationship between participant's marital status and QL.

# **Hypotheses and Research Questions**

Seven major hypotheses, with subhypotheses, as well as several research questions were investigated:

Hypothesis 1. Psychological QL would have a negative relationship to HLOC for women with IBC (Goal #1).

Research Question 1. Investigate the relationship between Psychological QL and HLOC for women with RBC (Goal #1).

Hypothesis 2. Women with IBC would have lower Psychological QL than women with RBC, controlling for level of HLOC (Goal #1).

Research Question 2. Investigated the possible statistical interaction between IBC and RBC with Psychological QL and HLOC (Goal #1).

Hypothesis 3a. Functional QL would have a positive relationship to HLOC for women with IBC (Goal #1).

Hypothesis 3b. Functional QL would have a negative relationship to HLOC for women with RBC (Goal #1).

Research Question 3. Investigated the difference in Functional QL for women with IBC versus RBC, controlling for level of HLOC (Goal #1).

Research Question 4. Investigated the possible statistical interaction between IBC and RBC with Functional QL and HLOC (Goal #1).

Hypothesis 4. Stages I or II BC cancers would be a significant predictor of higher quality of life than women classified within more advanced cancer (i.e., advancement in cancer stage will relate to lower QL) (Goal #1).

Hypothesis 5a. Women with RBC would be more optimistic than women with IBC (Goal #2).

Hypothesis 5b. Women with RBC would report higher Psychological QL than women with IBC (Goal #2).

Hypothesis 5c. Women with RBC would report higher levels of Functional QL than women with IBC (Goal #2).

Hypothesis 6: Marriage or having a significant other would be a predictor of higher Psychological and Functional QL than women without a significant other (i.e., having a significant other would relate to higher Psychological and Functional QL) (Goal #3).

Research Question 6a. Investigated the relationship between Social QL and Physical QL and Marital Status (Goal #3).

Research Question 6b. Investigated the relationship between overall composite QL ratings and Marital Status (Goal #3).

Hypothesis 7: RBC participants would report higher overall composite QL ratings than IBC participants (Goal #3).

### **CHAPTER II**

#### **METHOD**

# **Participants**

Recurrent breast cancer participants. Twenty-eight female participants diagnosed with recurrent breast cancer were recruited from doctors' offices and/or cancer support groups in the Dallas-Fort Worth area. According to the National Institute of Health, the stage of cancer refers to the size of the tumor, the number and location of lymph nodes involved, and the degree of how far the cancer has spread. Diagnosis of the stage of cancer falls within four ordinal categories: Stage I, Stage II, Stage III, and Stage IV. Stages I and II refer to early progression of cancers and Stages III and IV refer to advanced progression. Individuals in Stage IV cancers are classified as terminally ill because the cancer has spread out to other distant sites of the body such as from the breast to the bones.

Recurrent malignancy is operationally defined in two ways: 1) the clinical state in which a woman with breast cancer has successfully completed a course of treatment therapy, and 2) the patient has been in a period of stability (without signs and symptoms of cancer) for a period of at least 6-months but is then found to have further evidence of malignancy (Mahon et al., 1995; Rummans et al., 1998). Criteria for inclusion are that the participants: (a) have recurring breast cancer; (b) be able to speak, read, and write in English; (c) be able and give informed consent; (d) be able to complete a data collection instrument; and (e) be 18 years of age or older.

Information on stage of cancers will be obtained directly from participants. A diverse group of participants were chosen to identify the range and magnitude of functional and psychosocial issues associated with a cancer experience. Data collection was completed during an twenty-month period starting late November, 1997 to July, 1999.

<u>Initial breast cancer participants.</u> The second group of twenty-seven participants were chosen to be age-matched controls for the above participants with recurrent breast cancer. Similar recruiting and staging methods were used for these initial breast cancer participants, except these participants were chosen to be first time breast cancer patients.

Participation rates regarding completion of questionnaire. Approximately 35% of the initial BC participants declined participation in the current study when approached by either a nurse, breast cancer support group facilitator or the primary investigator of this study. These group of women consistently commented that the questionnaire was too long or they were not interested in participating in research. In comparison, approximately 100% of recurrent BC patients were agreeable to participation in the current study when approached. Initial BC patients also had a consistently lower response rate to the open-ended questions than the recurrent BC patients.

# Design

This is a cross-sectional study with two major dependent variables and multiple independent variables. The constructs being investigated are presented in Table 1. In this study, the focus is on the major dependent variable of interest, QL, consisting of two components: psychological and functional QL. Psychological QL represents an individual's overall mental state that influences their quality of life. Anxiety, fear,

depression, denial, distress, sense of well-being and/or hope are the factors of psychological QL. Functional QL represents an individual's task-oriented ability which includes self-care and the physical and intellectual efforts of accomplishing things in the home, community and at work.

The independent variables of major interest are health locus of control beliefs and optimism. Health locus of control refers to an individual's belief that their health is or is not determined by their behavior. Optimism refers to an individual's expectation that things will work out positively. The other independent variables that are assumed to affect QL are patient's age and stage of cancer.

Questionnaires were distributed to cancer patients via their doctor's office or a cancer support group. The questionnaire was composed of several standardized measures.

Materials

A demographic survey (Appendix C) was used to obtain basic information regarding participant's age, ethnicity, marital status, years of education, household annual income, and occupational status. Due to a large percentage of participants not providing occupational status, social economic status was not able to be calculated. Medical and treatment information was included in the demographic survey. This information included stage of disease, first diagnosis, duration of remission, the type of medical treatment, and the duration of the treatment.

A modified form of the Functional Living Index-Cancer (FLIC) was used as the dependent measure to assess QL (Appendix C). The original FLIC (Schipper, Clinch, McMurray, & Levitt, 1984) consists of 22 questions that were designed to assess overall functional quality of cancer patients' lives. The four domains of QL are included in the

FLIC and it is designed for self-administration. It has a visual analogue scale that is divided into 7 equal intervals. The numbers at the two ends of the scale (1 and 7) represent polar opposites. Subjects are instructed to place a slash mark on the scoring line at the point that best represents their responses to questions.

One major modification of the original FLIC has been made for the current study. The M-FLIC includes a more conventional response format, requiring participants to respond to questions by circling the numbers that best represents their responses on a seven point Likert-type scale. Wei (1993) conducted, in a sample size of ten BC patients, a rank-order correlation between the original FLIC and the (M-FLIC) and reported a correlation of .99. Additionally, Schipper, Clinch, McMurray and Levitt (1984) conducted a factor analysis of the FLIC items and reported strong factor loadings of .5 and higher. Even though the M-FLIC consists of 22 items, the scoring process will include only those items that loaded strongly on the psychological and functional domains. Furthermore in scoring the M-FLIC, two items related to chemotherapy treatment were not endorsed by a large percentage of participants because they had not undergone chemotherapy. To make both groups equal (with chemotherapy, without chemotherapy), these two items were eliminated when calculating an overall QL score.

The following psychometric data were provided by the test authors (Schipper et al., 1984). The FLIC has been validated on 837 patients in two cities over a 3-year period. Criteria for validity include stability of factor analysis and concurrent validation studies against other established measures such as the Cancer Rehabilitation Evaluation System (CARES). The index is also uncontaminated by social desirability issues. Additionally, Morrow, Lindke, and Black (1992) psychometrically analyzed the FLIC.

They tested the construct validity of the FLIC and reported a five-factor solution, which accounted for 70% of the variance and 68% in a cross-replication sample. Convergent-discriminant validity was also reported using independent measures of symptoms and anxiety. Cronbach's alpha was reported to be in the acceptable range (i.e., .64 and higher for a five-factor solution).

Optimism was assessed by the revised 13 item Life Orientation Test (LOT-R) designed to measure respondents' level of optimism in terms of general outcome expectancies (Scheier & Carver, 1985) (Appendix C). In the original Life Orientation Test (LOT) and (LOT-R), four items are fillers, which are included to obscure the central theme of the (LOT) and (LOT-R) (Table 2). These items were included in the scoring process. In the original 8 item (LOT), half of the items were stated in a positive manner, and the other half were stated in a negative manner. However, the authors of the (LOT), (Scheier & Carver) (1985), identified 2 problematic items: "I always look on the bright side of things" and "I'm a believer in the idea that every cloud has a silver lining". These items were identified as mediators of optimism effects (e.g., engaging in positive reinterpretation and growth). Scheier et al. (1994) assert that any correlations between optimism, as assessed by the (LOT), and other scales/instruments measuring these identified mediators will be suspect because of these 2 items on the (LOT) that measure positive reinterpretation (e.g., looking at things in a better light) and growth.

The (LOT-R) eliminates these two items (when scoring), resulting in only two positively worded items. In order to avoid difficulty of computing separate scores for positively and three negatively worded items, Scheier et al. (1994) added in one new positively worded expectancy item. The revised scoring process now includes three

positively and negatively worded items. Scheier et al. also suggest eliminating from the scoring process, one of the negatively worded items (Table 2).

Thus, items used to derive an optimism score on the (LOT-R) included only six items. Three items were keyed in the positive direction and three were keyed in the negative direction. A five point Likert-type scale ranging from "strongly agree" (scored as 0) to "strongly disagree" (scored as 4) was used. After reverse scoring for the negative items, total scores ranged from 0 to 24, with higher scores indicating greater optimism.

Items 1, 3, 5, 8, 12, and 13 were used to compute an overall optimism score.

The following psychometric data were provided by Scheier et al., 1994. Factor analysis of the LOT-R supported its unidimensionality (i.e., the scale items measure a single underlying construct). Cronbach's alpha was .78 on a combined sample of 2,055 and test-retest reliability with a sample of 187 over 28 months was .68 (4 months), .60 (12 months), .56 (24 months), and .79 (28 months). Additionally, the test authors tested the LOT-R against other measures of personality traits. Significant positive correlations were reported with original (LOT) and self-esteem, as were significant negative correlations with trait anxiety, neuroticism, and depression, hopelessness, perceived stress, and social anxiety. These findings provided support for the construct validity of the LOT-R. Additionally, the correlational findings between the (LOT-R) and (LOT) suggest the two instruments are assessing similar characteristics.

In order to assess the participant's beliefs about their control over their health, 18 items of the Multidimensional Health Locus of Control – Form C (MHLC-C) (Wallston, 1988) was incorporated into the survey (Appendix C). The (MHLC-C) is a disease specific version of the Multidimensional Health Locus of Control scale (MHLC)

(Wallston, Wallston, & DeVellis, 1978). The (MHLC-C) measures control beliefs among individuals having a variety of medical conditions (e.g., cancer, diabetes). It is designed so that the researcher can substitute a specific disease for the word condition. For example, "If my <u>cancer</u> worsens, it is my own behavior which determines how soon I feel better again". The (MHLC-C) was designed to allow optimal flexibility of investigating health locus of control beliefs under a variety of health conditions.

The (MHLC-C) consists of 18 items measuring the belief of internal control over the onset of a disease-specific condition. Six items assess each dimension of internal and chance factors and two separate 3 item subscales for the powerful others dimension The powerful others dimension contains items relating to doctors and other people, which is different from the original (MHLC, Forms A & B). Responses were offered on a sixpoint Likert-type scale, ranging from "strongly disagree" (scored as 1) to "strongly agree" (Scored as 6).

The following psychometric data were provided by Wallston et al. (1994). The (MHLC-C) was administered to participants in an arthritis and chronic pain study. Factor analysis of the measure supported its unidimensionality. Cronbach's alpha was greater than .70 on a combined sample of 588 and reliably yielded a four-factor solution.

Additionally, the test authors assessed the (MHLC-C) against another disease specific version of (MHLC – Forms A/B). The subscales of the (MHLC-C) correlated significantly with similar subscales and did correlated significantly with dissimilar ones on Form B. Wallston et al. reported that these findings demonstrate considerable convergent as well as discriminant validity. The correlations between Form B and Form C subscales did not exceed 43% shared variance.

### Procedure

Breast cancer patients diagnosed with both an initial and cancer recurrence were recruited through doctors' offices and/or cancer support groups. They were requested to participate in the study from a nurse, support group facilitator, or by the primary investigator of this study after having questions answered and completing the informed consent (Appendix C). Each potential participant who agreed to participate in the research project was administered a questionnaire packet. They were asked to read and keep the cover letter, including a brief introduction of the study and a request for participants' assistance. All participants were informed of the confidentiality of their responses. Participants were instructed to place completed questionnaires in an envelope and seal it to ensure confidentiality. Approximately thirty minutes was required to complete each questionnaire. If participants were not able to complete the questionnaire at either the doctors' offices or support group meetings, they were provided a self-addressed, stamped envelope to return at their convenience.

### Power

Since power (the probability of detecting an effect if one is present) is a concern, a power analysis was conducted to estimate the sample size necessary to detect an effect of disease stage on the relation of functional QL. Cohen (1988) has suggested that .80 is a good standard for the minimum power necessary before beginning a study (as cited in Aiken & West, 1991). Chang (1993) reported a significant negative correlation between cancer stage and QL ( $\underline{r} = -.15$ ). The sample size was one hundred and five female participants. Using power tables, a sample size of 85 participants should be sufficient to detect a small effect ( $\underline{r} = -.15$ ) with a power = .80. With 60 participants a correlation of  $\underline{r}$ 

= .32,  $\underline{p}$  = .05 (unidirectional) and a correlation of  $\underline{r}$  = .36,  $\underline{p}$  = .05 (two-tailed) should be detected with power of .80. Within each subsample of approximately 30, a correlation of  $\underline{r}$  = .50,  $\underline{p}$  = .05 (two-tailed) should be detected 80 percent of the time (i.e., power = .80).

#### **CHAPTER III**

#### **RESULTS**

# **Descriptive Statistics**

<u>Demographic and medical information</u>. The purpose of the study was to investigate the variables affecting both initial and recurrent BC patients' quality of life. Table 3 summarizes descriptive data for all participants and comparing IBC and RBC women on psychosocial measures. The chance MHLOC subscale was the only psychosocial measure to demonstrate significant differences between IBC and RBC women (t (df = 52) = -2.09, p = .041). Tables 4-6 summarize the descriptive information on all the major variables included in the following analyses. These tables include both separate and combined group frequencies for IBC and RBC women. SES could not be calculated because only a small number of participants included information about employment status.

One of the major descriptive findings from the following analyses was the negative skewness of the doctor, powerful other, MHLOC variable. Only three people (5.5%) from the entire sample reported low doctor, powerful other, MHLOC (1-3) compared to 52 people (94.5%) who reported high doctor, powerful other, MHLOC (4-6). Thus, interpretations using doctor MHLOC should be made with caution since the majority of IBC and RBC women placed high belief in their doctors. Descriptive statistics, including frequencies, means, standard deviations, stem-and-leaf displays, box-whisker plots, and skewness, kurtosis and standard error (SE) of skewness and kurtosis, were be performed on demographic and psychosocial information. Diagnostic statistics investigated the areas of normality, linearity, homoscadicity and heteroscadicity, and

checked for the presence of outliers. There were no outliers; however, violations of normality assumptions were found and log transformations were attempted. Overall, the transformations did not significantly change the majority of calculated results and are not reported. Perusal of scatterplots indicated no problems with linearity or heteroscadasticity.

Table 4 illustrates combined and separate frequencies and percentages of demographic variables for IBC and RBC participants. The mean age of participants was 55.02 years ( $\underline{SD} = 11.35$ ) years, and there was no significant difference in age for the RBC ( $\underline{X} = 56.64$ ,  $\underline{SD} = 11.88$ ) and IBC ( $\underline{X} = 53.39$ ,  $\underline{SD} = 10.75$ ) groups ( $\underline{t}$  (df = 53.47) = 1.07,  $\underline{p} = .288$ ). There were significant differences in education for the RBC and IBC groups ( $\underline{t}$  (df = 54) = -2.38,  $\underline{p} = .020$ ), with IBC women having a mean educational level of 4.96 ( $\underline{SD} = 1.62$ ) compared to 3.96 in the RBC group ( $\underline{SD} = 1.50$ ). See Table 4 for descriptives and scaling.

Participants' marital status as shown in Table 4 demonstrates that 58.9% were married, 23.2% were separated or divorced, 12.5% were widowed, and 5.4% were single or never been married. There was a trend toward differences in marital status between IBC and RBC women ( $\chi^2 = 6.97$ , df = 3, p = .073) with 57.6% of IBC women reporting being married compared to 42.4% of RBC women. Most of the participants were Caucasian (89.3%), some were African Americans (7.1%), and some reported "other" ethnicity (3.6%). There were no significant differences in ethnicity for the IBC and RBC women ( $\chi^2 = 4.32$ , df = 2, p = .115).

The majority of women (50.0%) were employed full-time, 18.0% were employed part-time, 12.0% were currently not working due to illness, and 20.0% were currently not

working outside the home. There were significant differences in employment status for the IBC and RBC women ( $\chi^2 = 9.52$ ,  $\underline{df} = 3$ ,  $\underline{p} = .023$ ). The majority of IBC women 55.6% were employed full-time compared to 43.5% for RBC women.

Table 5 illustrates combined and separate frequencies and percentages of medical demographic variables for IBC and RBC participants. The descriptive information on medical information shows that there were more women ( $\underline{n} = 18$ ) with Stage 1 (40.0%) than women with Stage II (28.9%), Stage III (13.3%), and Stage 4 (17.8%) cancer ( $\chi^2 = 45$ ,  $\underline{df} = 3$ ,  $\underline{p} = .000$ ). The mean cancer stage of participants was 2.09 ( $\underline{SD} = 1.12$ ), and there was a significant difference in cancer stage for the RBC and IBC groups ( $\chi^2 = 12.90$ ,  $\underline{df} = 3$ ,  $\underline{p} = .005$ ), ( $\underline{t}$  ( $\underline{df} = 43$ ) = 4.01,  $\underline{p} = .000$ ). The mean cancer stage of IBC participants was 1.52 ( $\underline{SD} = .67$ ) compared to 2.68 in the RBC group ( $\underline{SD} = 1.21$ ). Approximately 56.5% of IBC women were diagnosed as stage 1 cancers compared to 22.7% of RBC women. Less than one-third (29.2%) of RBC women also reported having additional, that is more, than 2 recurrent cancer diagnoses.

# Reliability

Cronbach's alpha coefficients were run for each scale in the analyses. Results demonstrated that reliabilities were adequate (Table 6). The alpha for the psychological subscale of the M-FLIC was 0.80. The alpha for the functional subscale of the M-FLIC was 0.88. The alpha for the psychological and functional subscales was 0.89. Additionally, an alpha of 0.92 was calculated for the M-FLIC. The LOT-R demonstrated an alpha of 0.79. Analyses were also reported on the original LOT and demonstrated an alpha of 0.85. The alpha for the MHLOC was 0.73. The alpha for the internal MHLOC subscale was 0.69. The alpha for the Powerful Others MHLOC subscale was 0.68. The

alpha for the Chance MHLOC subscale was 0.81. In addition, separate reliabilities were conducted for IBC and RBC samples (Table 6). The reliabilities were generally consistent with the exception of LOT-R. Reliabilities for RBC women were considerably lower than for the IBC women.

# **Hypothesis Testing**

Table 7 summarizes all statistical findings for the following hypotheses and research questions. The first hypothesis tested stated that there would be a negative relationship between psychological QL and internal MHLOC for women with IBC. Table 9 displays a correlation matrix between health locus of control and psychological QL for IBC women. Results revealed a non-significant correlation between these two variables ( $\underline{r} = 0.06$ ,  $\underline{p} = 0.378$ ). Additional analyses were conducted with psychological QL and the other subscales of the MHLOC (the doctor and people subscales of the powerful other MHLOC and chance factors MHLOC); the only subscale to yield marginally significant results was for doctor MHLOC and psychological QL ( $\underline{r} = 0.33$ ,  $\underline{p} = 0.093$ ) (Table 8).

Additional analyses were conducted on the research question of whether there would be a relationship between psychological QL and internal MHLOC for women with RBC (Table 8). Obtained results showed that there was no significant relationship between psychological QL and three of the four MHLOC domains: internal ( $\underline{r} = -0.006$ ,  $\underline{p} = 0.466$ ), people ( $\underline{r} = -0.24$ ,  $\underline{p} = 0.237$ ) and chance ( $\underline{r} = -0.02$ ,  $\underline{p} = 0.934$ ). However, results indicated that there was a significant relationship between psychological QL and doctor MHLOC ( $\underline{r} = 0.48$ ,  $\underline{p} = 0.011$ ).

The second hypothesis tested stated that women with IBC would have lower psychological QL than women with RBC. Results from a one-way ANOVA indicate that

there was no difference between women with IBC and RBC for psychological QL ( $\underline{F}$ , (1, 53) = 2.38,  $\underline{p}$  = 0.129,  $R^2$  = .08, adj  $R^2$  = .06). However, there was a trend in the hypothesized direction, with IBC women reporting lower mean scores for psychological QL (4.67) than RBC women (5.15). Although it was initially proposed that this analysis would be conducted with MHLOC as a covariate, the non-significant results indicated that this analysis would not be appropriate. Nevertheless, additional ANCOVAs were conducted using each of the four subscales of the MHLOC as covariates. For the ANCOVA using doctor, powerful other, MHLOC as the covariate, the analysis yielded significant results ( $\underline{F}$ , (2, 51) = 6.03,  $\underline{p}$  = 0.004,  $R^2$  = .10 and adj  $R^2$  = .16) with a significant effect for doctor, powerful other, MHLOC ( $\underline{F}$  = 10.94,  $\underline{p}$  = .003). However, it should be noted given the severe skewness of the doctor MHLOC and the large number of exploratory analyses using the subscales of the MHLOC, this result should be interpreted with caution.

The second research question tested stated that psychological QL would differ for women depending on their cancer group and MHLOC. A 2 (IBC vs. RBC group) X 2 (internal vs. external MHLOC) ANOVA was used, testing for main effects for group and MHLOC, as well as interactions between the two. However, these results did not yield significant results ( $\underline{F}$ , (3, 50) = 0.78,  $\underline{p}$  = 0.513). In addition, analyses were conducted using the other three scales of the MHLOC; however, none of these analyses yielded significant results. Initially, it was hypothesized that stage should be covaried from these analyses. Because of the non-significant results, however, it was determined that an ANCOVA was not appropriate for these analyses and was not conducted.

The third set of hypotheses suggested that there would be a differential relationship between functional QL and internal MHLOC, depending on whether the woman had IBC or RBC. Specifically, it was hypothesized that women with RBC would have a negative relationship between functional QL and internal MHLOC and women with IBC would have a positive relationship between functional QL and internal MHLOC. However, results indicated that there was no significant relationship between functional QL and internal MHLOC for either RBC ( $\underline{r} = 0.19$ ,  $\underline{p} = 0.177$ ) or IBC ( $\underline{r} = 0.04$ ,  $\underline{p} = 0.431$ ) groups (Table 9). In addition, analyses were conducted for the other three subscales of the MHLOC. Similar to previous analyses, a significant correlation was found between functional QL and doctor MHLOC for both RBC ( $\underline{r} = 0.39$ ,  $\underline{p} = 0.044$ ) and IBC ( $\underline{r} = 0.46$ ,  $\underline{p} = 0.015$ ), but not for people MHLOC, RBC ( $\underline{r} = 0.03$ ,  $\underline{p} = 0.887$ ) and IBC ( $\underline{r} = 0.22$ ,  $\underline{p} = 0.263$ ), or chance MHLOC, RBC ( $\underline{r} = -0.01$ ,  $\underline{p} = 0.971$ ) and IBC ( $\underline{r} = 0.04$ ,  $\underline{p} = 0.856$ ) (Table 9).

The third research question tested stated that women with IBC differ on functional QL compared to women with RBC. Results from a one-way ANOVA indicate that there was no difference between women with IBC and RBC for functional QL ( $\underline{F}$ , (1, 53) = 0.77,  $\underline{p}$  = 0.364). Although it was initially proposed that this analysis would be conducted with MHLOC as a covariate, the non-significant results indicated that this analysis would not be appropriate. Nevertheless, additional ANCOVAs were conducted using each of the four subscales of the MHLOC as covariates. For the ANCOVA using doctor MHLOC as the covariate, the analysis yielded significant overall results ( $\underline{F}$ , (2, 51) = 6.02,  $\underline{p}$  = 0.004,  $R^2$  = .101 and adj  $R^2$  = .159) with a significant covariate effect for doctor MHLOC ( $\underline{F}$  = 10.63,  $\underline{p}$  = .002) and a marginally significant main effect for group ( $\underline{F}$  = 2.96,  $\underline{p}$  = .092).

However, it should be noted given the severe skewness of the doctor MHLOC and the large number of exploratory analyses using the MHLOC, this result should be interpreted with caution.

The fourth set of hypotheses tested suggested that women with lower stages of BC (stage 1 or 2), regardless of initial or recurrent status, would have higher psychological QL, higher functional QL, and higher overall QL ratings than women with advanced stages of BC (stage 3 or 4). A point biserial correlation indicated that there was no relationship between stage of cancer and psychological QL ( $\underline{r} = 0.02$ ,  $\underline{p} = 0.446$ ). However, a point biserial correlation indicated that there was a significant relationship between stage of cancer and functional QL ( $\underline{r} = -0.28$ ,  $\underline{p} = 0.013$ ). A point biserial correlation indicated that there was no relationship between stage of cancer and overall QL, although there was a trend toward significance, with functional QL contributing to overall QL trend ( $\underline{r} = -.16$ ,  $\underline{p} = .093$ ).

The fourth research question stated that functional QL would differ for women depending on their cancer group and MHLOC. A 2 (IBC vs. RBC group) X 2 (internal vs. external MHLOC) ANOVA was used, testing for main effects for group and MHLOC, as well as interactions between the two. However, these results did not yield significant results ( $\underline{F}$ , (3, 50) = 0.48,  $\underline{p}$  = 0.695). In addition, analyses were conducted using the other three scales of the MHLOC; however, none of these analyses yielded significant results. Although, when the relationship between cancer stage (1-4) and MHLOC (internal and external) was examined, a significant relationship was found ( $\underline{F}$ , (7, 36) = 2.55,  $\underline{p}$  = 0.030,  $R^2$  = .33, adj  $R^2$  = .20), with a significant effect for stage ( $\underline{F}$  = 3.12,  $\underline{p}$  = .038) and women in stage 4 cancer having lower functional QL (4.10) than

women in stage 1 cancer (5.72). There was no significant difference between these two groups for functional QL compared to women with stage 2 (5.71) or stage 3 cancer (4.98).

The fifth set of hypotheses stated that women with RBC would be more optimistic, report higher psychological QL, and higher functional QL than women with IBC. However, results indicated that there were no significant differences between RBC and IBC women for optimism ( $\underline{t}$  (54) = 0.05,  $\underline{p}$  = .959), psychological QL ( $\underline{t}$  (52) = 1.55,  $\underline{p}$  = .128), and functional QL ( $\underline{t}$  (53) = -0.88,  $\underline{p}$  = .384). However, when these analyses were reanalyzed using an ANCOVA, with stage of cancer as the covariate, significant results were obtained between IBC and RBC women for functional QL ( $\underline{F}$ , (2, 42) = 5.75,  $\underline{p}$  = 0.006,  $R^2$  = .215, adj  $R^2$  = .177), with women with RBC reporting higher functional QL (5.634) and women with IBC reporting lower functional QL (5.002). In addition, a trend was found for psychological QL ( $\underline{F}$ , (2, 42) = 2.82,  $\underline{p}$  = 0.071,  $R^2$  = .118 and adj  $R^2$  = .076), with a significant main effect for group ( $\underline{F}$  (1) = 5.38,  $\underline{p}$  = .025) and with RBC women reporting higher psychological QL (5.315) and IBC women reporting a lower psychological QL (4.429). No significant relationship was found for optimism and type of diagnosis ( $\underline{F}$ , (2, 42) = 0.81,  $\underline{p}$  = 0.454).

The sixth set of hypotheses stated that having a spouse or a significant other would be correlated with higher psychological QL and functional QL than women without a significant other. Results indicated that neither psychological QL ( $\underline{t}$  (46) = -0.13,  $\underline{p}$  = .895) nor functional QL ( $\underline{t}$  (43) = -0.06,  $\underline{p}$  = .954) were affected by the presence of a significant other.

The sixth research question investigated the relationship between social QL and functional QL and having a significant other present. Results indicated that neither social QL ( $\underline{t}$  (41) = 1.33,  $\underline{p}$  = .191) nor family QL ( $\underline{t}$  (40) = -0.64,  $\underline{p}$  = .528) were affected by the presence of a significant other,

The final hypothesis suggested that RBC women would report higher overall composite QL ratings than IBC women. Results indicated that there was no significant difference between IBC and RBC women for composite QL ratings ( $\underline{t}$  (50) = -0.37,  $\underline{p}$  = .710).

# **Qualitative Analysis**

Twenty-three of the twenty-eight IBC participants (82.1%) responded to the first set of open-ended questions, which requested them to respond to how cancer impacted their life. The RBC participants had an equivalent response rate of 85.2% (23 of 27 participants) to this same set of open-ended questions. Descriptive Information referring to how cancer impacted participants' life will refer only to these twenty-three IBC and twenty-three RBC women.

Table 10 illustrates IBC and RBC frequencies for the themes that emerged from responding to how cancer impacted participants' life. Only those categories that had a significant number of answers will be reported. For in-depth review of qualitative analysis, refer to Table 10. Nearly one-third (30.4%) of IBC women reported psychological functioning as being impacted compared to 26.1% of RBC women. Two thirds of IBC women (65.2%) reported difficulties with functional well-being compared 30.4% of RBC women. Additionally, 13.0% of IBC women reported experiencing employment difficulties compared to only 4.3% of RBC women. Sixty-point-nine

percent of IBC women reported having their outlook changed in some way as did 65.2% of RBC women.

Twenty-five of the twenty-eight IBC participants (89.3%) responded to the second set of open-ended questions, which requested them to respond to what was the most significant way cancer impacted their life. The RBC participants had a response rate of 92.6% (25/27 participants) to this same set of open-ended questions. Descriptive Information referring to how cancer most significantly impacted participants' life will refer only to these twenty-five IBC and twenty-five RBC women.

Table 11 illustrates IBC and RBC frequencies for the themes that emerged from responding to how cancer most significantly impacted participants' life. Only those categories that had a significant number of answers will be reported. For in-depth review of qualitative analysis, refer to Table 11.

Twelve percent of IBC women reported spiritually as being significantly impacted by their cancer experience compared to a 16.0% of RBC women. Twenty-eight percent of IBC women reported that their social functioning was positively impacted compared to none of the RBC women. Eight percent of IBC women reported difficulties with functional well-being compared to 32.0% of RBC women. Eight-four percent of IBC women reported having a different outlook on life compared to 40.0% of RBC women.

Eleven of the twenty-eight IBC participants (39.3%) responded to the third set of open-ended questions, which requested them to respond to any additional comments or concerns they may have. The RBC participants had a response rate of 70.0% (17/27 participants) to this same set of open-ended questions. Descriptive Information referring

to any additional comments or concerns will refer only to these eleven IBC and seventeen RBC women.

Table 12 illustrates IBC and RBC frequencies for the themes that emerged from this set of open-ended questions. Only those categories that had a significant number of answers will be reported. For in-depth review of qualitative analysis, refer to Table 12. Twenty-seven point three percent of IBC women reported their health was significantly impacted by cancer compared to none of the RBC women. Seventy-two percent of IBC women reported medical care/research concerns compared to 41.2% of RBC women. A smaller percentage (27.3%) of IBC women reported Spirituality as being important compared to 81.8% of RBC women. A small percentage (18.2%) of IBC women reported psychological functioning a concern compared to 47.1% of RBC women. A moderate percentage (23.5%) of IBC women reported difficulties with functional well-being compared to none of the RBC women. Twenty-seven point three percent of IBC women reported having a different outlook on life compared to 23.5% of RBC women.

#### CHAPTER IV

#### DISCUSSION

The Discussion section is organized into three parts, referring to the three main research goals. The first one addresses how health locus of control beliefs and initial or recurrent cancer diagnosis relate to QL. The second question concerns the relationship between optimism and QL. Lastly, the third examines the relationship between participant's marital status and QL.

The relationship between Internal Health Locus of Control, Type of Diagnosis and Disease Stage on QL

The first hypothesis that perceptions of internal HLOC would be negatively associated with psychological QL for women with an initial BC diagnosis was not supported. In answering the first research question, exploratory analysis also revealed a non-significant association between psychological QL and internal HLOC for RBC women. De Valck and Vinck (1996) also reported a nonsignificant relation between health locus control orientation and quality of life in their study investigating health locus of control and quality of life in lung cancer patients. There is no relation to discuss here so rather than evaluating a relationship that was not found, inspection of mean levels is more appropriate. The mean internal HLOC levels, as illustrated in Table 3, are not significantly different from each other. These levels of approximately 3.1 for both groups may be somewhat low levels of internality. Even the scales creator, Wallston et al. (1994) did not provide data for normative samples.

Given that there were no significant mean differences, it is plausible that IBC and RBC women in this study do not believe that they can personally control their cancer.

An individual may cope with their cancer diagnosis and treatment more effectively if they do not view their cancer as being controllable by any factor(s). Additionally, the lack of a significant relationship between internal HLOC and psychological QL may be an adaptive coping strategy. If cancer is not perceived as being personally controllable, then a cancer diagnosis does not imply that a woman somehow failed or loss control and developed cancer. Therefore, the BC patient does not assume responsibility for failing to prevent the onset, progression or recurrence of cancer. The BC patient also does not assume responsibility for the pain, life disruption, progression of the disease, and/or the possibility of death. Both IBC and RBC women can cope better with their diagnosis and treatment, and focus on the outcome (i.e., health and longevity) without rationalizing why it happened to her and what she could have done to prevent it. By removing the control element, the BC patient can see it as a medical event and not, for example, bad karma, God's punishment, or due to some personal, psychological characteristic.

The saliency of making a distinction between perceptions of controlling one's general health versus controlling a life threatening disease such as cancer must be noted. The MHLC-C is a disease specific locus of control scale for cancer; BC patients may hold different locus of control beliefs about their cancer than they would about their general health status. One can see the mental health advantages for cancer patients who maintain different health locus of control beliefs regarding their cancer, general health, and overall life events (e.g., quitting smoking). Assigning control to the onset of cancer and control over the course of cancer is giving an individual the ability to change their current health status and/or to prevent illness recurrence. Having this type of control

orientation could lead to psychological distress, especially if the cancer progressed/reoccurred.

General perceptions about control over general health and other life events also may play a role in cancer adjustment. Perhaps BC patients do not view their cancer as being personally controllable but general health or other life events (e.g., ability to obtain an MBA, quitting smoking, etc.) are perceived as being personally controllable. Women may believe that by exercising and eating properly they can prolong their longevity and increase health, which is different from fighting off a disease like cancer.

No studies have investigated health locus of control beliefs in patients before they are informed of a cancer diagnosis. It may be that a shift in health locus of control beliefs occurs after communication of a cancer diagnosis. Establishing a baseline measure of health locus of control orientation prior to communication of a cancer diagnosis and then re-testing may provide valuable information as to whether or not health locus of control beliefs shift/fluctuate over time. Furthermore, the way in which a doctor informs BC patients about a cancer diagnosis may also interact with their health locus of control beliefs. If cancer education and alternative treatment(s) are not provided to the BC patient, she may feel that her cancer is not personally controllable and shift her health locus of control beliefs to a high doctor-health locus of control orientation. A sense of control that patients assign to their illness may be a key to understanding their psychological adjustment.

While an internal HLOC relationship was not established with psychological QL, exploratory analyses revealed a positive, significant relationship between doctor HLOC and psychological QL for IBC women. A marginally significant relation was found

between doctor HLOC and psychological QL for RBC women. Western philosophy still influences the perception individuals have regarding the relationship between their health, disease, and medicine. Many individuals maintain the belief that physicians are responsible for treatment of diseases like cancer and regard their own contribution to staying "disease free" as of trivial importance. A vast majority of the women in this study (94.5%) reported high HLOC belief in their doctor's ability to treat/cure them. This may be more a need to believe in the physician when someone is seriously ill.

Having a doctor HLOC may be psychosocially advantageous for a BC patient. If the cancer is to progress or reoccur, the BC patient will not view it as a fault of her own, rather a failure in medicine to control the disease. Since a minimal number of women (5.5%) in this study did not believe their physician was an effective agent of treatment suggests losing faith in a physician has a marked effect on psychological well-being.

The implications for a BC patient to have a doctor HLOC orientation are that physicians have an increased burden of maintaining BC patients' psychological QL. The saliency of establishing rapport and educating patient's about BC, its treatment (including alternative ones), and what to expect in terms of life after the cancer experience become increasingly important. Physicians need to be empathetic when providing a diagnosis and be patient and understanding of the questions asked and the fears that a cancer patient might possess. The patient should be educated about how cancer will affect them psychosocially, that is how psychological (e.g., depression and anger), functional (e.g., fatigue, role dysfunction), social (e.g., decrement in social activities), and physical (e.g., hair loss, pain, vomiting) QL will be affected. Doctors need to provide clients with referrals for psychological therapy, cancer education classes,

and/or support groups so that BC patients can vent out their fears and anger, learn ways to decrease familial stress, increase their understanding of cancer the experience, and to learn adaptive coping methods.

The MHLC-C has a four factor scale to it, that is internal, external (fate, chance, and powerful others – doctor and people). This instrument does not assess spirituality in any manner. Interestingly, qualitative analyses revealed that a large percentage of women mentioned the importance of spirituality. Many women reported that "having faith in God" has helped them through their cancer experience. Faith in God may increase coping. It appears that many women have an external orientation regarding their health. Comments, such as "God will take care of me" and "God will get me through this ordeal" makes one speculate that there may be an external, spirituality HLOC factor that is not measured on the MHLC-C. Using a HLOC measure that has a spirituality factor as one of its subscales is an area worthy of investigation.

Furthermore, a significant difference between IBC and RBC women for Psychological QL was not established. It was initially hypothesized that women with IBC would have a lower psychological QL than RBC women, after controlling for health locus of control. It is plausible that a cancer diagnosis, regardless of initial or recurrent group status, is equally devastating and distressing to both IBC and RBC women.

Women with an initial BC diagnosis have to experience the initial shock of receiving a diagnosis, as well as experience the fears associated with cancer. These fears can include uncertainty of the future, uncertainty of what to expect from treatment including side-effects and long-term effects of cancer, as well as realizing their mortality. These fears are similar to what RBC women may experience. Although, RBC women may

have knowledge regarding what to expect from the cancer experience, their mortality is threatened again and prognosis is generally not favorable. Additionally, recurrent cancers are generally more aggressive and treatment is more intensive (toxic) than an initial cancer. RBC women may experience the same anxieties IBC women experience, for example, fear of death and uncertainty of the future.

It was hypothesized that early cancers (Stage I or II) would be a significant predictor of higher psychological QL than advanced cancers (Stage III or IV). This hypothesis was not supported. It is plausible that although advanced cancers have a poor prognosis, BC patients (regardless of type of diagnosis) may have established adequate coping mechanisms early on during their diagnosis. It is also plausible that both IBC and RBC patients experience similar degrees of psychological distress during diagnosis, treatment, and post-treatment. Additionally, valued life activities may positively influence psychological functioning. If advanced staged BC patients are still engaging in valued life activities, this engagement might act as a buffer against the psychological distress associated with cancer progression. While social, physical and functional abilities may have declined, they are still able to enjoy activities that are satisfying to them.

Furthermore, the hypothesis that early staged cancers would predict higher overall QL ratings than advanced cancers was not supported. A marginally significant relation was found between women with early staged cancers reporting higher overall QL than women with advanced staged cancers; however, functional QL contributed toward this trend. These results suggest that overall QL ratings for both IBC and RBC may not be significantly different from each other and that the cancer experience impacts these

women in similar ways, therefore no overall relationship in QL is noted. Researchers hypothesize that recurrent BC patients experience greater levels of distress than initial BC patients because a recurrent diagnosis is generally more life threatening than an initial BC diagnosis (Worden, 1989). However, RBC women may have feared/expected a recurrent diagnosis and when diagnosed, these women did not experience more distress than IBC women. Qualitative analysis revealed that RBC women reported experiencing a sense of relief when diagnosed because their "greatest fear had come true". It is plausible that fears of recurrence can actually be more psychologically distressing than receiving a RBC diagnosis. A recurrent diagnosis may actually produce a sense of relief in RBC women because their greatest fear has come true and their attention can now focus again on surviving the cancer. Their prior cancer experience can actually serve as a buffer against psychological distress because not only are they familiar with treatment and side-effects, but RBC women survived their first bout with cancer. Additionally, RBC women may have developed strong social support systems and these systems may act as a buffer against any functional limitations experienced by more aggressive therapies or progression of cancer. Thus, both IBC and RBC women may have endorsed similar overall QL ratings because the impact of a cancer diagnosis and treatment is similar in both groups of women in terms of treatment related side-effects and social, psychological, and functional QL.

It was initially hypothesized that women with IBC would have a positive relationship between internal HLOC and functional QL while women with RBC would have a negative relationship between these two variables. These hypotheses were not supported. There is no relation to discuss here so rather than evaluating a relationship

that was not found, inspection of mean levels is more appropriate. The mean internal HLOC levels, as illustrated in Table 3, are not significantly different from each other. These levels of approximately 3.1 for both groups may be somewhat low levels of internality.

Given that there were no significant mean differences, it is plausible that BC patients may not view their cancer as controllable. This lack of association between internal HLOC orientation and functional QL may be an adaptive coping mechanism. The side-effects of active treatment can negatively affect a BC patient's daily routine and ability to self-care. An internal HLOC orientation may not be psychologically advantageous to a woman who is losing her ability to self-care. Having a loss of role functioning can be an extremely distressing event and may render an individual to feel and act helpless. In addition to the distress caused by loss of role functioning, an individual with an internal orientation may experience even more distress because health is viewed as being something that is controllable. BC patients, who do not have an internal HLOC orientation, are more likely to receive social support and assistance from others because they do not view their cancer as controllable and realize the need for assistance with functional abilities.

While relation between internal HLOC and functional QL was not significant, exploratory analyses revealed only the doctor subscale had a significant association with functional QL for both IBC and RBC women. Similar to the prior discussion regarding the relationship between doctor HLOC and psychological QL, it is evident that a physician plays an integral role in influencing the functional QL of a BC patient. Physicians need to educate patients about functional limitations and role dysfunction that

might be experienced from cancer treatment. This education will decrease the fears associated with having to depend on others and it will enhance BC patients' compliance of asking others to assist them. Therefore, by educating BC patients regarding functional loss, patients can plan ahead by scheduling a cleaning service and/or someone to provide food or transportation. Patients may also opt to work from their home instead of at the office in order to avoid employment disruption. Physician's can encourage patients to engage in valued life activities so that functional loss is not as distressing.

When internal HLOC was covaried, there was still no significant difference between IBC and RBC for functional QL. Typically, IBC women receive less toxic, aggressive cancer treatment than RBC women. Even though treatment may be more aggressive for RBC women and they may experience greater functional limitations than IBC women, RBC women may have established prior social support systems from their first bout with cancer. As a result of these established social support relations, RBC women may not report a decrement in functional QL because of the functional assistance received from their social support systems. Additionally, the saliency of valued life activities emerges again, acting as a buffer against the distress associated with functional limitations/disabilities. It is also plausible that RBC women have already learned to cope/adjust with functional limitations, discomfort, and pain associated with their initial cancer experience. These established coping mechanisms help buffer the distress associated with a recurrent diagnosis.

It was hypothesized that early cancers (Stage I or II) would be a significant predictor of higher functional QL than advanced cancers (Stage III or IV). The hypothesis was supported. Intuitively, advanced cancer patients should report greater

percentages of functional limitations than early staged cancer patients due to receiving more aggressive therapies. These type of therapy modalities may produce a significant decline in functional abilities, including ability to self-care and the ability to engage in valued life activities. Advanced cancer patients also have a poorer prognosis and may have greater functional limitations (e.g., loss of mobility, pain) compared to early staged BC patients. It is also hypothesized that advanced cancer patients are most likely not working full-time and this loss of role functioning may reduce their functional QL.

Lastly, the relationship between psychological and functional QL and type of diagnosis (initial vs recurrent) was explored. No significant difference was found between type of diagnosis and psychological QL. Additionally, there was a trend toward significance in the expected direction between RBC women having higher psychological QL than IBC women when stage was covaried. An initial diagnosis may be just as distressing as receiving a recurrent diagnosis because there is uncertainty, fear of the unknown, and other equally distressing stimuli affecting both groups. Furthermore, RBC women may be more receptive to receiving assistance from others, have more social support systems to assist them, and/or engage in more value life activities. Having been through cancer previously, it is not as devastating because they endured treatment previously and survived their cancer. RBC women may also have established adaptive coping mechanisms to aid them in deleterious circumstances such as the cancer experience and established a solid, social support system. In contrast, IBC women may not have developed an extensive social network, as did the RBC patient. It is plausible that friends and close family members of IBC patients may not know how to cope with someone who has cancer. A loss of social contacts may result. Some IBC patients may

be hesitant on revealing to others her cancer diagnosis for fear of rejection or being pitied by others. Either way, the IBC patient puts herself in a psychology vulnerable position, which may result in increase psychological distress. Lastly, RBC families have prior experience with cancer, whereas IBC families do not have this same experience. Qualitative analysis revealed that a larger percentage of IBC participants stated that their cancer diagnosis has created stress within the family above and beyond the stress associated with the cancer experience.

No significant difference was found between type of diagnosis and functional QL. However when stage was covaried, a significant difference emerged for type of diagnosis and functional QL. RBC women reported higher functional QL than IBC women. RBC women may be more receptive to receiving assistance from others, have more social support systems to assist them, and/or engage in more value life activities than IBC women. This finding also suggests that RBC women may anticipate a decline in functional abilities and do not try to engage in activities that they are not able to accomplish. Lastly, the RBC women has had a prior experience(s) with cancer and its treatment, and is more knowledgeable in the functional limitations imposed by the disease and has learned to cope with the functional loss more adaptively.

#### The relationship between Optimism and QL

Initially it was hypothesized that RBC women would report greater optimism than IBC women. This hypothesis was not supported. No significant differences existed between IBC and RBC women. As reported in the literature review, optimism may act as a buffer against adversity and lower the psychological distress associated with adversity (e.g., cancer diagnosis). It is plausible that while IBC patients are confronting adversity

for the first time, RBC patients also have to confront a recurrent adversity to their health. IBC patients, as well as RBC patients have their mortality threatened. Initial BC diagnoses have a better prognosis than recurrent cancers. An IBC patient may be optimistic about confronting the adversity because the majority of cancer diagnoses in this sample were in the early stages. In a similar vein, the RBC patient is confronting her mortality once again. Her optimistic strategy might be that since she "fought the cancer the first time, she'll beat it this time". One may see the advantageous of a high doctor-HLOC orientation in this situation. Women can maintain their optimism because their health is in the care of their physician. While RBC women may be optimistic, this level of optimism is not distinctly different from IBC women.

It is plausible that while optimism may positively impact QL, a BC patient may experience shattered beliefs if her cancer is to reoccur/progress. A decrement in optimism may occur because she became overly optimistic that the cancer would not reoccur. While still maintaining an optimistic orientation, her beliefs can be restructured reflecting a more realistic view of cancer and acceptance of the cancer. She may even positively reframe the situation, such as creating the belief that cancer has caused her to take time to experience things she has not experienced. One RBC patient wrote, "My cancer has caused me to live life fuller, become more positive, grow closer to my family, and enrich my relationship with God."

### The relationship between Marital Status, and QL

Initially, it was hypothesized that women who were married or having a significant other would report higher psychological and functional QL ratings. These hypotheses were not supported. These findings would suggest that the cancer experience

is distressing at all levels and may be just as distressing to a marriage or significant relationship as it is to someone who is single.

The social support theory that marriage or having a significant other can buffer stressful situations may not always be adaptive. For instance, the cancer experience may negatively impact a husband and wife. It may affect the communications between two individuals, as well as affect the intimacy shared. One woman wrote, "While I am thankful of the cancer because it has brought me closer to God, it has destroyed my family. The loss of my right breast was more than my husband could bear. I find myself abandoned, being a single mother, and having to raise two small children."

On the other hand, it is plausible that women who are separated, divorced, or widowed have strong social support systems, equaling the psychological and functional support received from a husband or significant other. These women may also need to rely on others more for functional assistance; however, this may not be different from a woman having a significant other. Furthermore, qualitative analysis revealed that many women reported the importance of attending support groups to vent their anger and share their emotions, fears, and concerns regarding the IBC or RBC experience. Attending a support group might be psychologically advantageous for both single women and women in significant relationships because they receive a type of support and cancer education not available from family, friends, and health care professionals.

Exploratory analyses revealed that neither social QL, family QL or overall QL ratings were affected by the presence of a significant other. Women without a significant other may have established strong social support systems which equal the social support received from having a significant other, resulting in no difference in social, family, or

overall QL. Qualitative analysis revealed that a BC patient's appreciation for life, friends, and family increased due to the cancer experience. These women also reported an increased sense of renewal since they were faced with their mortality. Many BC women reported wanting to spend more time with loved ones and thanking people more for their love and support. This appreciation for life, or sense of renewal, may have increase a BC patient's social support network which provides them with the necessary psychological, functional and overall quality of life needs. While a patient may suffer from cancer treatment or disease progression, having a new perspective on life may buffer the deleterious effects of cancer. One woman wrote, "While my cancer may beat me, it will never take my life. I take time now to smell the flowers and enjoy life".

#### Limitations

One of the major limiting factors of this study was the difficulty of collecting data from these participants. Over one-third of the initial breast cancer patients declined participation in the current study when approached by either a nurse, breast cancer support facilitator or the primary investigator. These participants commented that the measure was either too long or they were not interested in participating in research. Measuring psychosocial differences between those who participate and those who decline would have been interesting. Furthermore, the initial breast cancer patients who did participate had a consistently lower response rate to open-ended questions than the recurrent patients breast cancer patients.

Information regarding how many women were recruited from doctors' offices versus support groups is not known, it is plausible that women attending support groups may be different from women who do not seek out support groups. Additionally, the

majority of women were not able to include information on stage of cancer because many of their physician's did not inform them of the stage or grade of tumor. Calculations were run on the small sample size of women reporting stage; however, these findings have limited generalizability regarding psychosocial functioning and cancer stage.

Although all attempts were made at collecting an ethnically diverse population, the sample was predominately Caucasian. One can only speculate about how ethnically diverse women will differ on psychosocial measures. For instance, the literature presents differences in optimism for different ethnicities. African Americans tend to be more fatalistic/pessimistic regarding cancer diagnoses than Caucasians (Hoffman-Goetz, 1999). Future research is directed in obtaining a more diverse sample and investigating differences in quality of life, optimism, and health locus of control based on ethnicity as well as type of diagnosis.

Establishing SES was not possible because the majority of participants did not provide information regarding their occupations, which was necessary for calculating SES. Differences in SES regarding psychological and functional QL domains would have been interesting to explore. Future research should focus on gathering SES information and determining if SES status impacts quality of life, optimism, and health locus of control.

Lastly, evaluating differences in spirituality between IBC and RBC women was not performed. Due to the length of the questionnaire, spirituality questions were not included. Future research should investigate how IBC and RBC women differ on spirituality measures as well as quality of life.

### <u>Implications and Suggestions</u>

The evidence from the present study, though not conclusive, suggests that certain differences do exist between IBC and RBC groups between optimism, health locus of control, and quality of life and that these variables can significantly influence patient's general sense of well-being. The major limitations of this study, as discussed in the prior section were the small sample size, lack of an ethnically diverse population, and that the majority of participants were not able to include information on stage of cancer. The next logical step would be to increase the sample size, obtain an ethnically diverse population, and obtain information on stage prior to completing the survey. In the current study, many participants were not informed of the stage of their cancer, but they were aware of how many lymph nodes were involved and the size of the tumor. From this information, stage of cancer can be determined and the hypotheses can empirically tested again.

Significant implications arise for physicians treating BC patients. Physicians may not necessarily focus entirely on a curative approach, which may reduce functional well-being as well as psychological functioning. Instead, physicians can combine a palliative approach with a curative one, that is focusing on keeping a patient comfortable and eliminating their pain so that they can participate in valued life activities and engage in more social activities.

In the future quality of life research, development of subscales for each of the four QL dimensions, in addition to a global measure like the M-FLIC, will be beneficial in investigating an overall quality of life score to each dimension. Obtaining participants within one to two weeks after being informed of an initial or recurrent diagnosis would be useful and may provide a more accurate measure of quality of life, optimism, and perceptions of health locus of control. Utilizing this two-week time frame may provide

significant information regarding hypotheses that health locus of control orientation and optimism scores fluctuate over time. It is also important to assess control beliefs of BC patients in order to identify high risk patients who need psychological support. Lastly, examining patients' general perceptions of control as well as cancer-related control beliefs will increase our understanding of how BC patients adjust to their disease.

There also have been no studies that have investigated HLOC beliefs in cancer patients before they are informed of a diagnosis (De Valck et al., 1996). Further research is needed to verify whether patients who hold internal HLOC beliefs before they are aware of a cancer diagnosis differ in the informational needs from patients with an external HLOC orientation. For example, De Valck reported that patients with high internal HLOC orientations are more aware of bodily changes and may report more symptoms or treatment side-effects compared to individuals with external orientations. High internal patients may benefit more from stress-reducing self-control techniques, like relaxation, than more externally oriented control beliefs. Additionally, the original MHLC appears to assess somewhat distinct domains of health locus of control beliefs. By administering both a general health locus measure and a cancer specific measure to a BC population will aid researchers in exploring if BC women regard health and cancer as distinct entities that are or are not controllable.

Including a spiritual dimension to the MHLC-C subscale or using an existing HLOC measure which includes a spirituality subscale would be an area worthy of investigation since a large percentage of both initial and recurrent breast cancer patient endorsed faith in God as controlling their life/health. Future research needs to explore relationships between QL, toxicity, and survival.

Finally, in terms of clinical implications, the study has provided further evidence that both initial and recurrent BC patients have psychosocial needs that should be attended to. This study is the first to investigate some of the quality of life dimensions. While a person may report adequate quality of life ratings in the psychological dimension, an individual may report lower ratings in the functional dimensions. A total QL score may not reflect such differences. By separating out the QL dimensions and analyzing them, a more effective treatment plan can be implemented to aid the psychosocial needs of initial and recurrent BC patients.

APPENDIX A
TABLES

TABLE 1

<u>Constructs That are Being Investigated in this Study</u>.

CONSTRUCT	MEASURE
Health Locus of Control	MHLOC-C scale (18 items)  Internal HLOC subscale Powerful Others HLOC subscale Chance Factors HLOC subscale
Quality of Life Functional QL Psychological QL	M-FLIC (22 items)  FLIC – Functional items  FLIC – Psychological items
Optimism	LOT-R (13 items but only 6 are scored)

#### Table 2

## Items Composing the Revised Life Orientation Test (LOT-R)

- 1. In uncertain times, I usually expect the best.
- 2. It's easy for me to relax. [Filler Item]
- 3. If something can go wrong for me, it will.
- 4. I always look on the bright side of things. [Not Scored] [Positive Worded Item]
- 5. I'm always optimistic about my future.
- 6. I enjoy my friends a lot. [Filler Item]
- 7. It's important for me to keep busy. [Filler Item]
- 8. I hardly ever expect things to go my way.
- 9. Things never work out the way I want them to. [Not Scored] [Negative Worded Item]
- 10. I don't get upset too easily. [Filler Item]
- 11. I'm a believer in the idea that "every cloud has a silver lining." [Not Scored] [Positive Worded Item]
- 12. I rarely count on good things happening to me.
- 13. Overall, I expect more good things to happen to me than bad.

Table 3

Descriptive Data for All Participants and Comparing IBC and RBC Women on

Psychosocial Measures.

t-test	$\frac{df}{df}(52.42) = .098, p = .922$ $\frac{df}{df}(52) = -2.09, p = .041*$ $\frac{df}{df}(51.71) = .746, p = .459$ $\frac{df}{df}(52.97) = 1.34, p = .186$ $\frac{df}{df}(52.89) = .49, p = .627$	$d\underline{f}(52.42) = .05,  \underline{p} = .959$	$ \underline{df}(52.05) = .1.57, \mathbf{p} = .129 $ $ \underline{df}(48.03) =873, \mathbf{p} = .387 $
$\frac{\overline{SD}}{ \overline{SD} }$	0.91 1.21 0.83 1.08	.58	1.04
RBC X	3.16 2.97 4.02 5.18 3.20	2.85	5.15
	0.97 1.17 0.94 1.07	1.08	1.24
IBC	3.14 3.65 3.85 4.79 3.04	2.83	4.67
All Subjects $\overline{X}$ $\overline{SD}$	0.93 1.23 0.88 1.08	98.0	1.16
All Su	3.15 3.31 3.94 4.99 3.12	2.84	4.91
	MHLOC Internal Chance Powerful Others Doctor People	LOT-R	M-FLIC Psychological Functional

Note:  $* \underline{p} < .05$ 

Table 4

<u>Frequencies and Percentages of Demographic Variables and Separated by All Participants for IBC and RBC.</u>

	Frequency Percent
<u>Educ</u>	eation_
Eighth Grade (1) High School Degree (2) Trade School (3) Some College(4) College Degree (5) Some Graduate/Professional Experience (6) Graduate/Professional Degree (7) Total	All Subject         IBC         RBC           1         1.8         0         0.0         1         3.6           11         19.6         3         10.7         8         28.6           0         0.0         0         0.0         0         0.0           21         37.5         8         28.6         13         46.4           8         14.3         6         21.4         2         7.1           9         16.1         6         21.4         3         10.7           6         10.7         5         17.9         1         3           56         100.0         28         100.0         28         100.0
<u>Mari</u>	tal Status
Married Separated/Divorced Widowed Single/Never Married Total	All Subject         IBC         RBC           33 58.9         19 67.9         14 50.0           13 23.2         4 14.3         9 32.1           7 12.5         2 17.1         5 17.9           3 5.4         3 10.7         0 0.0           21 100.0         28 100.0         28 100.0
<u>Ethni</u>	<u>icity</u>
Caucasian African American Other Total	All Subject         IBC         RBC           50         89.3         27         96.4         23         82.1           4         7.1         0         0.0         4         14.3           2         3.6         1         3.6         1         3.6           56         100.0         28         100.0         28         100.0
<u>Empl</u>	loyment
Currently Employed Full-Time Currently Employed Part-Time Currently Not Working Due To Illness Currently Not Working Outside The Home Missing Data Total	All Subject         IBC         RBC           25         44.6         15         53.6         10         35.7           9         16.1         7         25.0         2         7.1           6         10.7         0         0.0         6         21.4           10         17.9         5         17.9         5         17.9           6         10.7         1         3.6         5         17.9           56         100.0         28         100.0         28         100.0

Table 5

Frequencies and Percentages of Medical Demographic Variables and Separated by All

Participants for IBC and RBC.

Stage I Stage II Stage III Stage IV Missing Data Total  Treatment Received Surgery Chemotherapy		<del></del>			
Stage II Stage III Stage IV Missing Data Total  Treatment Received  Surgery Chemotherapy		a 1 :			
Stage II Stage III Stage IV Missing Data Total  Treatment Received  Surgery Chemotherapy	10	Subject		<u>IBC</u>	<u>RBC</u>
Stage III Stage IV Missing Data Total  Treatment Received  Surgery Chemotherapy	10	32.1	13	46.4	5 17.9
Stage IV Missing Data Total  Treatment Received  Surgery Chemotherapy	13	23.2	8	28.6	5 17.9
Missing Data Total <u>Treatment Received</u> Surgery Chemotherapy	6	10.7	2	7.1	4 14.3
Total  Treatment Received  Surgery  Chemotherapy	8	14.3	0	0.0	8 28.6
Treatment Received Surgery Chemotherapy	<u>11</u>	<u>19.6</u>	5	<u>17.9</u>	<u>6</u> <u>21.4</u>
Surgery Chemotherapy	56	100.0	28	100.0	28 100.0
Chemotherapy	d Duri	ng First l	<u>Diagno</u>	<u>sis</u>	
Chemotherapy	A11	Subject		<u>IBC</u>	RBC
Chemotherapy	13	26.8	6	28.5	7 28.0
1.0	1	1.8	1	3.6	0 0.0
Surgery and Chemotherapy	10	17.9	2	7.1	8 28.6
Surgery, Chemotherapy and Radiation	11	21.4	5	21.5	6 21.4
Surgery and Radiation	16	28.6	10	35.7	6 21.4
Surgery, Chemotherapy, Radiation, and					
Bone Marrow Transplant	1	1.8	1	3.6	0.0
Missing Data	1	1.8	_1	3.6	1 3.6
Total	56	100.0	28	100.0	28 100.0
Treatment Received D	uring	Recurren	nt Diag	<u>nosis</u>	
		_	RBC		
Surgery		7	12.5		
Chemotherapy		1	1.8		
Radiation		2	3.6		
Surgery and Chemotherapy		8	14.3		
Surgery, Chemotherapy and Radiation		3	5.4		
Surgery and Radiation		4	7.1		
Tamoxifen		1 1	3.7		
Chemotherapy and Radiation					
Missing Data Total		1	1.8 1.8		

Table 6

Reliabilities for M-FLIC, LOT-R, LOT, and HLOC Scales, Including Separate
Reliabilities for IBC and RBC Groups.

-	Alph	ha Value			
	All Subjects	BC	RBC		
M-FLIC	0.92	0.92	0.93		
Psychological subscale	0.80	0.84	0.73		
Functional subscale	0.88	0.86	0.90		
Functional and Psychological subscale	0.89	0.92	0.86		
LOT-R LOT	0.79 0.85	0.90 0.93	0.46 0.60		
MHLOC-C Internal subscale Powerful Others subscale Chance subscale	0.73 0.69 0.68 0.81	0.67 0.74 0.73 0.81	0.77 0.62 0.62 0.80		

Table 7

<u>Summary of All Hypotheses, Research Questions and Statistical Values</u>

Hypot	heses		Statist Values	
H1.	Greater internal HLOC vlower Psychological QL			
		Internal-HLOC	$\underline{\mathbf{r}} = .063,  \underline{\mathbf{p}} = 0.378$	Hypothesis not supported
	Exploratory analyses on	additional HLOC Doctor-HLOC Chance-HLOC People-HLOC	variables $\underline{r} = .329,  \underline{p} = 0.093$ $\underline{r} = .060,  \underline{p} = 0.767$ $\underline{r} = .072,  \underline{p} = 0.720$	Marginally significant Non-significant relation Non-significant relation
RQ1.	Investigate the relation by and HLOC for RBC wor		ical QL	
		Internal-HLOC Doctor-HLOC Chance-HLOC People-HLOC		Non-significant relation Significant relationship Non-significant relation Non-significant relation
H2.	Women with IBC will h than RBC women, contr			
		$\underline{F}$ , $(1,53) = 2.38$ ,	<u>p</u> = .129	Hypothesis not supported Non-significant results
			pothesized direction, with I mean scores for Psycholog en (5.15).	
RQ2.	Investigate the possible group (IBC, RBC) and I		on between ternal) with Psychological	QL.
		$\underline{F}$ , (3,50) = 0.78,	p = .513	Non-significant results
Н3а.	RBC women would have Functional QL and Inter		nship between	
		Internal-HLOC	$\underline{\mathbf{r}} = 0.186,  \underline{\mathbf{p}} = 0.177$	Hypothesis not supported
	Exploratory analyses on	additional HLOC Doctor-HLOC Chance-HLOC People-HLOC	variables $\underline{r} = .390,  \underline{p} = 0.044$ $\underline{r} = .008,  \underline{p} = 0.971$ $\underline{r} = .029,  \underline{p} = 0.887$	Significant relationship Non-significant relation Non-significant relation

#### Table 7 (continued)

H3b. IBC women would have a positive relationship between Functional QL and Internal HLOC.

Internal-HLOC  $\underline{r} = 0.035, \underline{p} = 0.431$  Hyp

Hypothesis not supported Non-significant relation

Exploratory analyses on additional HLOC variables

 $\begin{array}{lll} \mbox{Doctor-HLOC} & \underline{r} = .464, \, \underline{p} = 0.015 & \mbox{Significant relationship} \\ \mbox{Chance-HLOC} & \underline{r} = .037, \, \underline{p} = 0.856 & \mbox{Non-significant relation} \\ \mbox{People-HLOC} & \underline{r} = .223, \, \underline{p} = 0.263 & \mbox{Non-significant relation} \end{array}$ 

RQ3.IBC women differ on Functional QL compared to RBC women, controlling for level of HLOC.

$$\underline{F}$$
, (1,53) = 0.770,  $\underline{p}$  = .364

Non-significant results

H4a. Advancement in cancer stage, regardless of initial or recurrent diagnosis, will relate to lower Psychological QL than women with early stages of BC (1 or 2).

$$\underline{\mathbf{r}} = 0.017, \, \underline{\mathbf{p}} = 0.446$$

Hypothesis not supported Non-significant relation

H4b. Advancement in cancer stage, regardless of initial or recurrent diagnosis will relate to lower Functional QL than women with early stages of BC (1 or 2).

$$r = -0.283, p = 0.013$$

Significant relationship

H4c. Advancement in cancer stage, regardless of initial or recurrent diagnosis, will relate to lower overall QL ratings than women with early stages of BC (1 or 2).

$$\underline{\mathbf{r}} = -0.157, \, \underline{\mathbf{p}} = 0.093$$

Marginally significant

RQ4. Investigate the possible statistical interaction between group (IBC, RBC) and HLOC (internal, external) with Functional QL.

$$\underline{F}$$
, (3,50) = 0.484,  $\underline{p}$  = 0.695

Non-significant results

H5a. RBC women will be more optimistic than IBC women.

$$\underline{t}$$
 (54) = 0.051,  $\underline{p}$  = .959

Non-significant results

H5b. RBC women will be report higher Psychological QL than IBC women.

$$\underline{t}$$
 (52) = 1.55,  $\underline{p}$  = .128

Non-significant results

#### Table 7 (continued)

H5c. RBC women will be report higher levels of Functional QL than IBC women.

$$\underline{t}$$
 (53) = -0.878,  $\underline{p}$  = .384

Non-significant results

H5a-c. Hypotheses reanalyzed utilizing ANCOVA, with stage of cancer as covariate

RBC women will be more optimistic than IBC women.

$$F_{x}(2,42) = 0.805, p = 0.454$$

Non-significant results

RBC women will be report higher Psychological QL than IBC women.

$$\underline{F}$$
, (2,42) = 2.817,  $\underline{p}$  = 0.071

Marginally significant

RBC women will be report higher levels of Functional QL than IBC women.

$$\underline{F}$$
, (2,42) = 5.746,  $\underline{p}$  = 0.006

Significant Difference

RBC reported higher Functional QL (5.634) and IBC women reporting lower Functional QL (5.002)

H6a. Having a spouse or significant other would be correlated with higher Psychological QL than women without a significant other.

$$\underline{t}$$
 (46) = -0133,  $\underline{p}$  = .895

Hypothesis not supported Non-significant results

H6b. Having a spouse or significant other would be correlated with higher Functional QL than women without a significant other.

$$t(43) = -0.058$$
,  $p = .954$ 

Hypothesis not supported Non-significant results

RQ6a. Investigate the relationship between Social QL and Family QL and having a significant other.

$$t(41) = 1.331, p = .191$$

Non-significant results

$$\underline{t}$$
 (40) = -0.637,  $\underline{p}$  = .528

Non-significant results

H7. RBC women would report higher overall composite QL ratings than IBC women.

$$t(50) = -0.374$$
,  $p = .710$ 

Hypothesis not supported Non-significant results

Table 8

<u>Correlation Matrix between Health Locus of Control and Psychological QL</u>

<u>for IBC and RBC Women</u>

		PSYCH QL	INT. MHLOC	POWER MHLOC	DOC. MHLOC	PEOPLE MHLOC	CHANCE MHLOC
PSYCH	Pearson Correlation		006	.009	.481(**)	236	017
QL	Sig. (2-tailed)		.466	.966	.011	.237	.934
INT.	Pearson Correlation	.063		.504(**)	.307	.574(**)	030
MHLOC	Sig. (1-tailed) IBC Sig. (2-tailed) RBC	.378		.003	.056	.001	.440
POWER MHLOC	Pearson Correlation	.170	048		.561(**)	.763(**)	.349
	Sig. (2-tailed)	.199	.813		.002	.000	.474
DOC	Pearson Correlation	.329	132	.713(**)		.038	.275
MHLOC	Sig. (2-tailed)	.047(*)	.511	.000		.850	.165
PEOPLE	Pearson Correlation	.072	.197	.893(**)	.479(*)		.031
MHLOC	Sig. (2-tailed)	.360	.326	.000	.011		.876
CHANCE MHLOC	Pearson Correlation	.060	024	.174	123	.070	
	Sig. (2-tailed)	.383	.906	.385	.542	.728	

<sup>\*\*</sup> Correlation is significant at the 0.01 level (2-tailed).

Note. Values above the main diagonal are for RBC women. Values below the diagonal are for IBC women.

<u>n</u>= 27

<sup>\*</sup> Correlation is significant at the 0.05 level (2-tailed).

Table 9

<u>Correlation Matrix between Health Lcus of Control and Functional QL for IBC</u>

<u>and RBC Women</u>

		FUNCT QL	INT. MHLOC	POWER MHLOC	DOC. MHLOC	PEOPLE MHLOC	CHANCE MHLOC
FUNCT.	Pearson Correlation		.186	.197	.390(*)	.029	008
QL	Sig. (2-tailed)		.177	.324	.044	.887	.971
INT.	Pearson Correlation	.035		.504(**)	.307	.574(**)	030
MHLOC	Sig. (1-tailed) IBC Sig. (2-tailed) RBC	.431		.006	.112	.001	.880
POWER	Pearson Correlation	.311	048		.561(**)	.763(**)	.349
MHLOC	Sig. (2-tailed)	.114	.813		.002	.000	.074
DOC	Pearson Correlation	.464(*)	132	.713(**)		.038	.275
MHLOC	Sig. (2-tailed)	.015	.511	.000		.850	.165
PEOPLE	Pearson Correlation	.223	.197	.893(**)	.479(**)		.031
MHLOC	Sig. (2-tailed)	.263	.326	.000	.011		.876
CHANCE MHLOC	Pearson Correlation	.037	024	.174	123	.070	
MILOC	Sig. (2-tailed)	.856	.906	.385	.542	.728	

<sup>\*\*</sup> Correlation is significant at the 0.01 level (2-tailed).

Note. Values above the main diagonal are for RBC women. Values below the diagonal are for IBC women.

IBC and RBC for Functional QL and Internal MHLOC are 1-tailed tests.

<u>n</u> = 27

<sup>\*</sup> Correlation is significant at the 0.05 level (2-tailed).

Table 10

Qualitative Analysis of Frequencies Separated by IBC and RBC

for Open-ended Questions

Frequency	Percent

## How Has Cancer Impacted Life?

## <u>Health</u>

		IBC	R	BC
Fear of recurrence	3	13.0	1	4.3
Constantly aware of health	0	0.0	1	4.3
Focus on health eating and exercise	2	8.7	1	4.3
At the mercy of medical community	1	4.3	0	0.0
Fear of developing Lymphodema	1	4.3	0	0.0
Health is not the same since diagnosis and treatment of cancer	0	0.0	2	8.7
Category not used	<u>16</u>	69.6	<u>18</u>	69.6
Total	23	100.0	23	100.0

# Psychological Functioning

		IBC	F	RBC
Initially devastating	1	4.3	2	8.7
Scary	0	0.0	1	4.3
Loss of control of life	1	4.3	0	0.0
Negativism	0	0.0	1	4.3
Depression	3	13.0	0	0.0
Anxiety	0	0.0	1	4.3
Coping with life better	0	0.0	1	4.3
Difficulty getting on with life	1	4.3	0	0.0
Life more stressful	1	4.3	0	0.0
Category not used	<u> 16</u>	<u>69.6</u>	17	73.9
Total	23	100.0	23	100.0

Table 10 (continued).

	Fr	equency	P	ercent
Functional W	ell-being			
	IB	C	R	BC
Can't do everything used to	4	17.4	2	8.7
Decreased mobility	3	13.0	2	8.7
More open to receiving help from others	0	0.0	1	4.3
Treatment side-effects problematic	1	4.3	1	4.3
Fatigued	3	13.0	1	4.3
In pain	1	4.3	0	0.0
Employment difficulties	3	13.0	0	0.0
Category not used	8	34.8	<u>16</u>	69.6
Total	$\frac{8}{23}$	$\frac{31.0}{100.0}$	23	$\frac{09.0}{100.0}$
Outlook o	n Life			
	IB	C	R	ВС
Different outlook on life	3	13.0	5	21.7
Created a positive effect on life	2	8.7	4	17.4
Realized mortality	2	8.7	1	4.3
Life not the same as before	0	0.0	1	4.3
Enjoy life more	2	8.7	2	8.7
Live in the here and now	1	4.3	1	4.3
Learn to say, "No"	1	4.3	1	4.3
More aware that others are ill	2	8.7	0	0.0
Uncertainty of future	1	4.3	0	0.0
Category not used	<u>9</u>	<u>39.1</u>	8	34.8
Total	23	100.0	23	100.0
Othe	<u>r</u>			
	IB	C	R	BC
Social Functioning	2	8.7	2	8.7
Family	1	4.3	2	8.7
Optimism	2	8.7	1	4.3
Insurance concerns	0	0.0	1	4.3
Self Care	0	0.0	1	4.3
Engage in Activities	0	0.0	1	4.3
Category not used	<u>9</u>	<u>39.1</u>	<u>4</u>	60.9
Total	23	100.0	23	100.0

Table 11

Qualitative Analysis of Frequencies Separated by IBC and RBC

for Open-ended Questions

	F	requency	Percent		
What is the Most Significant Way Cancer Impacted Life?					
<u>Health</u>					
		IBC	RBC		
Health is not the same since diagnosis and treatment of cancer	1	4.0	1 4.0		
Fear of recurrence	0	0.0	1 4.0		
Fear of developing Lymphodema	0	0.0	1 4.0		
Never thought would get cancer	0	0.0	1 4.0		
Category not used Total	24 25	96.0 100.0	$\frac{21}{25}$ $\frac{84.0}{100.0}$		
<u>Spirituality</u>					
		IBC	RBC		
Thankful to God Help heal self spiritually	1 1	4.0 4.0	1 4.0 0 0.0		
Engage in prayer more	1	4.0	0 0.0		
Led to believe in God	0	0.0	1 4.0		
Brought closer to God	0	0.0	2 8.0		
Category not used Total	<u>22</u> 25	88.0 100.0	$\frac{21}{25} \frac{84.0}{100.0}$		
Total	23	100.0	25 100.0		
Social Functioning					
		IBC	RBC		
Appreciate friends/family more More involved helping others now Category not used Total	5 2 <u>18</u> 25	20.0 8.0 <u>72.0</u> 100.0	0 0.0 0 0.0 25 100.0 25 100.0		

Table 11 (continued).

	Fre	Frequency		ercent		
<u>Fami</u>	<u>ly</u>					
	I	ВС	RI	BC		
Brought family closer	2	8.0	1	4.0		
Grown closer to husband	0	0.0	1	4.0		
Sad because children are hurting	0	0.0	1	4.0		
Created stress within family	1	4.0	0	0.0		
Concerns about being able to raise						
children	1	4.0	0	0.0		
Category not used	<u>21</u>	84.0	22	88.0		
Total	25	100.0	25	100.0		
Functional W	Vell-being					
	I	ВС	RI	RBC		
Relax More	1	4.0	1	4.0		
Can't do everything used to	0	0.0	2	8.0		
Fatigued	0	0.0	4	16.0		
Treatment side-effects problematic	1	4.0	0	0.0		
In pain	1	4.0	1	4.0		
Employment difficulties	0	0.0	1	4.0		
Category not used	<u>22</u>	88.0	_1	<u>100.0</u>		
Total	25	100.0	25	100.0		
Outlook o	on Life					
	Il	ВС	RI	BC		
Different outlook on life	5	20.0	2	8.0		
Created a positive effect on life	2	8.0	3	12.0		
Realized mortality	0	0.0	1	4.0		
Enjoy life more	4	16.0	2	8.0		
Live in the here and now	2	8.0	1	4.0		
Learn to say, "No"	1	4.0	0	0.0		
More aware that others are ill	1	4.0	1	4.0		
More organized	0	0.0	1	4.0		
Can't forget have cancer	0	0.0	1	4.0		
Don't get as stressed out	3	12.0	0	0.0		
Read more to better life	1	4.0	0	0.0		
Category not used	<u>6</u>	24.0	<u>13</u>	52.0		
Total	25	100.0	25	100.0		

Table 11 (continued).

		Fr	Frequency		ercent	
	<u>Other</u>	IBC		R	RBC	
Body Image		1	4.0	2	8.0	
Insurance concerns		0	0.0	1	4.0	
Financial concerns		1	4.0	0	0.0	
Self care		1	4.0	0	0.0	
Optimism		0	0.0	1	4.0	
Engage in activities		2	8.0	1	4.0	
Employment difficulties		0	0.0	1	4.0	
Category not used		20	80.0	<u>17</u>	80.0	
Total		25	100.0	<del>25</del>	$\overline{100.0}$	

Table 12

Qualitative Analysis of Frequencies Separated by IBC and RBC

for Open-ended Questions

	F	requency	Pe	ercent
Additional Comments	<u>3</u>			
<u>Health</u>		IBC	R	ВС
Fear of recurrence	2	18.2	0	0.0
Fear of developing Lymphodema Category not used	1 <u>8</u>	9.1 72.7	0 <u>17</u>	0.0 <u>100.0</u>
Total	11	$\frac{72.7}{100.0}$	17	100.0
Medical Care/Research Cor	ncerns	<b>S</b>		
		IBC	R	ВС
	1	0.1	0	0.0
Support clinical trials/new medications Doctor is uncaring	1 1	9.1 9.1	$0 \\ 0$	$0.0 \\ 0.0$
Good doctor/psychologist/nurse care	0	0.0	4	23.5
Doctors' need to emphasize entire body,	U	0.0	7	25.5
not just right/left breast	0	0.0	1	5.9
Educate patients about biopsies	1	9.1	0	0.0
More education regarding Lymphodema,				
Tamoxifen, and what to do after treatment	4	36.3	0	0.0
Psychosocial, emotional, spiritual aspect of				
cancer survival is neglected	1	9.1	0	0.0
Need to find a cure	0	0.0	1	5.9
Patient first to know that something is wrong then doctor	0	0.0	1	5.9
Category not used	3	27.3	10	58.0
Total	$\frac{3}{11}$	$\frac{27.5}{100.0}$	$\frac{10}{17}$	$\frac{50.0}{100.0}$

Table 12 (continued).

	Freque	ency Pe	ercent		
<u>Spirituality</u>					
	IBC	R	ВС		
Engage in prayer Faith in God Faith in God helps with coping Prayers of others have helped Category not used Total	2 18 0 0		0.0 41.2 5.9 5.9 47.0 100.0		
Psychological Functioni	ng				
	IBC	R	ВС		
Anger Fear of depending on others Depression More afraid now than ever Need to vent emotions Stress Category not used Total	1 9 1 9. 0 0. 0 0. 0 0. 0 0. 9 81. 11 100.	1 1 0 2 0 2 0 1 0 1 8 9	5.9 5.9 11.7 11.7 5.9 5.9 52.9 100.0		
Functional Well-being					
	IBC	R	ВС		
Can't do everything used to Fatigued Engage in Activities Category not used Total	0 0. 0 0. 0 0. 11 100 11 100	0 3 0 1 .0 12	5.9 17.6 5.9 <u>70.6</u> 100.0		

Table 12 (continued).

		F	requency	Pe	ercent
	Outlook on Life				
Realize mortality Enjoy life more Cancer is a 2 <sup>nd</sup> chance at life Makes you re-evaluate life		1 1 1 0	9.1 9.1 9.1 9.1 0.0	R1 1 1 1	5.9 5.9 5.9 5.9
Category not used Total		<u>8</u> 11	72.7 100.0	13 17	76.4 100.0
	<u>Other</u>				
			IBC	RI	BC .
Body Image		1	9.1	0	0.0
Self care		1	9.1	0	0.0
Optimism		0	0.0	4	23.5
Social Support		1	9.1	4	23.5
Insurance concerns		1	9.1	1	5.9
Financial concerns		0	0.0	1	5.9
Social Functioning		1	9.1	3	17.6
Family		1	9.1	1	5.9
Category not used		5	45.4	3	<u>17.6</u>
<u>Total</u>		11	100.0	17	100.0

APPENDIX B

FIGURES

Figure 1. Quality of life model illustrating the four traditional quality of life domains.

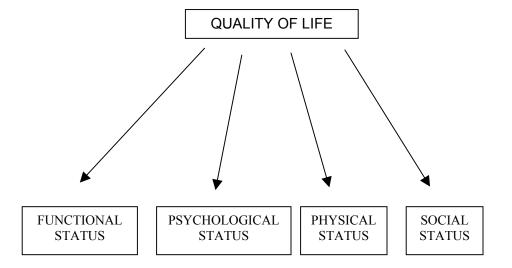
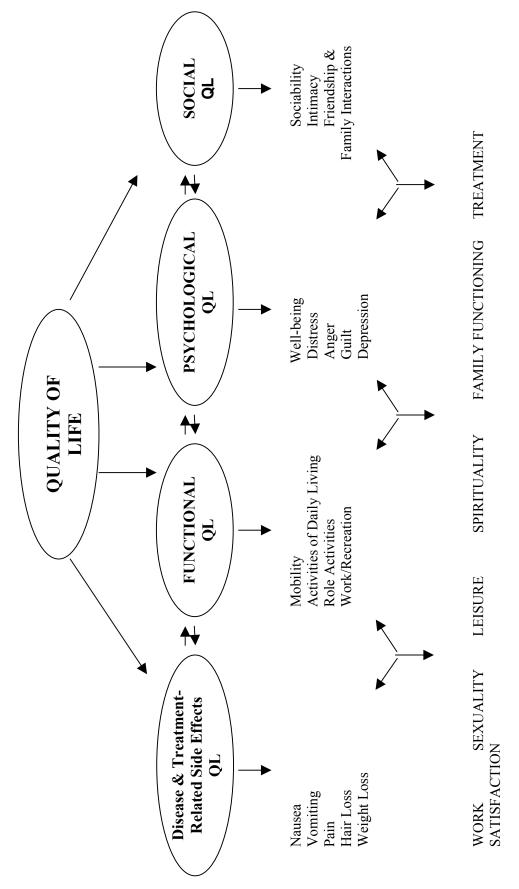
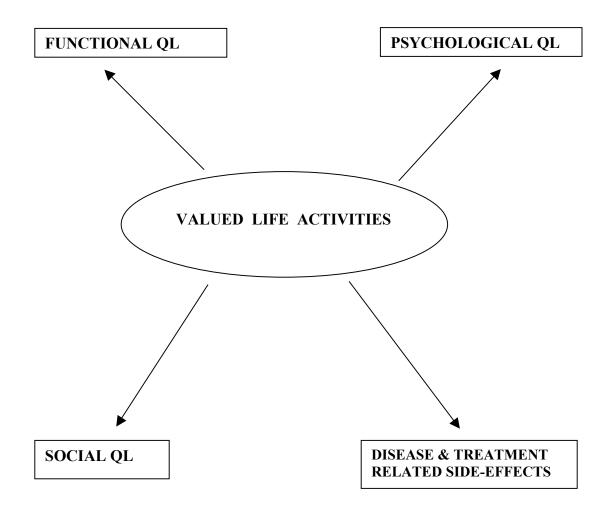


Figure 2. The multidimensional aspects of the quality of life construct.



Adapted from Tchekmedyian, Hickman, SiauGreco, and Aisner (1990).

Figure 3. Theoretical relationship between valued life activities and quality of life.



# APPENDIX C PACKAGE OF INSTRUMENTS

#### INFORMED CONSENT

Dear Patient,

Your doctor has agreed to present you with the opportunity to participate in a study assessing mental and physical factors that affect women with breast cancer. We hope to use this information to better understand the factors that affect the recurrent cancer experience and to provide insight to develop interventions to improve the quality of life for recurrent cancer patients like you. Your participation will involve completing a questionnaire that will take approximately 30 minutes. Participation is voluntary and anonymous. Completion of the questionnaire will be considered your consent to participate. All information will be kept <u>completely confidential</u>. We ask that you do not identify yourself in any way on the questionnaire. When the questionnaire is completed, place it in the enclosed envelope, seal it, and return it to Julia.

You are free to stop participation at any time without penalty. If you chose not to participate or to stop and withdraw from the study, it will not affect you or the services you receive in any way. We hope you will participate, as this information will increase our understanding of factors that influence how women perceive a cancer recurrence. If you desire, we will provide your support group with a summary of findings when completed.

You might experience minimal psychological upset as the content of items in the questionnaire that deal with cancer and health. If you should experience upset from the content of the questionnaire, the researcher, a doctoral student in Clinical Psychology, would like to help and discuss these concerns with you. If you experience any distress as a result of participating in this study or if you would like further information about the study or its results, please contact the researchers, Gina Graci, at (817) 361-9892 or the supervisor, Dr. Charles Guarnaccia, at the University of North Texas Department of Psychology (940) 565-2671. Thank you in advance for your consideration.

Gina M. Graci, M.S.	Charles A. Guarnaccia, Ph.D.
Researcher	Research Supervisor

THIS PROJECT HAS BEEN REVIEWED BY UNIVERSITY OF NORTH TEXAS COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS (Phone: 940-565-3940).

# INFORMED CONSENT (Recurrent Breast Cancer Participants)

Dear Support Group Participant,

Your group has agreed to present you with the opportunity to participate in a study assessing the mental and physical factors that affect women with recurrent breast cancer. We hope to use this information to better understand the factors that affect the recurrent cancer experience and to provide the insight to develop interventions to improve the quality of life for recurrent cancer patients like you. Your participation will involve completing a questionnaire that will take approximately 30 minutes. Participation is voluntary and anonymous. Completion of the questionnaire will be considered your consent to participate. All information will be kept completely confidential. We ask that you do not identify yourself in any way on the questionnaire. When the questionnaire is completed, place it in the enclosed envelope, seal it, and return it to your support group facilitator.

You are free to stop your participation at any time without penalty. If you chose not to participate or to withdraw from the study, it will not affect you or the services you receive in any way. We hope you will participate as this information will increase our understanding of factors that influence how women perceive a cancer recurrence. If you desire, we will provide your support group with a summary of findings when completed.

You might experience minimal psychological upset as the content of items in the questionnaire that deal with cancer and health. If you should experience upset from the content of the questionnaire, the researcher, a doctoral student in Clinical Psychology, would like to help and discuss these concerns with you. If you experience any distress as a result of participating in this study or if you would like further information about the study or its results, please contact the researchers, Gina Graci at (817) 361-9892 or the supervisor, Dr. Charles Guarnaccia at the University of North Texas Department of Psychology (940) 565-2671. Thank you in advance for your consideration.

Gina M. Graci, M.S.	Charles A. Guarnaccia, Ph.D.
Researcher	Research Supervisor

THIS PROJECT HAS BEEN REVIEWED BY UNIVERSITY OF NORTH TEXAS COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS (Phone: 940-565-3940).

# INFORMED CONSENT (Initial Breast Cancer Participants)

Dear Support Group Participant,

Your group has agreed to present you with the opportunity to participate in a study assessing the mental and physical factors that affect women with breast cancer. We hope to use this information to better understand the factors that affect the cancer experience and to provide the insight to develop interventions to improve the quality of life for cancer patients like you. Your participation will involve completing a questionnaire that will take approximately 30 minutes. Participation is voluntary and anonymous. Completion of the questionnaire will be considered your consent to participate. All information will be kept <u>completely confidential</u>. We ask that you do not identify yourself in any way on the questionnaire. When the questionnaire is completed, place it in the enclosed envelope, seal it, and return it to your support group facilitator.

You are free to stop your participation at any time without penalty. If you chose not to participate or to withdraw from the study, it will not affect you or the services you receive in any way. We hope you will participate as this information will increase our understanding of factors that influence how women perceive cancer. If you desire, we will provide your support group with a summary of findings when completed.

You might experience minimal psychological upset as the content of items in the questionnaire that deal with cancer and health. If you should experience upset from the content of the questionnaire, the researcher, a doctoral student in Clinical Psychology, would like to help and discuss these concerns with you. If you experience any distress as a result of participating in this study or if you would like further information about the study or its results, please contact the researchers, Gina Graci at (817) 361-9892 or the supervisor, Dr. Charles Guarnaccia at the University of North Texas Department of Psychology (940) 565-2671. Thank you in advance for your consideration.

Gina M. Graci, M.S.	Charles A. Guarnaccia, Ph.D.
Researcher	Research Supervisor

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## **DEMOGRAPHIC SURVEY**

Please answer these questions regarding your personal history as well as some medical information. Do not write your name on this form or identify yourself in any way. Your age: \_\_\_\_\_ Stage of Cancer (Stage I, II, III, IV) Please check the one that applies to you in each item: 1. Marital Status: Married \_\_\_\_\_ Separated/Divorced \_\_\_\_\_ Widowed \_\_\_\_ Single (never married) \_\_\_\_\_ Relationship To You Of Those In Your Household? Relationship Relationship Relationship Age Age Age Relationship Relationship Relationship Age Age Age Relationship Relationship Relationship Age Age Age 2. Your Ethnicity: White \_\_\_\_\_ African American \_\_\_\_\_ Hispanic \_\_\_\_\_ Asian American \_\_\_\_\_ Other \_\_\_\_ 3. Spouse/Partner's Ethnicity: White \_\_\_\_\_ African American \_\_\_\_\_ Hispanic \_\_\_\_\_ Asian American \_\_\_\_\_ Other \_\_\_\_ 4. Your Education: Eighth Grade \_\_\_\_\_ High School Diploma \_\_\_\_\_ Trade School \_\_\_\_ Some College \_\_\_\_ College Degree \_\_\_\_Some Graduate/Professional School \_\_\_\_Graduate/Professional Degree 5. Spouse/Partner's Education: Eighth Grade High School Diploma Trade School Some College College Degree \_\_\_\_Some Graduate/Professional School \_\_\_\_Graduate/Professional Degree\_\_\_\_ 6. Employment: Currently Employed Full-Time Currently Employed Part-Time \_\_\_\_\_ Currently Not Working Due To Illness Currently Not employed outside of the home \_\_\_\_ If Currently Not Employed, Is This Due To Illness? Yes\_\_\_\_\_ No\_\_\_\_ When Did You Stop Working? Current/Past Employment Retired \_\_\_\_\_ When?

7. <u>Spouse</u>	<u>/Partner's:</u>
Curre	ent/Past Employment
Retir	red When?
8. Medica	al Information:
Numb	ber of Cancer Diagnoses
I.	Date of First Diagnosis
	Type of Cancer (First Diagnosis)
Treatm	nent Received For First Diagnosis (Check All That Apply)
	Surgery
	Chemotherapy
	Radiation Therapy
	Bone Marrow Transplant
	Other (Please Specify)
	How Long Did Treatment Last?
II.	Date of Second Diagnosis
	Type of Cancer (For Second Diagnosis)
	Treatment Received For Second Diagnosis (Check All That Apply)
	Surgery
	Chemotherapy
	Radiation Therapy
	Bone Marrow Transplant
	Other (Please Specify)
	How Long Did Treatment Last?
	Is this treatment still on-going? YesNo
III.	Any Additional Diagnosis? Yes No
	Type
	Treatment Received
8. How Ha	as Your Cancer Impacted Your Life?
0 1371 47	The Mark Charles and War Constant Language 1 V 1 C 0
9. What Is	The Most Significant Way Cancer Has Impacted Your Life?

# M-FLIC

Please ans	swer all the following questions by circling the number that best represents your
response.	Remember there are no right or wrong answers.

respon	se. Remember the	ere are i	no right	or wron	ng answ	ers.	
1.	Most people expe often you feel the			elings o	of depre	ession at	times. Rate how
	1 Never	2	3	4	5		7 Il The Time
2.	How well are you	ı copinş	g with y	our eve	ryday s	tress?	
	1 Very Poorly	2	3	4	5		7 y Well
3.	How much time	do you	spend th	ninking	about y	our illne	ess?
	1 Never	2	3	4	5	6 Cons	7 tantly
4.	Rate your ability	to mair	ntain yo	ur usual	recreat	tion or l	eisure activities.
	1 Not Able At All	2	3	4	5	6 Very	7 Able
5.	Has nausea affec	ted you	r daily f	function	ing?		
	1 Not At All	2	3	4	5	6 A Gre	7 eat Deal
6.	How well do you	usually	feel?				
	1 Extremely Bac	2	3	4	5	6 Extren	7 nely Well
7.	How often do you chores?	u feel w	ell eno	ugh to n	nake a r	meal or	do minor household
	1	2	3	4	5	6	7

All The Time

Never

8.	Rate the degree to which your cancer has imposed a hardship on those closest to you.									
	1 No Hardship At All	2	3	4	5	6 7 Tremendous Hardship				
9.	Rate how often you feel discouraged about your life.									
	1 Never	2	3	4	5	6 7 Always				
10.	Rate your satisfacting diagnosis.	ction wi	th your	jobs an	d work	around the house since the				
	1 Very Dissatisfie	2 ed	3	4	5	6 7 Very Satisfied				
11.	How uncomfortal	ole do y	ou usua	ılly feel	?					
	1 Very Uncomfortable	2 e	3	4	5	6 7 Very Comfortable				
12.	Rate in your opin closest to you since				ur canc	er has been to those				
	1 Not Disruptiv At All	2 re	3	4	5	6 7 Totally Disruptive				
13. H	ow much is pain or	discon	nfort int	erfering	g with y	our daily activities?				
	1 Not At All	2	3	4	5	6 7 A Great Deal				
	ate the degree to whe diagnosis.	hich yo	ur canc	er has ir	nposed	a hardship on you (personally)				
	1 No Hardship At All	2	3	4	5	6 7 Tremendous Hardship				

15.	How much of your usual household tasks are you able to complete?										
	1 None	2	3	4	5	6 7 All					
16.	Rate how willing you are to see and spend time with those closest to you?										
	l Very Unwilling	2	3	4	5	6 7 Very Willing					
17.	How much nausea	did you l	have (or	do you	have) du	uring chemotherapy?					
	1 None	2	3	4	5	6 7 A Great Deal					
18.	Rate the degree to	which yo	ou are fri	ghtened	of the f	uture.					
	1 Not Afraid At All	2	3	4	5	6 7 Constantly Afraid					
19.	Rate how willing u	sually yo	ou are to	see and	spend ti	ime with friends.					
	1 Very Unwilling	2	3	4	5	6 7 Very Willing					
20.	How much of your related to your cand		discomfo	ort you h	nave had	since the diagnosis is					
	1 None	2	3	4	5	6 7 All					
21.	Rate your confiden	ce in you	ur prescr	ribed cou	arse of ta	reatment.					
	1 Not Confident At All	2	3	4	5	6 7 Very Confident					
22.	How well do you u	sually ap	pear?								
	1 Extremely Bad	2	3	4	5	6 7 Extremely Well					

#### LOT-R

For the next set of questions, please try to be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your **own** feelings, rather than how you think "most people" would answer.

- 1. In uncertain times, I usually expect the best.
  - 0 I agree a lot
  - 1 I agree a little
  - 2 I neither agree nor disagree
  - 3 I DISagree a little
  - 4 I DISagree a lot
- 2. It's easy for me to relax.
  - 0 I agree a lot
  - 1 I agree a little
  - 2 I neither agree nor disagree
  - 3 I DISagree a little
  - 4 I DISagree a lot
- 3. If something can go wrong for me, it will.
  - 0 I agree a lot
  - 1 I agree a little
  - 2 I neither agree nor disagree
  - 3 I DISagree a little
  - 4 I DISagree a lot
- 4. I always look on the bright side of things.
  - 0 I agree a lot
  - 1 I agree a little
  - 2 I neither agree nor disagree
  - 3 I DISagree a little
  - 4 I DISagree a lot

5	I'm alv	vays optimistic about my future.
	0 1 2 3 4	I agree a lot I agree a little I neither agree nor disagree I DISagree a little I DISagree a lot
6	. I enjoy	my friends a lot.
	0 1 2 3 4	I agree a lot I agree a little I neither agree nor disagree I DISagree a little I DISagree a lot
7	'. It's imp	portant for me to keep busy.
	0 1 2 3 4	I agree a lot I agree a little I neither agree nor disagree I DISagree a little I DISagree a lot
8	. I hardly	y ever expect things to go my way.
	0 1 2 3 4	I agree a lot I agree a little I neither agree nor disagree I DISagree a little I DISagree a lot
9	. Things	never work out the way I want them to.
	0 1 2 3 4	I agree a lot I agree a little I neither agree nor disagree I DISagree a little I DISagree a lot

10.	I don't get upset too easily.
	<ul> <li>I agree a lot</li> <li>I agree a little</li> <li>I neither agree nor disagree</li> <li>I DISagree a little</li> <li>I DISagree a lot</li> </ul>
11.	I'm a believer in the idea that "every cloud has a silver lining."
	<ul> <li>I agree a lot</li> <li>I agree a little</li> <li>I neither agree nor disagree</li> <li>I DISagree a little</li> <li>I DISagree a lot</li> </ul>
12.	I rarely count on good things happening to me.
	<ul> <li>I agree a lot</li> <li>I agree a little</li> <li>I neither agree nor disagree</li> <li>I DISagree a little</li> <li>I DISagree a lot</li> </ul>
13.	Overall, I expect more good things to happen to me than bad.
	<ul> <li>I agree a lot</li> <li>I agree a little</li> <li>I neither agree nor disagree</li> <li>I DISagree a little</li> <li>I DISagree a lot</li> </ul>

## MHLC-C

Each item blow is a belief statement about **your medical condition**, with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you agree or disagree with each statement. The more you agree with a statement, then the higher will the number you circle. The more you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer EVERY ITEM and that you circle ONLY ONE number per item. This is a measure of your personal beliefs; obviously, there are no right or wrong answers.

2 =	STRONGLY DISAGREE (SD) MODERATELY DISAGREE (MD) SLIGHTLY DISAGREE (D)	4 = SLIGHTLY AGREE (A) 5 = MODERATELY AGREE 6 = STRONGLY AGREE (SA						
			SD	MD	D	A	MA	SA
1.	If my cancer worsens, it is my own behavior which determines how soon I feel better again.		1	2	3	4	5	6
2.	As to my cancer, what will be will be.		1	2	3	4	5	6
3.	If I see my doctor regularly, I am less likely to have problems with my cancer.		1	2	3	4	5	6
4.	Most things that affect my cancer happen to me by chance	e.	1	2	3	4	5	6
5.	Whenever my cancer worsens, I should consult a medically trained professional.		1	2	3	4	5	6
6.	I am directly responsible for my cancer getting bette or worse.	er	1	2	3	4	5	6
7.	Other people play a big role in whether my cancer improves, stays the same, or gets worse.		1	2	3	4	5	6
8.	Whatever goes wrong with my cancer is my own fau	ılt.	1	2	3	4	5	6
9.	Luck plays a big part in determining how my cancer improves.		1	2	3	4	5	6
10.	In order for my cancer to improve, it is up to other people to see that the right things happen.		1	2	3	4	5	6

11. Whatever improvement occurs with my cancer is largely a matter of good fortune.	1	2	3	4	5	6
12. The main thing which affects my cancer is what I myself do.	1	2	3	4	5	6
13. I deserve the credit when my cancer improves and the blame when it gets worse.	1	2	3	4	5	6
14. Following doctor's orders to the letter is the best way to to keep my cancer from getting any worse.	1	2	3	4	5	6
15. If my cancer worsens, it's a matter of fate.	1	2	3	4	5	6
16. If I am lucky, my cancer will get better.	1	2	3	4	5	6
17. If my cancer takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18. The type of help I receive from other people determines how soon my cancer improves.	1	2	3	4	5	6

# QUALITATIVE QUESTIONNAIRE

Thank you for taking the time to complete this questionnaire. We would like to hear any
comments you may have. Please address any concerns on the space provided. Again, thank you
for your participation.

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