

ILLNESS MEANINGS AND PERCEPTIONS OF
CONTROL AND UNCERTAINTY IN WOMEN
WITH BREAST CANCER

CENTRE FOR NEWFOUNDLAND STUDIES

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Illness Meanings and Perceptions of
Control and Uncertainty in Women
with Breast Cancer
by

Pamela Margaret Faulkner Baker

A thesis submitted to the School of Graduate Studies in
partial fulfillment of the requirements for the degree of
Master of Nursing

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ABSTRACT

Illness Meanings and Perceptions of Control and Uncertainty in Women with Breast Cancer

A descriptive correlational study with longitudinal and cross-sectional components was conducted to (a) describe the factors shaping meanings of breast cancer, and how meanings changed during treatment, and (b) investigate relationships among illness meanings, perceptions of control, uncertainty, feelings about the illness, and attitudes toward chemotherapy. Fifteen women were included in the longitudinal portion of the study and nine in the cross-sectional component. The Multidimensional Health Locus of Control (MHLC) Scales, Meaning of Illness Questionnaire Self-Report (MIQ-SR), Personal Profile Record and the Cancer Meaning Questionnaire (CMQ) were the data collection instruments. Descriptive and inferential statistics were used for data analysis. Qualitative data were analyzed using the Constant Comparative Method of Analysis.

Appraisals of the illness and treatment varied from initial treatment to follow-up and were influenced by perceptions of control, feelings about the illness, uncertainty and attitudes toward chemotherapy. Results from repeated measures ANOVA analyses indicated significant changes in Chance Health Locus of Control (χ^2 7.65, $p < .02$) and attitudes toward chemotherapy (χ^2 6.61, $p < .03$). Step-

wise multiple regression analysis indicated that internal locus of control beliefs and feelings about the illness and chemotherapy treatment were significant predictors of illness meanings. Attitudes toward chemotherapy were significant predictors of illness meaning over time. Qualitative data analyses supported findings from the Meaning of Illness factors as measured by the MIQ-SR Questionnaire. Results also suggest that nurses are perceived as primary sources of information and support.

Key Words: breast cancer; meaning of illness; control; uncertainty; primary appraisal; secondary appraisal; coping; feelings/attitudes.

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CHAPTER 1

INTRODUCTION AND PURPOSE OF THE STUDY

It has been estimated that approximately one in nine women will develop breast cancer. Although curable, particularly when detected early, breast cancer kills nearly 5000 Canadian women a year. In women aged 35 to 55 it is the leading cause of death (Canadian Cancer Statistics, 1993).

The impact of a breast cancer diagnosis and its subsequent treatment is a major turning point in a woman's life. The high prevalence of breast cancer in young and middle-aged women, the challenging effects of coping with such an unpredictable illness, and the long term effects on both the woman and her family suggest that this is an especially important area for nursing research.

Meanings associated with illness are shaped by the nature of the disease, the people involved and the sociocultural context. Illness meanings, whether obvious to or concealed from the self and others, can amplify or diminish symptoms, exaggerate or lessen disability and impede or facilitate treatment (Mages & Mendelsohn, 1979; Way, 1990). One purpose of this study was to describe the factors shaping meanings of breast cancer, and how meanings changed during treatment. A second purpose was to investigate relationships among illness meanings,

perceptions of control, uncertainty, feelings about the illness and attitudes toward chemotherapy.

Background and Rationale

Meanings assigned to illness and treatment protocols impact an individual's ability to understand, accept and cope (Cohen & Lazarus, 1979; Lazarus & Folkman, 1984; Lipowski, 1970; Mages & Mendelsohn, 1979). Few diseases seem so burdened with problematic meanings as cancer (Sontag, 1978). The word "cancer" may conjure up images of certain death, prolonged pain and suffering, helplessness, social stigma, disfigurement, disability, or isolation (Dodd, Chen, Lindsey & Piper, 1985).

Lazarus and Folkman (1984) believe that cognitive appraisal or meaning given to illness is shaped by how an individual responds to stressful events. It is "the process of categorizing an encounter, and its various facets, with respect to its significance for well-being" (p. 31). Initial responses to a cancer diagnosis range from depression to shock, anger to guilt, anxiety to disbelief, and self-pity to bitterness (Friedman, 1980). Patients with cancer have also reported feeling helpless, worried about the future, and fearful of the diagnosis and treatment (Frank-Stromborg, 1989; Frank-Stromborg, Wright, Segalla & Dickman, 1984; Jarrett, Ramirer, Richards & Weinman, 1992; Krause, 1993; Milton, 1973; Northouse, 1989; Suominen,

1992).

The person with cancer is not confronted with a single stressful event, but rather a series of threats of varying intensity and duration. Exposure to unfamiliar events, inadequate or unclear explanations concerning chemotherapy, and difficulty differentiating treatment side effects from the original illness may enhance uncertainty and raise concerns about illness outcomes (Mishel, 1990). The greater the feelings of uncertainty about the illness, the more stress experienced by the individual. Even in remission patients must learn to cope with uncertainty and the painful residues of treatment (Mages & Mendelsohn, 1979). Fear is evoked by the possibility of recurrence and an unmanageable illness (Hilton, 1989).

While working on oncology units this researcher observed that patients often experienced increased difficulty as treatment progressed. Feelings of uncertainty and perceived threats to survival were captured in such phrases as "I'm just living moment to moment"; "You're scared its going to happen again"; "You have no concept about how this [breast cancer] is going to affect you and how things are going to impact you day to day" or "There are so many see-saws". Uncertainty about illness outcomes increases stress and fears about losing control over life situations (Lazarus & Folkman, 1984).

Perceptions of an event may be altered by the way people manage or try to influence it. Perceived or actual control over events may help patients interpret their situation as less threatening and, therefore, less stressful (Dennis, 1990). Conversely, feelings of not having control may increase the stress associated with unpleasant events. Averill (1973) points out that "stress-inducing or stress-reducing properties of personal control depend upon the meaning of the control response for the individual" (p. 301). Beliefs about control concern the extent to which a person believes that outcomes can be controlled (Hilton, 1989). Control may be desired by some people but not by others (Krantz, Baum & Wideman, 1980). If outcomes are perceived to be under the control of others (e.g. physicians, nurses), internally controlled individuals may lose hope and experience more stress and adjustment problems than those who desire less personal control.

Lazarus and Folkman (1990; 1987; 1984) suggest that personal factors (e.g. values, commitments, goals, and general beliefs such as self-esteem, mastery, sense of control, interpersonal trust and existential beliefs) and social-cultural environmental factors (e.g. demands, resources, constraints) influence appraisals of meaning. Regardless of whether primary appraisal of an illness or treatment results in a perception of harm or benefit, it is

the personal/environmental interaction that generates the feeling that action is possible. Subsequent to the realization that action is needed, there is mobilization to assess resources available for coping. The significance of an illness for the person experiencing it must be considered if health care professionals are to act as facilitators in the coping process.

Problem Statement

There are major gaps in the literature on meanings assigned to the cancer experience and treatment. There is a preponderance of conjecture and anecdotal writing on the subject, but limited scientific research. Cross-sectional studies have focused on perceptions of a cancer diagnosis but none investigated changes in meaning over time or how beliefs about control, feelings about the illness and attitudes toward treatment influence appraised meanings.

Within an illness experience the meaning and effectiveness of a particular intervention may be determined by the situational context (Krantz, Baum & Wideman, 1980). Dennis (1990) purports that nurses play a central role in identifying how patients search for control and in individualizing care to support control-related behaviors. If nurses are to help patients with breast cancer adapt to illness and treatment, it is necessary to understand first what meaning the cancer experience and its treatment have

for them, what perceptions influence these meanings, and how these meanings vary during treatment and follow-up. We cannot assume that all patients interpret and understand illness and treatment modalities within the same "meaning" framework (Kleinman, Eisenberg & Good, 1978; Lazarus & Folkman, 1984; Lipowski, 1970; Way, 1990). Understanding the meaning and significance of breast cancer and its treatment is an important prerequisite for effective care.

Research Questions and Hypothesis

This study addressed the following three research questions:

- (1) What are the key factors shaping meanings of illness and treatment for women experiencing breast cancer for the first time?
- (2) How do meanings change as the illness progresses from diagnosis through treatment?
- (3) How do beliefs about control, feelings about the illness, and attitudes toward chemotherapy affect meanings given to illness and treatment?

The quantitative portion of the study was designed to test the following hypothesis: As the side effects of treatment become more pronounced negative feelings about the illness and attitudes toward treatment increase, external locus of control beliefs predominate, and negative or unfavourable meanings of illness occur more frequently than

positive or favourable ones.

CHAPTER 2

LITERATURE REVIEW

An extensive literature search identified a limited number of longitudinal and qualitative studies that investigated changes in meaning appraisals of women with breast cancer during treatment. Most studies used a structured approach and cross-sectional design to investigate perceptions, attitudes, control and uncertainty with cancer patients.

The literature review highlights findings and conclusions from studies that have relevance for conceptualization of the problem. The review is divided into illness meaning, in relation to cancer in general and breast cancer in particular. Reference is also made to studies that considered the impact of treatment upon illness meanings and coping.

Illness Meaning

Meaning encompasses the concepts of feelings, emotions, beliefs, values and attitudes (Kleinman, 1988; Kleinman, et al., 1978; Lipowski, 1970; Mages, & Mendelsohn, 1979; Way, 1990). Meanings vary with the nature of the illness, the context in which it occurs, the person experiencing it, and the time interval between the illness episode and later reflections upon it (Way, 1990; Lazarus & Folkman, 1987). Support networks, feelings about the illness, attitudes

towards treatment, uncertainty, desire for personal control, self-concept, level of physical functioning, and access to sufficient information to make informed decisions are important factors impacting a person's ability to cope with and adjust to a long-term illness.

Cancer in General

Impact of the illness. In a retrospective study of 340 ambulatory patients with cancer, Frank-Stromborg, Wright, Segalla and Diekmann (1984) found that the majority held negative attitudes (i.e. fear, shock, disbelief, anger, depression, helplessness) toward cancer. Despite the prevalence of negative attitudes, twenty-seven percent of the responses were positive as reflected in the following themes: (a) I accepted it and/or decided to make the best of it, (b) I wanted to get on with the treatment, (c) I decided to beat/conquer the cancer, and (d) I was not worried or upset.

Krause (1993, 1987) used a qualitative approach to investigate feelings, problems and coping mechanisms of 125 Finnish women with cancer, of whom 35 percent had breast cancer. Problems identified by these women included fears and uncertainty about recurrence, interference with activities of daily living, and prolonged follow-up and rehabilitation. Approximately two-thirds of the verbal descriptions conveyed shock reactions. Suominen (1992) also

reported initial reactions of surprise and shock to a breast cancer diagnosis.

The Attitudes about Cancer and its Treatment Questionnaire (ACTQ), a semistructured interview schedule, was designed to investigate the meaning of cancer and treatment for patients in Taiwan, Egypt, and Switzerland. Taiwanese and Egyptian subjects perceived their illness as serious, hopeless and life-threatening (Dodd, Chen, Lindsey & Piper, 1985; Dodd, Ahmed, Lindsey & Piper, 1985). The Swiss subjects differentiated illness meanings into personal and relationship effects. Uncertainty, loss and fear of dying were major personal themes. Some perceived that relationships with significant others had improved, whereas others felt that relationships were more strained (Kesselring, Dodd, Lindsey & Strauss, 1986).

Arpin, Fitch, Browne & Corey (1990) investigated the influence of meaning of illness, as measured by the Meaning of Illness Questionnaire (MIQ), family functioning and type or severity of illness on long term adjustment in chronically ill patients with either cancer, or rheumatology, or gastrointestinal diseases. Meaning variables (illness viewed as harm, threat and loss; poor functional status; and negative impact of illness on daily living, relationships with friends and family, and work) and poor family functioning explained "47% of the variance in a

person's poor adjustment to chronic illness" (p.380). A second study investigating these variables with a comparable population produced similar results (Weir, Browne, Tunks, Gafni and Roberts, 1992).

High levels of uncertainty have been associated with low optimism and difficulty in psychosocial adjustment. The Mishel Uncertainty in Illness Scale (MUIS) was used to examine uncertainty in fifty-four women diagnosed with gynecological cancer. The Beck Hopelessness Scale and the Psychosocial Adjustment to Illness Scale were used to measure optimism and adjustment. Greater uncertainty was related to increased sadness, negative expectations about the future, less motivation, more psychosocial adjustment problems, and less confidence in physicians and the health care system. When family relations were seen as strained and members unsupportive, psychological distress was greater and the desire to participate in social activities less (Mishel, Hostetter, King & Graham, 1984).

The effects of uncertainty on personal control or mastery was investigated in a sample of 131 women with gynecological cancer. Uncertainty and mastery was assessed by the MUIS and Pearlin and Schooler Mastery Scale, respectively. Uncertainty explained 20% of the variance in mastery. The greater the uncertainty, the less the perceived adequacy of personal resources to manage the

situation (Mishel & Sorenson 1991).

Wallston and Wallston (1982) reviewed the literature on generalized locus of control beliefs in patients with chronic conditions including cancer. Beliefs in external locus of control (chance and powerful others) over one's health were high, whereas beliefs in internal locus of control were similar to those of healthy adults. Worthman and Dunkel-Schetter (1979) noted that internal beliefs may be maladaptive for cancer patients if their condition is incurable. Because patients with cancer are often dependent on health professionals or other people (family, friends, powerful others), external health locus of control beliefs are probably adaptive in these situations. It is important to take into account actual situational potential for control, and the patient's perceptions and expectancies regarding control.

Psychological adjustment to chronic illness was investigated in a longitudinal study by Felton and Revenson (1984). The study distinguished between illnesses with limited control (rheumatoid arthritis and cancer) and those more responsive to individual and medical efforts at control (hypertension and diabetes). Information seeking as a coping strategy had favourable effects on adjustment, but wish-fulfilling fantasy had deleterious consequences. Contrary to expectations, ability to control the illness did

not play a significant role.

Impact of treatment. Confrontation with one's mortality and the unpredictability of the future may leave permanent scars (Mages & Mendelsohn, 1979). Besides the impact of the illness upon the individual, there is also the impact of treatment. The adverse effects of treatment on physical and psychological functioning may be so intense that it supplants the effects of the illness itself. In fact, coping with the effects of treatment may be more of a challenge initially than coping with the illness.

Self-report ratings of sixty-one patients receiving chemotherapy for malignant melanoma indicated higher coping efforts for the current than the first treatment (Nerenz, Leventhal & Love, 1982). The findings also suggested that the number of side effects, as opposed to duration or severity of effects, was positively correlated with the degree of emotional distress experienced.

Christman (1990) examined psychosocial adjustment in a sample of fifty-five patients following the first, fifteenth and final radiotherapy treatment. Uncertainty seemed to increase after the fifteenth treatment and was correlated with greater adjustment difficulties. The findings support Mishel's et al. (1984) assumption that uncertainty influences the stressful nature of illness. Less hope was consistently associated with poor adjustment. Control

preferences were not significantly related to uncertainty, hope or adjustment.

Individuals with cancer experience mood, outlook and function fluctuations during, immediately following and six to twelve months after treatment. Ambivalent feelings often characterized subjects' reaction to cancer treatment (Mages & Mendolsohn, 1979). Similar findings were reported by Todres and Wojtiuk (1974) and Love, Leventhal, Easterling and Nerenz (1989). Difficulty holding a job and working in the home, poor family relationships, moodiness, and diminished physical strength and overall health were identified as major consequences of the negative effects of chemotherapy.

Beliefs about the effectiveness of treatment for cancer often vary within study samples as well as across sample groupings. Some individuals with cancer may be very hopeful, place high trust in physicians and believe that the treatment will provide moderate symptom relief (Dodd, Chen, Lindsey & Piper, 1985). Others are divided on whether cancer treatment will be beneficial (hopeful for cure or remission) or ineffective (deteriorating health, long-term stress, discomfort and suffering) in altering the disease process (Dodd, Ahmed, Lindsey & Piper, 1985; Kesselring et al., 1986).

While chemotherapy is often associated with negative

side effects, it may still be perceived as effective in combating or retarding the progress of cancer. Despite the stress of cancer, interpersonal difficulties and medical problems, many patients emerge from diagnosis and treatment with positive attitudes. Patients often report a greater appreciation of life, more positive attitudes toward living, and increased self-esteem (Frank-Stromborg & Wright, 1984; Frank-Stromborg, Wright, Segalla, & Diekmann, 1984; Lanham & DiGiannantonio, 1988; Longman & Young-Graham, 1986).

Breast Cancer

Impact of the illness. Exposure to an illness, like breast cancer, generates high levels of stress and impedes coping. The uncertainty associated with treatment efficacy is compounded by the emotional distress and psychological trauma of losing a breast. Body image, self-esteem, sexuality, uncertainty, perceptions of control, and self-attribution have been identified as significant themes in studies of women with breast cancer.

Breast cancer is more than the stress of having cancer and dealing with the adverse effects of treatment. Women with breast cancer must strive to achieve a sense of wholeness. The first task is to accept the illness, and then accept the loss of a breast.

Using a phenomenological approach Hilton, (1988) explored uncertainty for sixteen women diagnosed with breast

cancer. Uncertainty was experienced in terms of an unpredictable future, not feeling safe and secure, doubt and indecision, and not being able to rely or count on someone or something. Uncertainty was influenced by beliefs, characteristics of the cancer and personal situations. Minimizing, avoiding and denying behaviours were used to neutralize the impact of cancer by controlling the meaning of the problem. Perceptions of control by others such as doctors, therapies and faith in God, and self-control such as one's actions and attitudes were evaluated positively.

Lovey's and Klaich (1991) explored the experience of illness demands with seventy-nine women newly diagnosed with breast cancer. Forty-eight women reported uncertainty regarding test results, recurrence, the adequacy of information needed to make choices, and the future.

Feather & Wainstock (1989) examined the relationships among social support, attitudes toward mastectomy (Mastectomy Attitude Scale) and self-esteem in 456 women one year post-mastectomy. The findings suggested that women's attitudes toward the mastectomy experience were more strongly related to self-esteem than to either social support, age, education, marital status, or adjuvant chemotherapy. The greatest variation in attitudes was accounted for by sexuality issues, emotions, and satisfaction with appearance. The authors concluded that

although these women had a positive outlook and were fairly satisfied with their bodies, they did not display positive emotions or positive attitudes towards sexuality.

One hundred and forty-five women who had a modified radical mastectomy for stage I or II breast cancer showed greater psychological distress with social and interpersonal relationships than 90 women who had a cholecystectomy for gall bladder disease, 87 women with a negative biopsy for breast cancer, and 90 healthy women. Women with stage II breast cancer evidenced more distress, negative attitudes toward self and the future, concern with physical symptoms, anxiety, strain and interpersonal difficulties than other groups, but were comparable on psychopathological symptoms severe enough to warrant psychiatric intervention (Bloom et al., 1987).

Hilton (1989) investigated the relationships among commitments, uncertainty about the cancer situation, threat of recurrence, control of the cancer and coping strategies in 227 women with a breast cancer diagnosis. Uncertainty was positively related to threat and negatively related to control over the disease. Women who had low commitment, high uncertainty, high threat of recurrence, and low sense of control of their cancer did not use positive reappraisal or accept responsibility for their situation, and depended upon the coping strategy of escape-avoidance. Women who had

a high threat of recurrence but a high sense of control over their cancer used strategies of seeking social support, planful problem solving, escape-avoidance, positive reappraisal and self-control.

Locus of control beliefs have also been used as a framework for understanding health-related behaviour (Lewis, 1982; Taylor, Lichtman & Wood, 1984; Thompson, 1981; Wallston & Wallston, 1981; 1982; Wallston, Wallston & DeVellis, 1978; Watson et al., 1990). Watson, Greer, Pruyn and Van Den Borne (1990) defined locus of control as the assignment of cause to specific events in terms of personal (internal control) or situational (external control) elements. Sixty-eight patients receiving radiotherapy for breast cancer completed the Cancer Locus of Control Scale, the Mental Adjustment to Cancer Scale, the Hospital Anxiety and Depression Scale, and the Courtauld Emotional Control Scale. High internal control over the course of the illness, such as managing side effects, was associated with a tendency to adopt a 'fighting spirit', whereas, self-blame for the cause of illness was associated with anxiety and stress (Watson et al., 1990).

Taylor, Lichtman, and Wood (1984) examined the relationship between beliefs about control and adjustment in 78 women with breast cancer. Subjects completed the Rotter Internal/External Locus of Control Scale, the Wallston,

Wallston and DeVellis Multivariate Health Locus of Control Scale, the Profile of Mood States (POMS), the Rosenberg Self-Esteem Scale, the Campbell, Converse and Rogers Index of Well-Being, and the Locke-Wallace Scale of Marital Adjustment. Qualitative data on beliefs about control, sexual functioning, religious affiliation, and marital, family, and social relationships were also collected. Beliefs about internal control and external control (e.g. powerful others) over cancer were significantly associated with good adjustment. Whether responsibility for the occurrence of cancer was attributed to the self, environment, another person, or chance, a negative relation resulted between adjustment and attribution of cause.

Penman et al. (1987) measured self-concept and social function in a sample of 1,715 women following radical, modified radical, or simple mastectomy for stage I or II breast cancer, biopsy for benign breast disease, or cholecystectomy. Locus of control (Levenson Locus of Control Scale) emerged as a significant predictor of self-esteem (Rosenberg Self-Esteem Scale) for women across all groups. The more illness outcomes were seen to be contingent upon the actions of powerful others, the lower the self-esteem and body image (Berscheid Body Image Scale), and the greater the intimacy concerns (Intimacy Scale of the Schain Personal Problem List). When chance played a key

role in life events, poorer social health (low supports and less social activity, and more dysfunctional family interactions) resulted.

Burgess, Morris and Pettingale (1988) investigated cognitive responses to a cancer diagnosis in a sample of 178 newly diagnosed patients with breast cancer, or non-Hodgkin's or Hodgkin's Lymphoma. Responses were examined in relation to anxiety, depression, health locus of control, and clinico-pathological variables. Patients completed standard psychological tests, including the Wakefield Self Assessment Depression Inventory, Trait Measure of The Spielberger State-Trait Anxiety Inventory and the Multidimensional Health Locus of Control Scale. High internal locus of control was associated with lower psychological morbidity and a positive/confronting response to the diagnosis. Subjects who viewed the diagnosis with disbelief had diminished expectations of life, made attributions involving blame, and had significantly lower scores on the 'powerful other' scale.

Impact of treatment. Fallowfield & Clarke (1991) interviewed 269 women with a diagnosis of breast cancer in the post-operative period. Most subjects identified 'fear of cancer' as their worst concern whether they had a mastectomy or the more conservative treatment of lumpectomy.

The relationships between hopelessness and locus of

control, and helpfulness of religious beliefs and social support were examined in a sample of 31 women with breast cancer receiving their first chemotherapy course. Subjects completed the Beck Hopelessness Scale and the Rotter Internal-External Scale. High external locus of control beliefs were associated with greater hopelessness (Brandt, 1987).

Thirty-eight women with breast cancer were studied before and after adjuvant treatment (Ward, Viergutz, Tormey, DeMuth & Paulen, 1992). The authors investigated whether perceptions of acute versus chronic illness, efficacy of treatment and severity of side effects were significant predictors of the degree of distress associated with termination of treatment. Although depression scores had decreased significantly from initial treatment for the majority of women, approximately 30% viewed treatment termination as upsetting. Those most upset at treatment end had been more depressed at treatment onset, viewed their illness as chronic, and had more side effects during their last cycle of chemotherapy.

Moch (1990) conducted a qualitative study of 20 women, aged 38 to 60, with previously diagnosed breast cancer and receiving chemotherapy. The following themes were generated from the data: getting information and making choices; coping with the physical aspects; dealing with lack of

control or possible recurrence; being hopeful about the prognosis and optimistic about life; changing relatedness; finding meaning in the experience; and, developing new perspectives on life.

Discussion

The symptoms of an illness are interpreted as outward expressions of the disease. With some forms of cancer, illness symptoms may be silent until diagnosis. This is often the case with breast cancer. The warning signs of a destructive internal disorder are limited to the detection of a lump in the breast. The 'real' illness symptoms emerge following a lumpectomy or mastectomy, especially if the woman is subjected to chemotherapy and/or radiotherapy. Because of the rapid pace of change, it is often difficult for the individual to effectively temper the onslaught of so many physical, psychological and social insults. Feelings of being overwhelmed are common because defenses are often attacked at each level of existence. Adjustment is a problem when the illness is characterized by a number of factors that vary in intensity and duration, and are potentially life-threatening.

Much of the research in the area of cancer and breast cancer is inconclusive because there are no clear answers with regard to the factors promoting or impeding coping and adjustment. Research studies have produced conflicting

results concerning the importance of any one factor or combination of factors on effective coping with an illness and adjustment to the adverse effects of chemotherapy. There are a number of possible explanations for these discrepancies. First, the instruments used to measure feeling and attitude states, control, uncertainty, self-esteem, family functioning, coping and adjustment vary across studies. This prevents meaningful comparison of findings. Second, sample subjects are not always comparable. Unless key extraneous variables believed to impact coping are considered during sample selection and analysis of results, findings from cross-sectional studies have limited utility in promoting understanding of why some people manage poorly and others manage well. Third, the theoretical literature suggests that coping, adjustment, and meanings are complex processes that are continuously evolving over time (Lazarus, 1990; Lazarus & Folkman, 1987; 1984).

Based on this knowledge, we know that a snapshot of psychosocial adjustment at one or two points during an illness will not tell the "whole story". It is necessary to examine both longitudinally and cross-sectionally not only the factors shaping illness meanings but also how people cope with the changes in meanings of the illness, the ability to perform activities of daily living, and the

desire and energy to engage in social activities and maintain relationships with others. The logical approach to take when investigating factors that have multidimensional causes and outcomes involves a deliberate attempt to restrict sample size while at the same time employing methodological and analysis triangulation (Burns & Grove, 1993). The literature on findings from studies focusing on patients with cancer highlights the separate and interactive effects played by personal and environmental factors in shaping illness meanings and long-term adjustment and coping with this disease. A longitudinal design with repeated measures at key points during the course of illness and treatment will not only capture the factors shaping meanings, but how the importance of different factors change over time, and consequentially lead to variant meanings, and coping and adjustment potential.

Summary

The literature suggests that feelings, attitudes, emotions, self-confidence, self-concept, and expectancies regarding personal control interact with the situational potential for control to shape meaning. Though fraught with methodological limitations empirical studies have indicated the significance of control, feelings, attitudes, supports, adequate information systems, uncertainty and self-concept for effective physical and psychosocial adaptation in cancer

patients.

Studies on the meanings of cancer and its treatment illustrate the tremendous personal impact of this illness. Feelings and attitudes toward the illness and treatment modalities fluctuate over time. Uncertainty, fear and shock may be replaced by certainty, acceptance and challenge, and vice versa, as the illness progresses towards its ultimate conclusion. Prescribed treatment modalities may be more stressful for the patient than the cancer itself, which until diagnosis was concealed from the person.

Fear of losing control of life events may be more pronounced if supports are tenuous, feelings and attitudes are embodied by negativity, and physical functioning is impaired. Perceptions of not being in control may be potentiated by uncertainty and negative attitudes and emotions associated with the experiences of cancer and treatment. Living with these uncertainties is a challenge, for the person does not know if the disease will recur or be cured, or controlled.

Women with breast cancer appear to be especially vulnerable to fears of losing the support of significant others. The importance of having the spouse or partner assume an active role from the beginning of treatment must not be overlooked. It is not only the woman's response to the illness and treatment that shapes meaning, but also

family and friends. If illness and treatment meanings determine coping effectiveness, then the logical first step is to investigate the factors shaping meaning. It is necessary to consider the key role played by feelings about the illness, attitudes toward treatment, support networks, preference for personal control, uncertainty, self-esteem and information systems in shaping meanings before investigating how meanings affect adjustment to an illness. Until these are explicitly acknowledged, effective interventions will not be developed to meet the needs of women with breast cancer.

Conceptual Framework

The conceptual framework for this study was based on Lazarus and Folkman's (1984) cognitive - phenomenological theory of stress, appraisal and coping. The model incorporates a transactional process that allows the researcher "to observe or infer what the person is thinking and doing at various points during an encounter or in different encounters" (p. 306). Because a breast cancer diagnosis is a stressful experience incorporating the threats of illness, treatment and possible death, Lazarus & Folkman's transactional model had considerable utility for the study of individuals diagnosed with cancer and receiving treatment over time.

According to Lazarus and Folkman (1984), cognitive

appraisal is the process of categorizing an encounter and its various facets with respect to its significance for well-being. Appraisal shapes the degree of stress and the strength and content of the emotional reaction to an event such as illness (Lazarus, 1993; Lazarus & Folkman, 1987).

Lazarus & Folkman (1984) postulate that cognitive appraisal and coping mediate between the person and environment in any stressful encounter. Through cognitive appraisal a person evaluates a situation on the basis of potential harmful and beneficial effects, and resources that may be available to deal with it. There are two components of cognitive appraisal: primary appraisal - evaluation of the significance of an event for one's well-being; and, secondary appraisal - evaluation of coping resources. Cognitive appraisal and coping strategies influence adaptational outcomes. Primary and secondary appraisals converge to shape the meaning of every encounter (Folkman, 1984; Lazarus & Folkman, 1984).

There are four major types of stressful appraisals: (a) harm/loss - damage that has already been sustained; (b) threat - harm or loss that is anticipated but has not yet occurred; (c) challenge - opportunity for growth, mastery, or gain; and, (d) benefit - non-anticipated harm. The emotional response to harm/loss is anger/disgust, to threat, fear/worry, to challenge, eager/confident, and to benefit,

relief/happiness (Lazarus & Folkman, 1987; 1984).

Uncertainty contributes to the perception of events as stressful and may impede coping strategies. An uncertain situation, especially when it involves a highly significant aspect of life, is evaluated as a threat due to inability to obtain a clear impression of what is in store. Uncertainty can also reduce threat by allowing alternative interpretations of the significant encounter (Lazarus & Folkman, 1984).

Generalized beliefs about the extent to which individuals assume they can control outcomes are identified as significant factors influencing primary appraisal. Situational appraisals of control, or personal beliefs about the possibilities for control in a specific encounter are part of secondary appraisal (Folkman, 1984; Lazarus & Folkman, 1984). Lazarus and Folkman (1987) indicate that secondary appraisal is critical to primary appraisal since harm, threat, challenge, and benefit depend also on how much control we think we can exert over outcomes. "If there is a risk of a damaging outcome but one is confident that this can be prevented, threat is apt to be absent or minimal" (p. 140).

The literature review provided support for the assumption that women with breast cancer receiving chemotherapy experience uncertainty, negative feelings and

attitudes, and loss of control during the illness. These perceptions influence cognitive appraisal - thus illness meaning. "Whether general or specific, illusory or realistic, belief in one's ability to control an event influences how that event is appraised and, through appraisal, subsequent coping activity" (Lazarus & Folkman, 1984, p. 77).

The literature suggests that cognitive appraisal of events - the meaning given to cancer and treatment - is a powerful predictor of adjustment to illness outcomes. The position taken by this researcher was that greater consideration should be given to how illness and treatment meanings are appraised before investigating the effects of meanings upon short-term coping and long-term adaptation. Following the logic of Lazarus and Folkman's model, specific attention was given to personal factors (control, uncertainty, feeling/attitudinal states) and environmental factors (social supports, demands) upon the meanings assigned to illness and treatment over time (see Figure 1). The model guiding this research allowed for assessment of changes in meaning patterns from initial treatment to six to eight weeks follow-up.

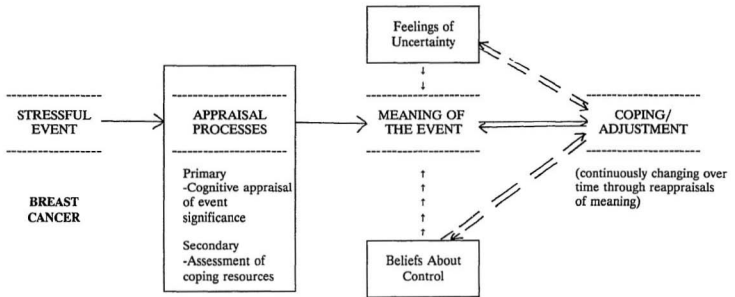


Figure 1. Transactional Model = Continuous Appraisal and Reappraisal: Individual, Situational and Cultural Dependent
 Note. Adapted from Stress appraisal and coping by R.S. Lazarus and S. Folkman, 1984, New York: Springer Publishing.

Definition of Terms

Breast Cancer

Breast cancer is conceptualized as a chronic disease with far-reaching social, psychological, and physical impact (Silberfarb, Maurer, & Crouthamel, 1980; Snyder, 1986).

Meaning of Illness

Meaning of illness is defined as the cognitive appraisal of an illness event. Meaning of illness involves both primary and secondary appraisal processes (Browne, Byrne, Roberts, Streiner, Fitch, Corey & Arpin, 1988; Folkman, 1984).

Control

Control is considered in two ways: as a generalized belief of an individual concerning the extent to which she can control outcomes of importance and as a situational appraisal of the possibilities for control in a specific stressful encounter (Folkman, 1984).

Uncertainty

Uncertainty is the inability to determine the meaning of illness related events and occurs in situations where the decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking (Mishel, 1988; 1993).

Primary Appraisal

Primary appraisal consists of the judgement that an encounter is irrelevant, benign-positive, or stressful. It includes the process through which the person evaluates the significance of a specific transaction with respect to well-being (Lazarus & Folkman, 1984).

Secondary Appraisal

The process through which the person evaluates coping resources and options (Folkman, 1984).

Coping

Coping is a process employed by an individual to manage psychological stress. Cognitive and behavioural actions work to influence adaptational outcomes by confronting the problem causing stress (problem-focused coping) and trying to modify the meaning of the stressful event (emotion-focused coping). Adaptational outcomes are ultimately shaped by the effectiveness of coping efforts (Lazarus & Folkman, 1987).

Feelings/Attitudes

Feelings/attitudes refer to predominant emotions that vary from individual to individual because of differences in personality factors and coping tendencies (Lazarus & Folkman, 1987). Emotional reactions reveal what a person has at stake in an encounter or in life in general, and how the person interprets self and world and copes with harms,

threats, challenges, and benefits (Lazarus, 1990).

CHAPTER 3

METHODOLOGY

A descriptive correlational study with longitudinal and cross-sectional components was used to examine meanings of illness and perceptions of control and uncertainty in women with breast cancer. The longitudinal component examined illness meanings, feelings/attitudes and beliefs about control at two points during chemotherapy and at six to eight weeks follow-up. With the cross-sectional component data was collected on a second sample of women with breast cancer at one or two predetermined points in the treatment cycle.

Sample

The target population was all women newly diagnosed with breast cancer. A non-probability convenience sample was obtained from the accessible population at the Newfoundland Cancer Clinic. Subjects eligible for inclusion in the sample had to meet the following criteria: primary diagnosis of breast cancer with no evidence of metastases; scheduled to receive or were receiving chemotherapy; nineteen years of age and over; and, physically and mentally competent to participate in the study.

A total of fifteen women participated in the longitudinal component and nine in the cross-sectional component of the study. The Nursing Manager and

Chemotherapy Nurse Coordinator of the Newfoundland Cancer Clinic approached women meeting the inclusion criteria to obtain permission for their names to be released to the investigator (see Appendix E,F). The Chemotherapy Nurse Coordinator was contacted a minimum of twice weekly for a list of names.

Setting

Subjects were interviewed by the researcher at each of the data collection periods in the library of the Newfoundland Cancer Clinic (NCC) or in the subject's home or work place. In the longitudinal sample twelve subjects were interviewed in their homes at each data collection period, two were interviewed twice in the NCC and once in their homes, and one subject was interviewed three times in a conference room at her work place. Of the cross-sectional group three subjects were interviewed twice in their homes, three were interviewed once in the NCC, two were interviewed once in the home and one subject was interviewed once at her work place.

The clinic setting afforded privacy yet subjects were not as relaxed as when in the home environment. When subjects were interviewed at the clinic prior to chemotherapy treatment, they answered questions briefly, and displayed less emotion. There was a sense of waiting for the treatment to begin.

Except for one instance, all interviews conducted in the home or place of work were private and conducive to a relaxed atmosphere. One lady had a female relative living with her who was often invited to participate in the conversation by the subject. Interviews conducted in the home environment tended to take longer, were more indepth and subjects were inclined to ask more questions concerning management of medical and nursing problems. This may have been related to the availability of complete privacy and absence of a time restraint, such as, when waiting for treatment.

Ethical Considerations

The researcher attempted to minimize any potential psychologically emotional risks for study subjects by instituting a number of measures. Nurses working at the clinic served as intermediaries between patients and the investigator. Patients who were willing to speak with the investigator were contacted either in clinic or, through a telephone call to their home, and were offered a thorough explanation of the study. The explanation provided information concerning the purpose of the study, extent of participation, interview procedure, subjects rights and preservation of confidentiality and anonymity. The consent form (see Appendix G) was explained in detail and only when the researcher was confident that the subjects fully

understood what was expected were they asked to participate. If they agreed, two consent forms were signed, one for the participant and one for the researcher's records.

The interview was then completed or scheduled for a time that was convenient for the patient. Subjects participating in the study were not exposed to any physical or psychological risks. Although several subjects became slightly emotional, they did not want the interview to be terminated. At the end of each interview, and particularly at the follow-up period, the majority indicated that they enjoyed sharing their feelings and experiences with a health professional.

Confidentiality was maintained throughout the study. Each subject was given a file number on entry into the study. The form identifying the client name and assigned number was kept separately in a locked filing cabinet accessible only to the researcher. Only the subject's number was recorded on questionnaires. Tape recorded data were transcribed immediately after the interview with care taken to remove any identifying information. All completed instruments, tapes and data records were stored separately from consent forms in different locked filing cabinets. Access to raw data was restricted to the researcher and members of the thesis committee.

The proposal for the research study was approved by the

Human Investigation Committee of Memorial University of Newfoundland (see Appendix I). Permission was also obtained from the Newfoundland Cancer Treatment and Research Foundation to conduct the study in the Newfoundland Cancer Clinic (see Appendix J). In the event that hospitalization occurred during data collection, permission to interview patients in the affiliating General Hospital was obtained (see Appendix M). Clinic oncologists were informed about the study along with a request for their assistance (see Appendix B).

Data Collection Instruments

Data were collected using the Multidimensional Health Locus of Control (MHLC) scales, Meaning of Illness Questionnaire Self Report (MIQ-SR), Personal Profile Sheet (PPS) and Cancer Meaning Questionnaire (CMQ). Although reliability and validity of the MHLC and the MIQ-SR had been established in cross-sectional studies, the reliability of these scales for documenting changes over time in women with breast cancer has not been determined. This study was a further test of the reliability and validity of these scales for the target population.

Multidimensional Health Locus of Control (MHLC) Scales

The MHLC scales, developed by Wallston, Wallston and DeVellis (1978), were used to collect data on beliefs about control (see Appendix H). Permission to use the scales and

scoring instructions were received from Dr. K. Wallston (see Appendix K). The MHLC scale (Wallston et al., 1978) is an 18-item self-report instrument with two equivalent forms (A and B) developed for an eighth grade reading level. The items are measured on a 6-point Likert rating scale ranging from strongly disagree (1) to strongly agree (6). Possible scores on each subscale range from six to thirty-six.

The MHLC scales consist of: 1) Internal Health Locus of Control (IHLC) Scale - personal behaviour is responsible for health or illness; 2) Chance Health Locus of Control (CHLC) Scale - health or illness is determined by luck, chance, fate, or uncontrollable factors; and 3) Powerful Others Health Locus of Control (PHLC) Scale - health or illness is determined by individuals perceived to have control such as physicians, parents, or friends. The two external scales - PHLC and CHLC - are treated as separate measures of health locus of control beliefs. The IHLC and PHLC scales are statistically independent, IHLC and CHLC scales are negatively correlated, and PHLC and CHLC scales are positively correlated (Wallston et al., 1978).

Wallston et al. (1978) administered the MHLC scales to a sample of 115 healthy persons over sixteen years of age. Coefficient alphas ranged from 0.83 to 0.86, suggesting that the subscales had high internal consistency. Concurrent validity was assessed by correlating MHLC Scale scores with

Levenson's internal (I), powerful others (P), and chance (C) scales. Levenson's scales had alpha reliabilities ranging from .508 to .733 (Wallston et al., 1978).

The MHLC scales were most highly correlated with their theoretical counterpart in Levenson's scales (values ranged from $r = .567$ to $r = .799$). These findings suggest that both scales are measuring the same theoretical construct, Health Locus of Control (Wallston et al., 1978; Wallston & Wallston, 1981). Predictive validity was supported when IHLC correlated positively with health status ($r = .403$, $p < .001$) and CHLC correlated negatively with health status ($r = -.275$, $p < .01$) (Wallston et al., 1978).

Rock, Meyerowitz, Maisto and Wallston (1987) used cluster analysis with the MHLC scales to identify groupings of individuals with similar responses in two independent samples of 200 (N=400) healthy undergraduate students. Six clusters were generated (pure internal - high internal, low chance and powerful other; pure chance - high chance, and low internal and powerful others; double external - high chance and powerful others, low internal; believer in control - high internal and powerful others; yea-sayer - high on all scales; and nay-sayer - low on all scales. The modified Rand statistic for cluster analysis was .8541, indicating a high degree of scale reliability. The six-group MHLC cluster was shown to be equivalent in two

independent samples, modified Rand statistic = .893, demonstrating cross validation. Construct validity was also demonstrated between the simulated and empirical data (Rock et al., 1987).

Further analysis (with the two samples) assessed cross validation, construct validity of the six clusters and external validity with health related variables as measured by the Krantz Health Opinion Survey (KHOS) (Rock et al., 1987). The KHOS is a measure of control preferences in health care - information seeking behaviour and attitudes towards involvement in care. Internal consistency was reported as ranging from .74 to .76 for the subscales and .77 for the total scale. Predictive, construct and discriminant validity were also established (Krantz, Baum & Wideman, 1980). In subsequent studies the binary rating scale was replaced by a 6-point likert scale. Smith, Wallston and Wallston (1984) confirmed the high internal consistency of the KHOS subscales (informational 0.73 to 0.78; and behavioural 0.78 to 0.83). KHOS subscales scores varied significantly with cluster membership [$F(10, 166.00) = 108.91, p < .0001$]. The analysis suggested that MHLCC cluster membership can be used to predict health related behaviours more accurately than individual MHLCC scales (Internal, Powerful Other and Chance) (Rock et al., 1987).

Meaning of Illness Questionnaire-Self Report (MIQ-SR)

The MIQ-SR was developed by Roberts, Byrne, Browne and McAdams (1992) to replace the Meaning of Illness (MIQ) questionnaire. The MIQ was designed to measure primary appraisal of illness and secondary appraisal of coping resources available to deal with it. The MIQ content is based on the work of Lazarus and Folkman (1984).

The original MIQ scale consisted of 33 items (McAdams, Byrne, Browne, Roberts & Streiner, 1987). Each item was rated with a three point or seven point scale, ranging from not at all to a great deal. Responses to two open-ended questions were classified into twelve mutually exclusive categories of life commitments: values/cognition, emotions, leisure activities, health and physical functioning, future orientation, family and other relationships, work, financial/material, religion, other, everything and nothing (McAdams et al., 1987).

Reliability and validity of the MIQ were assessed on chronically ill populations with mixed cancer, rheumatological or gastroenterological disorders (Browne, Byrne, Roberts, Streiner, Fitch, Corey & Arpin, 1988). Test-retest reliability of the total MIQ ranged between .45 and 1.00, with the majority falling between .60 to .77. Kappa was used to assess interrater reliability on the two open-ended items. A score of .64 was obtained. Raters

judged the categories to be mutually exclusive and exhaustive (Browne et al., 1988).

Research findings support content, concurrent and construct validity of the MIQ. Concurrent validity was demonstrated when significant correlations were obtained between the MIQ and adjustment to illness, as measured by the Psychosocial Adjustment to Illness - Self-Report Scale (PAIS-SR). Reliability and validity of the criterion, PAIS-SR, was based on the responses of subjects with cardiac, lung cancer and renal disease. There was a high degree of internal consistency, .80 to .90, and interrater reliability for rating change in adjustments in breast cancer and Hodgkin's disease patients (intraclass correlation coefficients, .61 to .86) (Browne et al., 1988).

Concurrent validity of the MIQ was also established by McAdams et al. (1987) in a study of 60 subjects with cancer. Results indicated that unfavourable or negative meanings of illness were associated with poor adjustment. Correlations between the MIQ scaled items and the total adjustment score, as measured by the PAIS-SR, ranged from .30 to .51. Further concurrent validity of the MIQ was assessed in a sample of adolescent and adult cancer patients. Items in the MIQ were positively related to questionnaires with similar content, such as the Crumbaugh Purpose in Life Questionnaire, the Beck, Weissman, Lester and Trexler Hopelessness Scale, the

Mishel Uncertainty Scale, and the Paulhus and Christie Spheres of Control (Browne et al., 1988).

Factor analysis was performed on the responses of 246 subjects who completed the MIQ. Fifty percent of the variance in the responses to the MIQ were accounted for by five factors. Most of the items clustered into factors as predicted by the theoretical assumptions underlying the instrument, and by performance as expected with other variables. Two independent coping behaviour items and one temporal context item were retained, even though they did not correlate with each other or with the factors generated (Browne et al., 1988). The authors claim that the factor structure of the MIQ and the content of the two items correspond closely to Lazarus and Folkman's (1984) cognitive-phenomenological theory of stress, appraisal and coping.

Predictive validity was established when regression analysis revealed that 60 percent of the variance in patients' poor adjustment to illness, as measured by the PAIS-SR total score, was explained by items that assessed (a) illness as adversely affecting day-to-day living, family, friends, and job, (b) (dis)satisfaction with outlook, and (c) degree of worry and stressfulness associated with the illness. Browne et al. (1988) assert that these associations between the MIQ and adjustment

corroborate the findings of Byrne et al. (1988) and McAdams et al. (1987) on separate groups of chronically ill subjects.

Following the initial study the MIQ was reworded to reflect clarity and simplicity in application. The MIQ-SR was reduced to 30 items (Roberts et al., 1992). Each item is now rated on a 7-point scale ranging from not at all (0) to definitely yes (6), to enhance scoring consistency. The two open-ended questions were removed. Investigators have two options when using the MIQ-SR, score each item separately or calculate a composite score from the items constituting a factor. Five factors comprise the MIQ-SR: Factor 1 - Impact of illness; Factor 2 - Type of stress: negative attitude of harm, loss, threat and functional context; Factor 3 - Degree of stress, change in commitments, secondary appraisal of coping resources; Factor 4 - Positive attitude, challenge, hope, motivation, control; and Factor 5 - Expectancy and reoccurrence (see Appendix O). Because higher factor scores denote more positive illness meanings, some questions are reversed scored.

Information on scale scoring and permission for use were received from Ms. J. Roberts (see Appendix L). The MIQ-SR was used in this study to assess cognitive appraisal or meaning of illness (see Appendix H). The MIQ-SR was recently used in two research projects (J. Roberts, personal

communication, January, 1992). Reverse scoring has only been implemented in recent studies using the MIQ-SR. The most recent study investigated 293 subjects with mixed chronic illness, none of whom had a diagnosis of cancer. Reliability and validity data are unavailable at present (J. Roberts, personal communication, October, 1993).

Personal Profile Sheet (PPS)

The Personal Profile Sheet (PPS), a 16 item self-report instrument, was developed by the researcher to elicit information on subjects' personal background, and present and past illness history (see Appendix H). Subjects were asked questions about: (a) marital status, (b) age, (c) number of children and ages, (d) place of residence, (e) education level, (f) occupation, (g) disruption in work, (h) time since diagnosed with cancer, (i) support system, (j) time interval since hospitalization, (k) length of hospitalization, (l) type of surgical intervention, (m) type of chemotherapy treatment, (n) other medical diagnoses, and (o) current medications. The data on the PPS were collected through face-to-face interviews with the subjects. This was to enhance subjects understanding of the questions and to promote information accuracy. Hospital records were also reviewed to obtain data pertaining to other medical diagnoses and current medications for the PPS.

Cancer Meaning Questionnaire (CMQ)

The Cancer Meaning Questionnaire (see Appendix H) was developed by the researcher to elicit qualitative data on uncertainty, illness and treatment meanings, family reactions to the illness and treatment, and how nurses can be most helpful. It was anticipated that the qualitative data would augment findings from the MIQ-SR and the MHLIC scales.

The CMQ also has a quantitative component. Two semantic differential scales were constructed to assess subject's feelings about the illness and anticipated illness outcomes (CMQ1), and attitudes toward chemotherapy (CMQ2). Perceptions of uncertainty about the illness, its outcome, and chemotherapy were also generated from the scales. Key words in the CMQ scales originated from a review of the literature and interactions with oncology patients. Subjects were asked to rate the illness and anticipated illness outcomes on five bipolar rating scales (eg. good/bad) ranging from one to ten. The same procedure and number of bipolar rating scales were used to rate chemotherapy. Ten on the scales represented more positive feelings/attitudes, whereas, one denoted more negative feelings/attitudes about the illness and its outcome, or about chemotherapy.

Pilot Study

The questionnaires were pretested on three women approximately two weeks prior to data collection. The pretest indicated that approximately fifteen minutes was required to complete the MIQ-SR and the MHLC scales, and 45 minutes to complete the CMQ; the questionnaire items were understood, and all questions were answered appropriately. The women were asked to comment on the clarity and ease of answering the questions, and to suggest revisions. Since there were no difficulties or suggestions, revisions were not required.

Data Collection Procedure

Data were collected from early March 1992 to mid June 1993. Subjects were interviewed by the researcher at each data collection period: (1) following diagnosis and immediately prior to or during the first chemotherapy treatment (time 1), (2) mid-way through therapy, i.e. following the third cycle and before the fourth cycle of chemotherapy (time 2), and (3) six to eight weeks following completion of treatment (time 3). The data obtained from these time periods were assessed for short and long-term changes in illness meaning, control, feelings and attitudes.

Each questionnaire was introduced with standardized instructions. The MHLC scales were randomly ordered, that is, Form A and Form B were given alternately to subjects at

times 1, 2 and 3. The MHLC scales and the MIQ-SR were self-administered with the investigator present. Demographic data on the PPS were obtained from each participant following administration of the MHLC and MIQ-SR questionnaires. Interviews with the CMQ were the final step in data collection.

All the interviews were tape recorded to prevent data loss due to incomplete notes and the inability to accurately recall subject responses after the interview. To avoid possible anxiety because of the presence of the tape recorder, a miniature 3 x 3 x 1 inch tape recorder with a built-in microphone was used and unobtrusively positioned outside the subjects direct line of vision. Each interview lasted approximately 60 minutes. During data transcription and analysis the opportunity to listen to how the subjects responded to each question helped the researcher grasp a better understanding of each subject's meaning.

Data Analysis

Descriptive and inferential statistics were used for data analysis. All data from the self-administered questionnaires and the semantic differential rating scales were coded and analyzed using the Statistical Package for the Social Sciences (SPSS-X). The alpha level for statistical significance was set at .05. Only the 13 subjects with quantitative data at each time period, or who

participated in the longitudinal component of the study, were included in the statistical analyses. This was because the small sample size for the cross-sectional component precluded meaningful statistical inferences.

Frequency distributions were used to summarize the demographic data. Descriptive statistics (means and standard deviations) were used to describe the values of the MHLC scales and MIQ-SR factors. The Pearson product moment correlation coefficient was used to assess the degree of correlation among the study's major variables at initial treatment, mid-treatment and follow-up. The five factors of the MIQ-SR were correlated with each of the MHLC scales - IHLC, CHLC, PHLC and subscales of the CMQ - feelings about illness and illness outcomes, and attitudes toward chemotherapy.

Repeated measures analysis of variance were conducted to identify changes in the MHLC scale scores, the MIQ-SR and the semantic differential rating scales from initial treatment to six to eight weeks post treatment. The small sample size and minimal symmetrical distributions required the use of Friedman's non-parametric repeated measures analysis of variance to document changes over time. Stepwise multiple regression analysis was used to determine whether beliefs about control, feelings about the illness and its outcome, and attitudes toward chemotherapy were

useful predictors of illness meanings. Using Cronbach's alpha, reliability assessment was performed on the MIQ-SR, MHLC scales, CMQ1 and CMQ2.

Qualitative data from the CMQ were analyzed by the researcher and classified into theoretical categories using a modification of the constant comparative method (Chenitz & Swanson, 1986; Glaser & Strauss, 1967). Data from the interviews were analyzed immediately following transcription. This enabled the researcher to compare each interview transcript with the preceding one for the purpose of identifying commonalities and differences in the data. Data were initially coded to reflect the substance of what subjects verbalized. In this stage, the words of subjects were used. Then, these substantive categories were compared with each other. Similar categories were clustered.

Simultaneous coding and data analysis helped confirm or add more properties to existing categories and generate new ones as dictated by the data. Category generation and definition continued until all the major themes in the data were captured. Interrater reliability for theoretical categories and their properties was established with four Master's prepared nursing colleagues who had several years of experience in the care of patients with acute or chronic illness. An interrater reliability coefficient of .98 was achieved.

CHAPTER 4

PRESENTATION OF FINDINGS

The data are presented in two sections in this chapter. The first section contains the demographic characteristics of the study sample. The second section summarizes the results of the correlational, repeated measures and multiple regression analyses. The qualitative findings are presented in Chapter Five.

Characteristics of the Sample

Over a fifteen month period 30 women were approached by the chemotherapy nurse co-ordinator and clinic nurses of the Newfoundland Cancer Clinic. Of this number, one refused to participate, two had suspected metastatic disease and did not meet inclusion criteria, and three were scheduled to receive treatment in distant areas of the province.

A total of twenty-four subjects were given an explanation of the study. Fifteen women were interviewed at the three allotted time periods. However, only thirteen were included in the quantitative analyses. This was due to the six month delay in completing the final interview for two subjects.

In the cross-sectional sample four women participated at time one only, three at times two and three, and two at time three only (N=9). Three women were lost following time one due to a geographical move. All subjects interviewed

completed the paper and pencil questionnaires and answered the six interview questions.

Although the quantitative analyses included thirteen subjects, the qualitative analyses included data on twenty-four subjects. Tables 1, 2, and 3 display the demographic characteristics of the fifteen subjects interviewed at each of the study's longitudinal time periods. Subjects' ages ranged from 36 to 53 years with the mean age 42.2 years ($SD \pm 5.12$).

The majority (60%) were married and living with their spouse. Most had completed high school education (80%), and fifty-three percent of these women had some post secondary education. All were English speaking (100%), and except for two subjects, appeared to be able to read English sufficiently well enough to complete the self-administered questionnaire. In these two cases the researcher read the questionnaires along with the subject. Most women experienced a disruption in work routine (93.3%) (see Table 1).

At the first interview time since diagnosis ranged from three weeks to ten months, with a mean time of less than two months for most (66.7%) (see Table 2). The majority (86.7%) were hospitalized from four days to one week and had modified radical mastectomies (66.7%). The remainder had lumpectomies with axillary node dissection. At the first

Table 1

Demographic Characteristics of Study Subjects
(N = 15)

Variable	Subjects included in analyses n=15	
Age		
Mean \pm Standard Deviation	42.2 \pm 5.12	
Range of Ages	36-53	
	n	%
Marital Status		
Single	2	13.3
Married	9	60.0
Divorced	3	20.0
Other	1	6.7
Education		
Less than high school	1	6.7
Some high school	2	13.3
High school or greater	12	80.0
Disruption in Work Routine		
Yes	14	93.3
No	1	6.7

interview most subjects (80%) had been discharged from the hospital for over 30 days (see Table 2).

Subjects received one of two chemotherapy treatment profiles: a combination of cyclophosphamide, methotrexate and fluorouracil (53.3%), versus a combination of cyclophosphamide, epirubicin and fluorouracil (46.6%). Eleven (73.3%) women in the longitudinal sample received a course of radiation treatment versus six (40%) in the cross-sectional group. Only two subjects had a medical diagnosis other than cancer. One had both diabetes insipidus and diabetes mellitus, the other had hypertension (see Table 3).

Mean number of children was 2.1 with a range from zero to three. The mean age of the children was 13.17 ($SD \pm 8.61$) with a range from four months to twenty-seven years. The major support network identified was family (93.3%) followed by faith and friends, 20.0% respectively. Other sources of perceived support were doctors, nurses, work, and colleagues (see Table 3).

In summary, the characteristics of individuals with breast cancer in this study were similar to breast cancer populations described elsewhere in the literature (Moch, 1990; Taylor et al. 1984). As well, no major differences were found between subjects included in both the qualitative and quantitative analyses versus those included in the qualitative analyses only.

Table 2

Other Selected Characteristics of Study Subjects
(N = 15)

Variable	n	%
Months Since First Diagnosed		
< 1 month	1	6.7
1 month to 2 months	10	66.7
2 months to 5 months	2	13.3
5 months to 10 months	2	13.3
Time Interval Since Hospitalization		
14 days to 30 days	3	20.0
> 30 days	12	80.0
Length of Hospitalization		
4 days to 1 week	13	86.7
> 1 week to 2 weeks	2	13.3
Type of Surgery		
Modified radical mastectomy	10	66.7
Lumpectomy with axillary node dissection	5	33.3

Table 3

Other Selected Characteristics of Study Subjects
(N = 15)

Variable	n	%
Type of Chemotherapy		
CMF - Cyclophosphamide Methotrexate Fluorouracil	8	53.3
CEF - Cyclophosphamide Epirubicin Fluorouracil	7	46.7
Number of Medications		
1-3	15	100.0
4-6	8	53.3
Medical Diagnosis Other Than Cancer		
0-1	2	13.3
Supports ^b		
Family	14	93.3
Friends	3	20.0
Faith	3	20.0
Others (health care providers/ co-workers)	6	40.0
Number of Children		
Mean	2.1	
Range	0-3	
Age of Children		
Mean \pm Standard Deviation	13.17 \pm 8.61	
Range	4 months-27 years	

^bNote. Some subjects identified more than one support.

Illness Meanings, Control and Feelings/Attitudinal States

The study sought to capture perceptions of meanings of breast cancer and adjuvant treatment at initial treatment, mid-treatment, and six to eight weeks following completion of treatment. The objective was to determine if illness and treatment meanings changed over time, and how beliefs about control and feelings toward the illness, and attitudes toward chemotherapy affected meanings given to illness and treatment.

Meaning of Illness

The Meaning of Illness Questionnaire Self Report (MIQ-SR) (see Appendix H) was used to collect data on key concepts believed to play a significant role in shaping meaning for women experiencing breast cancer for the first time. Higher scores denote more positive meanings. The five MIQ-SR factors (see Table 4 and Appendix N) were examined individually.

Descriptive data. Table 5 illustrates the mean factor scores and standard deviations for times one, two and three. Mean scores for factor one (F1), impact of illness, changed only slightly over time. The illness seemed to have a

Table 4

Principal Components Factor Analysis Data on the Meaning of
Illness Questionnaire, Self Report (MIQ-SR)

Variables	MIQ-SR Factors
Factor 1	
	Impact of Illness
Factor 2	
	Type of Stress: Negative Attitude of Harm, Loss, Threat, Functional Context
Factor 3	
	Degree of Stress, Change in Commitments, Secondary Appraisal
Factor 4	
	Optimism, Positive Attitude, Challenge, Hope, Motivation, Control
Factor 5	
	Expectancy and Reoccurrence

Source. Roberts, J., Byrne, C., Brown, G.B., and McAdams, C. (1992). Scoring Information: MIQ-SR.

moderately negative impact at initial treatment, mid-treatment and treatment follow-up on normal activities of daily living, work responsibilities, and relationships with family and friends. However, negative impact was slightly more severe at mid-treatment with activities of daily living more adversely affected than relationships (see Appendix O). Relationships with family members became progressively more negative over time.

With regards to the type of stress factor, two (F2), the mean scores are in the low to moderate range. The subjects tended to view their illness as low to moderately stressful (harm, threat, loss) and disabling, deteriorating and disfiguring. Negative views of the illness were lowest at initial treatment and highest at mid-treatment. In a recent study of individuals with mixed chronic illnesses (N=293) the mean score for type of stress and negative attitudes was 14.88 ($SD \pm 9.0$) (J. Roberts, personal communication, October 28, 1993). This value is consistent with the mean scores derived in this study.

The mean scores for factor three (F3), degree of stress and effective coping resources, suggest that the subjects perceived their coping resources to be lowest at time one. Negative perceptions improved from time one to time two and then stabilized with no appreciable change detectable from mid-treatment to follow-up. Most subjects perceived the

Table 5

Mean Scores for Meaning of Illness Questionnaire-Self Report
(MIQ-SR) (N = 13)

Variable	Mean Score (\pm Standard Deviation)		
	Time 1	Time 2	Time 3
MIQ-SR			
F1 Impact of illness	15.77 (\pm 5.04)	13.15 (\pm 6.97)	14.69 (\pm 5.51)
F2 Type of stress	21.54 (\pm 7.80)	17.62 (\pm 9.95)	19.15 (\pm 6.40)
F3 Degree of stress/ coping resources	20.31 (\pm 4.80)	22.23 (\pm 4.07)	22.08 (\pm 4.05)
F4 Optimism	21.46 (\pm 5.21)	21.54 (\pm 5.29)	22.62 (\pm 4.7)
F5 Expectancy and reoccurrence	12.23 (\pm 4.38)	11.77 (\pm 4.38)	12.77 (\pm 3.39)

Note. F = Meaning of illness factor.

Possible score ranges for each factor: F1 (0 - 24), F2 (0 - 36), F3 (0 - 30), F4 (0 - 30), F5 (0 - 18)

illness as moderate to highly stressful but felt that they had experienced positive life changes, and had adequate coping resources (see Appendix 0). The mean scores for degree of stress, change in commitments and adequacy of coping resources are comparable to those of oncology subjects with mixed cancer disorders ($\bar{x}=20.10$, $SD\pm4.13$), but slightly more positive than those of rheumatology and gastroenterology subjects (Arpin et al., 1990).

Subjects mean scores for factor four (F4), optimistic attitude, challenge, hope, motivation and control, demonstrate little change over time, but are slightly more positive at treatment follow-up. These scores were slightly more positive than those of patients with mixed cancer disorders reported elsewhere ($\bar{x}=19.11$, $SD\pm4.63$) (Arpin et al., 1990). Subjects felt a significant degree of control, were functioning independently, and were hopeful for a good outcome despite feeling limited by what they could do to change the illness (see Appendix 0).

Although expectancy and reoccurrence of the illness, factor (F5), varied little over time there was a great deal of variation among subjects regarding possible recurrence. Mean scores indicated that most respondents did not expect the illness, nor feel responsible for it. These perceptions were very different from those of oncology subjects ($\bar{x}=4.69$, $SD\pm3.18$) (Arpin et al., 1990) but are comparable with

the most recent study using the MIQ-SR ($\bar{x}=11.61$, $SD\pm4.35$) (J. Roberts, personal communication, October 28, 1993). Individual items indicated that the greatest uncertainty was with the possibility of reoccurrence. However, these concerns were less by treatment follow-up (see Appendix 0).

Repeated measures. Friedman's repeated measures analysis of variance was used to examine the extent to which perceptions of illness meanings varied over time (see Table 6, p. 64). There was no statistically significant difference observed among subjects scores on each of the MIQ-SR factors from initial treatment to follow-up.

Raw scores reflected fairly large individual and within group variations at differing times in terms of perceived impact, stressfulness, optimism, and vulnerability. These differences were substantiated by the qualitative data. Lack of statistically significant differences may be attributed to small sample size.

Perceptions of Control

The three subscales of the Multidimensional Health Locus of Control (MHLC) Questionnaire - Internal Health Locus of Control (IHLC), Chance Health Locus of Control (CHLC), and Powerful Other Health Locus of Control (PHLC) were used to assess perceptions of control at each of the time periods (see Appendix H). Higher scores indicate greater internal control, greater chance and greater belief

Table 6

Repeated Measures Analysis of Variance for Meaning, Control, and Feeling Variables (N = 13)

Variable	Friedman's Test (Non-Parametric)		
	Chi-Square	D.F.	Sig.
MIQ-SR			
F1 Impact	1.65	2	.43
F2 Type of Stress	1.65	2	.43
F3 Degree of Stress	.15	2	.92
F4 Optimism	4.15	2	.12
F5 Expectancy	.73	2	.69
MHLC			
IHLC	1.42	2	.49
CHLC	7.65	2	.02*
PHLC	3.23	2	.19
CMQ 1	1.88	2	.38
CMQ 2	6.61	2	.03*

Note. * $p \leq .05$

in powerful others. The data in this section documents the changes in beliefs about control over time.

Descriptive data. Table 7 summarizes the means and standard deviations for the MHLC scales (internal, powerful other, and chance). Perceptions of internal responsibility for health or illness (IHLC) are slightly greater at time one ($\bar{x}=24.46$, $SD\pm4.72$). Scores for IHLC approached the mean scores of chronically ill ($\bar{x}=25.78$), healthy individuals ($\bar{x}=25.55$), and cancer patients ($\bar{x}=25.52$) in other studies using the MHLC scale (K. Wallston, personal communication, January 1992).

Belief in CHLC, or health and illness as a function of luck, chance, fate or uncontrollable external factors, is greatest at mid-treatment ($\bar{x}=20.85$, $SD\pm8.64$) and lowest at treatment follow-up ($\bar{x}=17.31$, $SD\pm6.89$). Mean scores were considerably lower ($\bar{x}=28.40$) than that of cancer patients ($N=51$), but higher ($\bar{x}=17.64$) than those of chronically ill patients in other studies, with the exception of time three. Only at treatment end do the results approach the mean scores of healthy adults ($\bar{x}=16.61$) (K. Wallston, personal communication, January 1992).

Belief in PHLC, or that illness outcome is determined by important figures such as physicians or nurses, was highest at initial treatment ($\bar{x}=23.46$, $SD\pm8.22$) and lowest at mid-treatment ($\bar{x}=21.62$, $SD\pm6.36$). Sample PHLC scores

Table 7

Mean Scores for Multidimensional Health Locus of Control Scale (MHLC), Feelings Toward Illness (CMQ1) and Chemotherapy (CMQ2) (N = 13)

Variable	Mean Score ¹ (\pm Standard Deviation)		
	Time 1	Time 2	Time 3
MHLC			
IHLC	24.46 (\pm 4.72)	23.54 (\pm 6.33)	23.62 (\pm 5.78)
CHLC	19.15 (\pm 7.9)	20.85 (\pm 8.64)	17.31 (\pm 6.89)
PHLC	23.46 (\pm 8.22)	21.62 (\pm 6.36)	22.62 (\pm 5.56)
CMQ 1	38.46 (\pm 12.7)	42.0 (\pm 7.44)	37.54 (\pm 10.01)
CMQ 2	36.54 (\pm 12.65)	33.31 (\pm 11.64)	31.62 (\pm 10.79)

Note. IHLC = Internal health locus of control; CHLC = Chance health locus of control; PHLC = Powerful others health locus of control.

1. The scale scores ranged from 6 - 36 on the MHLC scales and from 5 - 50 on the CMQ1 and CMQ2 scales.

were considerably lower ($\bar{x}=36.40$) than that of cancerpatients ($N=51$) in other studies and higher ($\bar{x}=17.87$) than those of healthy adults ($N=1287$) (K. Wallston, personal communication, January 1992). Subjects' mean scores for PHLC more closely approximate chronic illness ($N=609$) mean scores ($\bar{x}=22.54$).

The results of this study suggest that sample subjects were more likely to view health or illness as being externally controlled by powerful others rather than by chance factors. IHLC scores are consistently higher than those of external health locus of control scores (CHLC, PHLC) from initial treatment to follow-up.

Repeated measures. Friedman's test was used to compare the mean rank on each MHLC scale across the time periods (see Table 6, p.64). The results indicate that CHLC was the only locus of control belief score to demonstrate significant changes over time ($\chi^2=7.65$, $df=2$, $p<.05$). The mean scale scores (Table 7) show that the greatest change in CHLC occurred between time two and three.

Feeling/Attitude States

Feelings about the illness and attitudes toward chemotherapy were examined by the semantic differential scales comprising the Cancer Meaning Questionnaire (CMQ) (see Appendix H). Higher scores indicated more positive feelings about the illness and more positive attitudes

toward chemotherapy. The mean scores and standard deviation for each subscale are summarized in Table 7.

Descriptive data. The results indicate that women in the study were more positive about the illness and its outcome at mid-treatment ($\bar{x}=42.0$, $SD\pm7.44$), and less positive at treatment follow-up. Negative attitudes towards chemotherapy increase with time. By treatment follow-up subjects appeared to be less positive about both the effects of chemotherapy treatment and illness outcome.

Two items from the MIQ-SR (questions 18 and 19) related to uncertainty asked subjects, "Are you certain about how things will turn out, such as effectiveness of treatment" and "Do you believe it is likely that this illness will reoccur, or a second illness like it will reoccur?" Mean scores (see Appendix O) demonstrated that subjects were more uncertain about treatment effectiveness at follow-up but were more concerned about illness recurrence at initial treatment.

Repeated measures. Friedman's test (see Table 6, p.64) indicated that subjects' attitude toward chemotherapy (CMQ2) changed significantly over the study time periods ($X^2=6.61$, $df=2$, $p<.03$). The mean scores on attitudes toward chemotherapy (see Table 7) indicate a significant change from initial to mid-treatment to follow-up. However, the greatest change occurred between time one and time two.

Feelings about the illness and illness outcomes (CMQ1) did not demonstrate statistically significant changes across the time periods. The mean scores (Table 7) show that the most change in feelings about the illness occurred between time two and time three.

Intercorrelations Among the Scales

The Pearson product moment correlation coefficient was used to measure the correlation between the MIQ-SR factors and the MHLC, CMQ1 AND CMQ2 scales at initial treatment, mid-treatment, and six weeks follow-up. Results of these correlations are summarized in Tables 8, 10 and 12. Pearson's r was also used to assess the degree of association between the MHLC scales and the CMQ1 and CMQ2 scales. The results of these analyses are summarized in Tables 9, 11 and 13.

Initial treatment. Impact of illness (F1) demonstrated a significant positive relationship with PHLC ($r=.6106$, $p=.027$) and feelings about the illness/illness outcomes ($r=.6481$, $p=.017$). Subjects with low to moderate negative perceptions of illness impact on daily activities and informal supports tended to perceive their health/illness as a function of external control by powerful others. They were also more likely to experience low to moderate positive feelings about the illness and its outcome (see Table 8).

Degree of stress and appraisal of coping resources (F3)

demonstrated a significant positive relationship with IHLC ($r=.5899$, $p=.034$), feelings about the illness ($r=.8542$, $p=.000$), and attitudes toward chemotherapy ($r=.7778$, $p=.002$). Subjects who rated the illness and treatment experience as low to moderately stressful and who perceived adequate coping resources seemed more optimistic about the illness and treatment outcomes, and had a greater sense of internal control (see Table 8).

Statistically significant positive relationships were evident between optimistic attitude, hope, and control (F_4) and feelings about the illness ($r=.7251$, $p=.005$) and attitudes toward chemotherapy ($r=.7933$, $p=.001$) (see Table 8). Subjects with moderately positive attitudes and a sense of hope and control have less negative feelings about the illness or negative attitudes toward chemotherapy.

A statistically significant positive relationship ($r=.6092$, $p=.027$) also resulted between CHLC and PHLC (see Table 9). Subjects who attribute health or illness to chance tend to have strong faith in powerful others. These findings are consistent with earlier results ($r=.204$, $p < .05$) (Wallston et al., 1978).

Statistically significant positive relationships were evident between PHLC and feelings about the illness

Table 8

Correlations Among Meanings of Illness, Control, and Feeling Variables at Initial Treatment (N = 13)

Variable	Time 1: Initial Treatment				
	IHLC	CHLC	PHLC	CMQ 1	CMQ 2
<u>MIQ-SR</u>					
F1	.0084 (P=.978)	.4574 (P=.116)	.6106* (P=.027)	.6481* (P=.017)	.4784 (P=.098)
F2	.4480 (P=.125)	.5138 (P=.072)	.4600 (P=.114)	.2624 (P=.386)	.3856 (P=.193)
F3	.5889* (P=.034)	.0387 (P=.900)	.4688 (P=.106)	.8542*** (P=.000)	.7778** (P=.002)
F4	.3400 (P=.256)	-.0626 (P=.839)	.4599 (P=.114)	.7251** (P=.005)	.7933*** (P=.001)
F5	.1476 (P=.630)	-.1022 (P=.740)	-.0055 (P=.986)	.1148 (P=.709)	.0156 (P=.960)

Note.

- * $p \leq .05$
 ** $p \leq .01$
 *** $p \leq .001$

Table 9

Correlations Among Control and Feeling Variables at Initial Treatment (N = 13)

Variable	Time 1: Initial Treatment				
	IHLC	CHLC	PHLC	CMQ 1	CMQ 2
IHLC	-	-.0467 (P=.879)	.2239 (P=.462)	.3494 (P=.242)	.4298 (P=.143)
CHLC		-	.6092* (P=.027)	.1520 (P=.620)	.2826 (P=.350)
PHLC			-	.6634* (P=.013)	.7419** (P=.004)
CMQ 1				-	.8233*** (P=.001)
CMQ 2					-

Note. * $p \leq .05$
 ** $p \leq .01$
 *** $p \leq .001$

($r=.6634$, $p=.013$), and attitudes toward chemotherapy ($r=.7419$, $p=.004$) (see Table 9). Subjects who saw their health/illness as being controlled by important persons, such as physicians or nurses, had more positive feelings about the illness and its outcomes, and more positive attitudes toward chemotherapy.

A statistically significant positive relationship ($r=.8233$, $p=.001$) was found between feelings about the illness and attitudes toward chemotherapy (see Table 9). The more positive the feelings about the illness, the more positive the attitudes towards treatment.

The CMQ1 was positively correlated with the MIQ-SR question 18 on uncertainty about treatment effectiveness ($r=.5567$, $p<.01$) and with question 19 (Reverse Scored) on the possibility of illness recurrence ($r=.5580$, $p<.04$). The CMQ2 was positively correlated with question 18, ($r=.6273$, $p<.02$) and with question 19 ($r=.5645$, $p<.04$). More positive feelings about the illness were associated with greater certainty regarding treatment effectiveness and non-recurrence of the disease. More positive attitudes toward the chemotherapy were associated with greater certainty regarding treatment effectiveness and non-recurrence of the disease.

Mid-treatment. A statistically significant positive relationship ($r=.5725$, $p=.041$) was evident between

perceptions of harm and threat to self (F2) and attitudes towards chemotherapy (CMQ2). Low to moderate perceptions of harm and threat were associated with more positive attitudes towards chemotherapy (see Table 10). A statistically significant positive relationship ($r=.5487$, $p=.036$) was also found between degree of stress, secondary appraisal of coping resources (F3) and attitudes towards chemotherapy. Subjects who perceived the illness as low to moderately stressful and who had adequate coping strategies tended to have more positive attitudes towards chemotherapy (see Table 10).

A statistically significant positive relationship ($r=.7500$, $p=.003$) was evident between optimistic attitude, hope, control (F4) and attitudes toward chemotherapy. The greater the perception of hope, adequate coping resources, and being in control the more positive the attitudes toward chemotherapy (see Table 10).

There continued to be a statistically significant positive relationship between CHLC and PHLC as at time one (see Table 11). Although the relationship between PHLC and feelings about the illness disappears at mid-treatment, there is still a statistically significant positive relationship between PHLC and attitudes toward chemotherapy ($r=.6075$, $p=.028$). This relationship is particularly significant because women with strong belief/trust in

Table 10

Correlations Among Meanings of Illness, Control, and Feeling Variables at Mid Treatment (N = 13)

Variable	Time 2: Mid Treatment				
	IHLC	CHLC	PHLC	CMQ 1	CMQ 2
MIQ-SR					
F1	.2718 (P=.369)	.0133 (P=.966)	.1342 (P=.662)	.2747 (P=.364)	.4601 (P=.114)
F2	.4343 (P=.138)	-.0253 (P=.935)	.2760 (P=.361)	.1768 (P=.563)	.5725* (P=.041)
F3	.0455 (P=.883)	-.3314 (P=.269)	-.1147 (P=.709)	.1483 (P=.628)	.5487* (P=.036)
F4	.2584 (P=.394)	-.2506 (P=.409)	.3311 (P=.269)	.3179 (P=.290)	.7500** (P=.003)
F5	.3096 (P=.303)	-.1085 (P=.724)	-.0409 (P=.895)	.5319 (P=.061)	.1714 (P=.576)

Note.

- * $p \leq .05$
 ** $p \leq .01$
 *** $p \leq .001$

Table 11

Correlations Among Control and Feeling Variables at Mid Treatment (N = 13)

Variable	Time 2: Mid Treatment				
	IHLC	CHLC	PHLC	CMQ 1	CMQ 2
IHLC	-	.3013 (P=.317)	.4700 (P=.105)	.5189 (P=.069)	.5075 (P=.078)
CHLC		-	.6387* (P=.019)	.2618 (P=.388)	.1313 (P=.669)
PHLC			-	.2723 (P=.368)	.6075* (P=.028)
CMQ 1				-	.6196* (P=.024)
CMQ 2					-

Note. * $p \leq .05$

external control by powerful others might be more inclined to continue with chemotherapy in the presence of unpleasant side effects (see Table 11).

A statistically significant positive relationship also persists between feelings about the illness and attitudes toward chemotherapy ($r=.6196$, $p=.024$) (see Table 11), but it is not as strong as initial treatment ($r=.8233$) (see Table 9). The more positive the feelings toward the illness and its outcome the more positive one's attitude toward chemotherapy.

Six to eight week follow-up. Only one correlation between the MIQ-SR and the CMQ and MHLC scales achieved statistical significance at six to eight weeks follow-up. A statistically significant positive relationship ($r=.6196$, $p=.024$) was found between optimistic attitude, hope, and control (F4) and attitudes toward chemotherapy (CMQ2) (see Table 12). This suggests that the greater the perception of hope, and control over the illness, and the availability of adequate coping resources, the more positive the attitudes toward chemotherapy.

Statistically significant positive relationships were evident between IHLC and feelings about the illness ($r=.6112$, $p=.026$), and attitudes toward chemotherapy ($r=.5871$, $p=.035$) (see Table 13). Subjects who had moderately high internal beliefs of control over health or illness had

Table 12

Correlations Among Meanings of Illness, Control, and Feeling Variables at Six Week Follow-Up (N = 13)

Variable	Time 3: Six Week Follow-Up				
	IHLC	CHLC	PHLC	CMQ 1	CMQ 2
F1	.0130 (P=.966)	.1537 (P=.616)	-.0750 (P=.808)	.1693 (P=.580)	.1295 (P=.673)
F2	.4468 (P=.126)	.2621 (P=.387)	.1793 (P=.558)	.4549 (P=.118)	.5222 (P=.067)
F3	.2304 (P=.449)	-.4399 (P=.133)	-.3964 (P=.180)	.1530 (P=.618)	.3153 (P=.294)
F4	.4864 (P=.092)	-.2732 (P=.366)	.0731 (P=.812)	.3908 (P=.187)	.6196* (P=.024)
F5	.4535 (P=.120)	.0556 (P=.857)	.1728 (P=.572)	.2344 (P=.441)	.2271 (P=.455)

Note.

- * $p \leq .05$
 ** $p \leq .01$
 *** $p \leq .001$

Table 13

Correlations Among Control and Feeling Variables at Six Week Follow-Up (N = 13).

Variable	Time 3: Six Week Follow-Up				
	IHLC	CHLC	PHLC	CMQ 1	CMQ 2
IHLC	-	.1385 (P=.652)	.0770 (P=.803)	.6112* (P=.026)	.5871* (P=.035)
CHLC		-	.5542* (P=.049)	.4080 (P=.166)	.0791 (P=.797)
PHLC			-	.1260 (P=.682)	.3303 (P=.270)
CMQ 1				-	.4001 (P=.176)
CMQ 2					-

Note. * $p \leq .05$

more positive feelings about the illness and more positive attitudes toward chemotherapy at treatment follow-up. This is the first time in the treatment cycle that internal beliefs about control are correlated with feelings about the illness and attitudes toward chemotherapy. Further, relationships demonstrated at times one and two have now changed between PHLC and feelings towards the illness and attitudes toward chemotherapy. There is no longer evidence of a statistically significant relationship.

As in time one and time two a statistically significant positive relationship ($r=.5542$, $p=.049$) continues between CHLC and PHLC at six to eight weeks follow-up. The significant relationships evident between feelings about the illness and attitudes toward chemotherapy at initial and mid-treatment disappears at follow-up.

Predictors of Illness Meanings

Another focus of this study was to identify the role that control and feelings/attitudes played in shaping meanings. Stepwise multiple regression was used to assess the impact of control (MHLC scales) and feelings/attitudes (CMQ1 and CMQ2) on illness meanings (MIQ-SR Scales). The results of the analysis for each time period are presented in Table 14.

Initial treatment. Results indicate that at initial treatment feelings about the illness and possible outcomes

Table 14

Regression Analysis Results of Significant Predictors of Meanings (MIQ-SR Factors) Times 1,2,3 (N = 13).

Time 1						
Ind Var	Dep Var	Mult R	R ²	R ² Adjusted	F Value	P
CMQ 1	F1	0.6481	0.4200	0.3673	7.968	.0166
CMQ 1	F3	0.8542	0.7297	0.7051	29.690	.0002
IHLC	F3	0.9087	0.8258	0.7909	23.697	.0002
CMQ 2	F4	0.7933	0.6293	0.5956	18.678	.0012
Time 2						
CMQ 2	F2	0.5724	0.3277	0.2666	5.362	.0409
CMQ 2	F3	0.5847	0.3418	0.2820	5.713	.0358
CMQ 2	F4	0.7499	0.5624	0.5227	14.141	.0032
Time 3						
CMQ 2	F4	0.6196	0.3839	0.3279	6.855	.0239

(CMQ1) accounted for 42.0% of the variance in illness impact (F1). Feelings toward the illness and its outcome are significant predictors of the degree of perceived negative impact of the illness.

Feelings about the illness accounted for 73.0% of the variance in degree of stress and perceived adequacy of coping resources (F3). When Internal Health Locus of Control (IHLC) was entered into the model, it combined with feelings about the illness to explain 83.0% of the variance in perceived stress and adequacy of coping resources. That is, internal locus of control beliefs and feelings about the illness and its outcome surfaced as significant predictors of illness meaning as measured by perceived degree of stress, change in commitments and reappraisal of coping resources.

Attitudes toward chemotherapy (CMQ2) accounted for approximately 63.0% of the variance in feelings of control, optimism, challenge, motivation and hope (F4). Thus, attitudes toward treatment surface as significant predictors of illness meanings in terms of positive attitudes, sense of challenge and control.

Mid-treatment. At mid-treatment feelings about the illness and beliefs about internal control no longer surface as significant predictors of meanings. The only factor predicting meaning is attitudes toward chemotherapy.

Attitudes toward chemotherapy (CMQ2) accounted for approximately 33.0% of the variance in perceptions of harm and threat to self (F2), and 34.0% of the variance in perceived adequacy of coping resources (F3) (see Table 14). Additionally, attitudes toward chemotherapy accounted for 56.0% of the variance in optimism, hope and sense of control (F4). Attitudes regarding treatment effectiveness are significant predictors of illness meaning at mid-treatment.

Six to eight week follow-up. At treatment follow-up, attitudes toward chemotherapy continued to be the only predictor of illness meanings. However, it was restricted to explaining one component of the factor structure of meaning as depicted by the MIQ-SR scales. Attitudes toward chemotherapy (CMQ2) accounted for 38.0% of the variance in optimism, hope and control (F4). It is noteworthy that attitudes toward chemotherapy were a consistent predictor of this factor over time.

Reliability Analysis MIQ-SR, MHLC, CMQ1 and CMQ2

Alpha coefficients for factors one and two of the MIQ-SR ranged from .54 to .82 and .63 to .88, respectively, indicating moderate to high internal consistency. Factors three and four ranged from .49 to .62 and .59 to .65, respectively, indicating moderate internal consistency. Factor five had alpha coefficients ranging from .02 to .49 indicating low to moderate internal consistency. For

factors one through four reliability was highest at mid-treatment (see Table 15).

Alpha coefficients for the MHL scale were as follows: IHLC (.63 to .79), CHLC (.66 to .84), and PHLC (.57 to .86). All of these scales demonstrated moderate to high internal consistency (see Table 16).

Alpha coefficients for the CMQ1 ranged from .83 to .92, and for the CMQ2 .84 to .89, indicating high internal consistency (see Table 16).

Summary of the Findings

The results of the study indicate that appraisals of the illness varied from initial treatment to follow-up, and were influenced by perceptions of control, feelings about the illness and attitudes toward chemotherapy. Negative appraisals of stress (harm, loss, threat), combined with poor functional status (disability, deterioration, disfigurement) and perceptions of illness as "adversely affecting daily living" had the greatest impact at mid-treatment. Initial views of the illness as stressful, causing change in commitments and negatively impacting coping resources improved at mid-treatment. Although subjects perceived the illness as moderately stressful, overall they felt that they had adequate coping resources and experienced a "change in commitments" over time.

Appraisal of the illness as a challenge, coupled with a

Table 15

Results of Reliability Analysis for Meaning of Illness
Questionnaire-Self Report (MIQ-SR) Factors (N = 13)

Factor	Items	Time	Alpha
1	4	1	0.5393
		2	0.8294
		3	0.7080
2	6	1	0.6339
		2	0.8869
		3	0.6593
3	5	1	0.4919
		2	0.6245
		3	0.5381
4	5	1	0.5996
		2	0.6511
		3	0.6065
5	3	1	0.4900
		2	0.2064
		3	0.0267

Table 16

Results of Reliability Analysis for Multidimensional Health Locus of Control Scales (MHLC) and Cancer Meaning Questionnaire (CMQ1, CMQ2) (N = 13)

Scale	Items	Time	Alpha
IHLC	6	1	0.6321
		2	0.7935
		3	0.6517
CHLC	6	1	0.7617
		2	0.8457
		3	0.6616
PHLC	6	1	0.8648
		2	0.6828
		3	0.5736
CMQ1	5	1	0.9183
		2	0.8312
		3	0.8650
CMQ2	5	1	0.8932
		2	0.8902
		3	0.8438

sense of hope, motivation and control remained relatively stable across the illness and treatment. However, as expected, perceptions were slightly more positive at treatment follow-up. Although most respondents did not expect the illness, breast cancer, or feel they had caused its occurrence, there was a great deal of anxiety regarding a recurrence.

Perceptions of internal responsibility for health or illness were slightly greater at time one. By mid-treatment subjects were perceiving the illness and treatment to be a function of chance or uncontrollable external factors. At treatment follow-up subjects were again feeling more in control and responsible for their health. CHLC demonstrated significant changes over time with the greatest change occurring between mid-treatment and follow-up.

Statistically reliable changes occurred in subjects attitudes toward chemotherapy treatment. Negative attitudes towards chemotherapy increased with time, so much so, that at follow-up appraisal of treatment was consumed by overwhelming negative attitudes toward the treatment as being stressful and debilitating. At follow-up subjects were less positive about both the effects of chemotherapy and about illness outcomes.

Over all, across diagnosis and treatment the less the perceived harm and threat to self the more subjects felt in

control of their health or illness. The greater the sense of control, the more positive were feelings about the illness and attitudes toward chemotherapy. Subjects who perceived their health to be externally controlled by powerful others experienced moderately positive attitudes towards chemotherapy.

Perceptions of low to moderate stress and adequate coping resources were associated with more positive feelings about the illness and attitudes toward treatment. Finally, subjects who viewed the illness as a challenge with hope and an optimistic attitude experienced more positive feelings about the illness along with more positive attitudes toward chemotherapy.

It was postulated that as the side effects of treatment became more pronounced, negative feelings about the illness and attitudes towards treatment would increase, external locus of control beliefs would predominate (outcomes would be perceived to be under the control of powerful others) and negative or unfavourable meanings of illness would occur more frequently than positive or favourable ones. The correlation and regression findings support this hypothesis. Non significant, and conversely significant findings are questionable because of small sample size. The reader must therefore interpret the findings cautiously. Locus of control beliefs did vary significantly over time as did

feelings about the illness and attitudes towards chemotherapy treatment. Although mean scores for impact of illness (F1) and type of stress, perceived harm and threat to self (F2) demonstrated changes over time, the findings were not statistically significant. Positive meanings also tended to be associated with increased feelings of internal control and less negative feelings about the illness and more positive attitudes toward chemotherapy.

Key factors shaping meanings of illness and treatment were clearly evident at each of the study's time periods. The fact that these meanings changed was validated by responses to the open-ended questions of the Cancer Meaning Questionnaire. Due to the changes in the factors shaping illness and treatment meanings the predictor variables also changed over time. This was supported by the regression analysis.

CHAPTER 5

ILLNESS MEANINGS: DIAGNOSIS, TREATMENT AND BEYOND

The Cancer Meaning Questionnaire (CMQ) gave subjects an opportunity to express feelings about illness and treatment meanings, uncertainty, family reactions to the illness and treatment, and how nurses can be most helpful. Three major thematic categories emerged from the data: factors shaping illness meanings, uncertainty, and coping with the uncertainty of illness outcomes.

Illness Meanings

Beliefs are influenced by past experience and the historical anecdotes of others. Personal factors and the experience with cancer interact with the sociocultural context to create meaning about breast cancer.

As illness progressed from diagnosis to six to eight weeks post-treatment, a number of themes emerged to define the meanings of breast cancer. Fear of death, feelings of losing control over one's health and life events, psychological and physical losses, adverse treatment side-effects, and the negative and positive effects of the experiential context of others' illness were the most predominant themes identified from the interview data.

Harm, Threat, Loss

For most women, death surfaced as a real possibility. Instead of being "out there" as the end point after a long,

productive life, death suddenly surfaced as "nearby" on a shortened time line. Fear of death was greatest at diagnosis and surgery.

Upon reflecting, all women stated that the initial meaning of the illness was death.

First when the doctor told me I had it [cancer] I thought about dying...and I know in most cases cancer takes your life.

Seems like it changed my life...it seems like every day is the last.

First when I knew I had cancer all I could think of was that I would die.

With the passage of time the focus on mortality issues diminished. Meanings of cancer and chemotherapy emerged from a similar context. It became more difficult to separate out perceptions of the illness from the treatment.

Besides the heightened awareness of the reality of death, perceptions of loss were significant themes. Subsequent to "cancer" was "breast cancer" and the meaning shaped by the loss of a significant body part. Physical loss was expressed in terms of the mind's difficulty in adjusting to the absence of something familiar.

The hardest part was the adjustment of one breast.

It interferes with life...I mean I stand up in front of the mirror now and I see I got one breast instead of two.

Psychological loss was expressed in terms of loss of control over one's health,

I think it's a loss of control...all of a sudden; I'm normally a healthy person and...I find I'm losing control in just about everything.

or a potential loss of supports.

I don't know how he's [fiance] is taking it...this is what upsets me most.

Well right now I feel like I'm half a woman...I wonder if he's just sticking by me now because he feels sorry for me.

Such psychological losses were also perceived as a deterrent to maintaining relationships with others.

I said they should have a place for people taking chemo like they used to have for people going into the sanatorium when they had T.B...You should not be allowed to mix amongst people...Because you are not fit to live with and I know I am making his [husband] life miserable.

Whether the perceived loss was physical or psychological or both, it clearly surfaced as a major pre-occupation early in the treatment cycle.

Several women felt more and more controlled by the treatment as time progressed.

Cancer is something you have no control over...if you are going to get it.

And this has such a hold on me...that frustrates me...chemo takes away your control...chemo it controls you.

The perceived loss of control over one's health at the initial phase gradually progressed to a sense of being externally controlled where feelings of powerlessness predominated. One woman stated: "I have never felt so out

of control and uncertain in my whole life".

Feelings of loss were also expressed in terms of perceptions of an altered sense of self. Body image is a mental picture of the "physical self" and includes attitudes and perceptions regarding one's physical appearance, state of health, skills, and sexuality (Roid & Fitts, 1988). One woman provided colourful insight into how she was experiencing a major change in how she perceived herself.

You look at yourself...there are certain things about yourself you don't like right...I always used to have saggy breasts...And I used to say oh...where did I get them but now you see, once I lost my breast that was a big difference. You don't care what it was like as long as it was there.

Loss of a body part that is significantly related to feminine sexual identity results in a potentially negative alteration in body image and self-concept.

Denial of the presence of cancer could not be maintained for long because the physical appearance of the self was so irrevocably different. The impact of the loss of a breast was profound and dramatic.

I said I'm all falsies now...You look at me and you don't know what's real but touching me you can.

I don't mind all day long looking at myself...It seems like I still have two breasts...but at night it bothers me...looking in the mirror and there is only one breast there...even making love...I like to have a cotton night gown on.

The association of breast cancer with a permanent physical loss along with an altered body image and lowered

self-esteem persisted at treatment follow-up. For several women anger and resentment were quite pronounced.

To me it is degrading...when God made women he punished them all the way...You got to live with it the rest of your life...and stand up in front of the mirror and look and see that you are without a breast...it is degrading and I'm sure he meant for women to suffer...And I mean God when I say it.

You lose a part of your body you'll never get back...It's scary...I find I'm not a woman...I feel that all the time since my operation...with my husband I feel that I am not a woman.

The mental picture of the "physical self" and conceptions of "womanhood" or sexuality were being reshaped as these women struggled to find meaning in what was happening to them. In some cases, the subjects experienced emergence of a new self during the illness. They saw themselves as being more self-centered and subject to emotional ups and downs. Depressive feelings also surfaced: "Depression is not easily explained...just like I got no life, I'm old."

Fears and Adverse Effects

Treatment was a constant reminder of breast cancer. Treatment-related behaviour was variable, undesirable, unpredictable, and a deviation from normal.

Cancer and treatment changes your whole life....You are really thrown off now.

Chemotherapy means cancer. Chemo is a dose of reality. I couldn't hide...And I walked through the door and it said Newfoundland Cancer Clinic and it was a kick...like a splash of cold water.

Negative impact of illness arising directly out of treatment

choice were described by all of the women more frequently than any other consequence. Adverse effects, such as nausea, vomiting, fatigue, depression and infection, had increased by mid-treatment.

Chemotherapy is worse than cancer at this point.

You are almost afraid to wake up in the morning and see what's going to happen to you in the day.

The treatments make me feel terrible...I am sick, sick...and it's a long haul...it's a whole week gone out of your life...you know every third week and you are sick like that...I'm not used to being sick.

Some also reported being hypervigilant to every symptom experienced. One woman stated: "I feel more aware of every ache and pain in my body".

Anticipatory nausea was not uncommon. Subjects reported the heightened awareness of and sensitivity to tastes and smells; feelings of hot, cold, and tingling; focusing on the size and colour of the injection apparatus; and feelings of anxiety while receiving chemotherapy. A few women became physically ill in the days prior to chemotherapy.

I believe there is a mental set that goes with this...about two days before I went in...I was starting to get physical symptoms of nausea...It had to be emotional just knowing I was going in and it's anticipation.

As the treatment progressed, the side effects became more severe. One woman stated:

It seemed like each one...was making me sicker...You

died and came to life again...It's not something I'd recommend for sure.

Anticipatory nausea was now accompanied by vomiting. It was particularly severe with the last three treatments.

The last few times I threw up thinking about it on the way in...I even threw up on the gravel.

I was a lot sicker in the end...Kind of got to the point where I was sick even driving in there.

The overwhelming side effects of treatment seemed to supplant fears about death.

The completion of chemotherapy generated new fears. It was as if a "safety net" or protective barrier against cancer had been removed.

The only thing is now the chemotherapy is finished...there is nothing to protect me right.

While suffering through chemotherapy these women held perceptions of the treatment as a temporary protective mechanism. Chemotherapy had been "hope in the midst of despair".

In summary, recurring thoughts about death coupled with the loss of a significant body part and the experience of an unpredictable illness tainted with suffering and destructiveness forced many of these women to confront their own mortality. From the time of diagnosis to immediate treatment follow-up, these women experienced dramatic changes in illness meaning. Life as they knew it prior to the diagnosis of breast cancer had been changed forever.

Some were able to find new meaning in life, while others continued to struggle to understand what had happened and to come to grips with an uncertain future.

Uncertainty

Uncertainty is a lack of surety about the present, past, and future. In living with a diagnosis of breast cancer one can never be sure a cure has been achieved. Instead of being a single event or even a series of events which provide some closure, uncertainty in breast cancer is a continuous unremitting situation which ebbs and flows throughout one's entire life (Hilton, 1987; Mages & Mendelsohn, 1979).

Feelings of uncertainty emerged as the second major theme. Uncertainty was present from diagnosis onward. Six to eight weeks after treatment, the most dominant theme was the "unknown" or uncertainty about the future. Life/death issues, and the potential of recurrence affected the perceived quality of life. The uncertainty of treatment decisions and tenuous supportive networks generated doubt and negatively impacted coping.

Recurrence and Mortality

Inability to foretell the future generates a profound sense of insecurity. All women in the sample expressed uncertainty about the future and treatment outcomes. Women

were asking, "Will I have a future?":

Unsure about the rest of my life...You just don't know what's coming next.

Not knowing what's going to happen to me, will the treatment work, will I get better...will I be cured...

One woman described cancer as being unpredictable because it doesn't cause immediate death.

Cancer is not like...someone hits you with a car or something and can kill you...I suppose the way it is with cancer it's usually something that does come back...and I know in most cases it takes your life.

Uncertainty and fear of recurrence was also evoked by emergence of new symptoms, hearing of others who had been diagnosed with or died from breast cancer, and exposure to treatment controversies. Beliefs, values and personal situations, along with characteristics of the cancer and treatment influenced the uncertainty.

Meaning was shaped across treatment and follow-up by the lingering fear and uncertainty of recurrence of the illness. Dealing with the possibility of recurrence was especially difficult for these women.

Nobody knows if it will come back...if someone gave me a sealed signed document of 100% cure...signed by God...I wouldn't believe them...I would still doubt.

Well the outcome...how are they going to be able to tell me after...all my treatments without cutting me open and seeing if there is any cancer left in my body.

I guess the word cancer is uncertainty for me...wondering will it come back, if it's gone, do they know if it's gone, will it come back somewhere else.

I keep wondering God will it grow again or what if I find another lump, what am I going to do...it's kind of a waiting game really.

Varying beliefs about the causes of cancer seemed to influence uncertainty about the controllability and predictability of the illness. Since causal agents could not be identified, it was difficult to predict the likelihood of occurrence and recurrence.

The unique personal history of subjects created variable meanings regarding expectations about occurrences and anticipated outcomes.

Never entered my mind about getting breast cancer...But getting cancer that was something that I always thought was going to happen to me anyway...My brother died with leukemia, my father died with stomach cancer...My biggest fear was that it was in my liver...and after I found out it wasn't in my liver I was okay...I knew that the biggest thing about cancer was that when it struck the liver you were gone...That was my one fear.

Previous experience with cancer and death also influenced family perceptions. When prior experience with the disease was absent, the event could not be placed in a meaningful context for interpretation.

They were like me shocked, could not believe it. Nobody was ever sick in this family, they're not used to it...They never thought I would get cancer.

He lost everything...It just drained him...cause he had never been faced with anything like this before.

While positive experiences of others provided hope for a good outcome,

There is an awful lot of hope. I know a good many

women who have had it, even younger than me. My cousin had it. She's fifty something now, 25 years ago. She's doing well. She's had recurrences but she's doing fine...I guess it's in my family.

negative experiences lead to doubt and uncertainty.

I know a girlfriend...she's taking chemo...she got a year and a half and she was back...spread to the bone...and she keeps asking should I have had treatment?

Like I talked to more people that have had recurrences than were healthy.

At treatment follow-up, anecdotes of women who had died with breast cancer were particularly disturbing. For some women, the possibility of death was ever present. Hearing stories about others who had cancer or who had died from cancer, particularly people they knew, was an unsettling experience since it reminded them of their own vulnerability.

Then when you look in the paper and you see people in their 40's and 50's...you know...you question was it not finding it in time, was it too far advanced...it makes you wonder about yourself.

You get scared especially when you hear on the radio or television about young people dying with breast cancer.

Information about relatives, friends or acquaintances who had died from cancer lead to illness reappraisals and conjecture about possible outcomes.

Control and Uncertainty

Beliefs about cancer controllability were instrumental in influencing uncertainty. Many believed they had no

control over recurrence.

I think cancer is something you have no control over...if it's going to come back it will come back...You just go on and hope that you never get it again.

Those who felt they had some control believed that it came through treatment, faith in God, and having faith and confidence in their doctors. Several women felt that their own attitudes and actions, such as participating in treatment decisions, going for checkups, modifying their dietary intake of fat, and doing things that would improve overall health, imposed control over disease progression and hence reduced uncertainty.

Quality of life was reduced as a consequence of uncertainty. "It is very scary...every night you go to bed and you check." Apparent also was a lack of closure to the illness, even at six to eight weeks post treatment.

I work...I go home and I am so tired...all I want to do is to lie down and go to sleep...It's like my life has not returned to normal and I think that affects how I feel about this illness itself...It's like it's not all over yet.

I am more present oriented not future...there are no long range plans....There is always that uncertainty.

Others related constant wondering, hypervigilance and suspicion signalling uncertainty.

Have they got it all, where is it going to show up next...When you get an ache or pain you feel nervous wondering...is this cancer or is this something else?

I always wonder if they got it...probably it will come

back in some other spot or in the other breast...I'll always be conscious of it I think...Is it gone?

Doubts about the effectiveness of treatment haunted women from diagnosis to follow-up.

Was the treatment effective...Will I be able to go back to work and live a normal life?

They give you the treatments to hopefully get rid of it. You just have to hope for the best after that and hope that it doesn't recur.

Perceptions of Social Support and Uncertainty

There was also a great deal of uncertainty associated with the continued presence of social supports. Fear that support would be withdrawn and questioning the genuineness of significant others generated uncertainty about the future.

It hurts when the person you want is not with you...it seems like you are lost...one part of you is gone [the physical]...the other part is gone too.

Like anybody who gets sick the loved ones always stick by them...but then the uncertainty comes in there right.

Well right now I feel like I'm half a woman...I mean my hair is gone and whatever else...I think of him...I wonder is he just sticking with me now because he's feeling sorry for me.

The uncertainty of psychological and emotional support seemed to be far reaching. Positive feelings resulted when families were supportive. In such cases, family reactions instilled confidence and optimism for a good outcome. Negative feelings prevailed when attempts to maintain

traditional roles lead to misconceptions of the women's level of wellness.

The women's tendency to refrain from expressing their needs generated further frustration and uncertainty regarding family support.

They are all over it now...I think they see me as well...it hardly gets mentioned any more.

Some women needed constant reassurance from family members. When the illness was not talked about, it was difficult to determine how they were being perceived by significant others.

Reappraisal of Treatment Options

Ambivalence concerning treatment efficacy plagued most women from diagnosis to treatment follow-up.

They give you the treatments to hopefully get rid of it. You just have to hope for the best after that and hope that it doesn't recur.

The uncertainty of the effects of chemotherapy on the body was distressing. The tremendous side effects continued to impact these women long after treatment completion, generating a great deal of doubt.

I still wonder how much damage it does to you that you never know about...something so powerful and can make you feel so miserable I can't see it being all that good...I think there's got to be some damage done to parts of your body that'll never recover.

Reappraisal of treatment options was stressful.

Although many women were certain they had had the proper

treatment, others had doubts or were ambivalent about choice of surgical intervention - mastectomy versus lumpectomy. Insufficient information and timing of the giving of information were factors responsible for these concerns.

Like...I know you don't know what you should do and what you shouldn't do...But I think that if I had to have the breast removed I wouldn't be going through any of this today...If I had my time back... .

The stressfulness of dealing with the shock of diagnosis and having to make decisions regarding treatment options are particularly difficult at a time of high anxiety.

I wonder if I had known then what I know now would I have had the breast removed...or a lumpectomy...the lump I had was a very small lump.

Some women recommended that information be given more slowly and a longer period of time allocated for decision making.

I'm after hearing...listening to a few programs and they are saying they are having as much success with lumpectomies...So I wonder...Really a few more days to give you time to think is not going to make much difference.

Others suggested that they be encouraged to examine the possible outcomes of treatment alternatives before selecting therapy. As two women stated:

I don't know, it's like I went through all this without any information. Like even going to the doctor at the beginning, it was like it was all rushed...my head was spinning...everything was so rushed...At the time I thought it was great that I didn't have to wait for a month for a mammogram...and surgery...After it was all over my head was spinning...so much happening so fast...too fast...and no information.

The doubts about whether the appropriate decisions had been made at diagnosis signalled attempts to cope with and adjust to a permanent physical change. For these women uncertainty resulted from the experience of having to make rapid decisions about a situation - breast cancer and treatment - which was unfamiliar, unpredictable, and unreliable.

Coping with Breast Cancer

Coping is how people respond to demands or strains in their lives. Coping activity may be directed towards changing or eliminating the source of a stressor, or controlling or altering its meaning, or their response to the stressor. The uncertainties surrounding breast cancer and its treatment seemed to generate adjustment demands in both the emotional and physical spheres during treatment. Ways of coping are broadly divided into emotion-focused coping and problem-focused coping (Lazarus & Folkman, 1984). Because breast cancer is a disease with harmful, threatening, and challenging connotations and considered to be outside one's control, the use of strategies for regulating emotions may seem more appropriate and achievable than attempting to change or modify illness and treatment conditions.

For all of these women, sharing their feelings with and seeking support from family and friends was the primary

means of coping with illness and treatment.

Communication I think is the most important thing there is...especially with someone close to you.

When communication was strained and the subject of the illness taboo, there was a tendency to perceive significant others as less supportive.

At mid-treatment there was a feeling that family and friends no longer wished to discuss the illness. Cancer was now something in the past, so why talk about it: "They don't want to talk to you...That's all passe...They don't want to hear anything about it." As well, at treatment follow-up talking with others was not always felt to enhance coping particularly when support was perceived to be absent. These women had endured the experience of cancer - the insult of breast cancer to the self, suffering through the adverse effects of treatment - now they were reappraising the situation and critically evaluating the nature of their relationships to others.

I have a sister who never bothered me...she never called me...and it hurts to know that...Probably she can't cope with it.

Because family members are expected to be supportive during illness, their lack of support was evaluated very negatively.

My mother always said she knew people that didn't miss a day's work...so I felt there was something wrong with me when I had to stay home...when I was too sick to go to school.

The perception that others did not understand what they were going through was based on hearing non-therapeutic cliché type responses to their concerns and feelings.

Cause all their answers are...some of it is consoling but it's like they say God you are so lucky...So many people are worse of than you...I feel like saying gee I don't feel very lucky...Cause I've heard people say even in a death situation...It's God's will...gee that's nuts...It kind of makes you feel...like I'm almost afraid to say exactly how I feel cause they think it's too foolish.

Responses of others, while probably genuine and intended to comfort, were sometimes seen as inappropriate and lacking true understanding.

If only they could step into your shoes for a little while just to see what it's like.

You don't experience it until you experience it yourself...Talking with others only works sometimes because how can somebody else really understand how much you are tormented.

Seeking solace in religious beliefs or having faith in God was a significant source of support for many women. Religious support emerging from faith and belief was greatest at mid-treatment with all of the women.

I don't know how anybody can go through anything without faith in God. I do believe I'm going to be fine after...The higher power, I believe in many ways he started this.

My religion and my family...We have a strong hope for the future....

Another woman expressed: "Well God is first and I have good friends".

By mid-treatment coping was enhanced by sharing experiences and comparing their situations with others who also had breast cancer.

I've talked with people and they say they had it 30 years ago...They are still going strong.

The ladies I met who had surgery 3 years ago...some others 20 years...some just diagnosed...They are living proof.

Sharing positive experiences remained a significant source of support at post treatment. As one woman stated. "I hear about somebody who did well and it's such a perk...nobody knows...It's like being reborn".

Although seeking support, strength, and relief from others was the major coping strategy used to manage the illness, many attempted to neutralize the negative impact of breast cancer by minimizing the emotional distress it generated. Blocking, repressing, avoiding, and denying behaviours were frequently used. Sometimes deliberate attempts were made to repress feelings.

I just sit down, pick up crocheting, knitting or watch T.V., get involved...and totally block it out.

I don't dwell on them [uncertainties]. I have a little room in my mind where I can put things.

I don't want to know what's in the future for me...I don't think about it. I don't want to know about it.

Keeping busy through activity and return to work were other effective strategies.

I make myself busy...I don't dwell on it too much...but

there are times when it does cross my mind.

Now the 4 hours a day or whenever I work...It doesn't even come in my mind...It's helped me.

The best thing I can do is get back to work...as long as I have something to take my mind off it, it doesn't even cross my mind.

However, the visible markers of disease redirected attention to the illness, making total repression difficult or impossible.

I can push it away...keep busy...start thinking about something else. I just don't think about it...I can not go around all day saying I've got cancer...But how can you deny it with this stupid thing on my head and the prosthesis.

Coping was also enhanced by comparing themselves to others viewed as being more seriously ill than themselves.

There are elderly people in there...they got their life lived, but than you look around and you see young ones in their 20's...they haven't lived yet and don't know if they are going to see 30...so there is always someone worse than yourself.

You rationalize, that's how you cope with it...by saying thank God I am not as sick as the other person...it could have been ten times worse...I could have it somewhere else or it could have progressed even further...I could be very ill like these individuals.

Other stress management strategies included crying, anger, and complaining. One woman stated. "I am making his life miserable with all this complaining". Humour was sometimes an effective buffering technique. "I think you have to have some humour in it cause if you couldn't laugh at some of it, it would be so depressing". Displaying

emotions was seen as a form of weakness. "Cause if I get emotional I try right away to cover it up".

Positive thinking or extracting positive meanings from the negative experience of breast cancer and uncertainty was an important psychological resource for many women.

I've got to keep a positive attitude here. I gotta fight this thing to the bitter end...Because I'm not going anywhere until I'm ready because life is too precious to me.

If you think negatively you are going to be a lot sicker then if you were positive thinking. Your mind had a lot to do with it. Your mind is a healer. It gives you strength.

Although attempts to focus on the positive were less effective at mid-treatment, by treatment follow-up they were once again able to use positive thinking as a useful coping strategy.

My hope for the future is a good one, so I look forward to that.

The positive attitude communicated by clinic personnel was also perceived as useful.

Everyone I met at the clinic were positive people...I don't know if it's the illness itself that's how people figure they have to take on this positive attitude or project through a positive image because to me that's what helps you through it.

Active involvement in decision making regarding procedures and/or medications choices also provided a sense of empowerment and control. One woman, having tried prescription medications, found that Gravol was more

effective in controlling nausea and vomiting.

After I talked to them [nurses] they reassured me that I needn't be that ill, that we could switch around the medications. They spent a lot of time with me. I think they gave me some encouragement to control my own medications...Yes again it gave me that little bit of control.

Another woman, in collaboration with clinic nurses, arranged to have blood work completed in her home by home care nurses. This not only eliminated the need for a baby sitter and a long clinic wait, but also gave her freedom to call for lab results, and arrange treatment time.

Effective communication with health care professionals and having faith and trust in nurses and physicians was important in facilitating coping for all women.

I say what the doctor told me is true and that the cancer stayed in my breast...It didn't spread anywhere else.

You can't sit down and tell someone what you feel because they probably wouldn't understand. But the nurses know what you are going through and know what it is like going through it.

Opportunities to openly express feelings in an atmosphere of genuine concern facilitated discussion.

And their concern, it was genuine concern...like how you make out during the weeks you were gone and always volunteering little bits of information, tips on things you could do.

For several women a cordial approach by nurses and physicians facilitated a trusting relationship with caregivers.

I mean...the first thing I said to him was am I going to lose my hair and he said yes. I said my eyebrows and he said no...The nurse said you might...I appreciated that.

Nursing kindness, caring, understanding, patience, consideration and compassion were prominent throughout diagnosis, treatment, and follow-up. Perceptions that nurses were available to answer questions and provide support, direction, and understanding within a positive framework facilitated the coping process.

With their honesty and support...They [nurses] are uplifting...You can go in there and be in the lowest kind of mood and they bring you right up...They always have such positive attitudes...They help you to keep a positive attitude.

In addition to providing supportive reassurance, the majority of the women felt that nurses helped them cope by providing information and explanations. In most instances nurses were available and prepared to answer questions.

Nurses have been really good and even their attitude...They explain everything...They tell you what to expect.

If I have any questions...I call...At different times...They were right there to give me the answers...They are just wonderful down there.

However, several women did not perceive nurses to be very supportive because they were too busy to be readily available to answer questions and provide explanations.

No I don't...well I wouldn't want to because they are too busy. I don't think they would come and ask...I hate to be complaining about them. They are run of

their feet.

They [nurses] gave me these pills and it said on the prescription take every 3 hours for 24 hours...I didn't know what they were for so I didn't know when I needed them...And they were for nausea and I could have taken them.

Empathy is defined as "the capacity for participating in or vicariously experiencing another's feelings" (Carper, 1979). Empathetic nursing behaviour is the ability to understand feelings and experiences from each woman's perspective. Being accepted and recognized as an individual was especially meaningful to all women.

Their helpful down to earth approach and the personal knowing...You were not treated as another patient...But as an individual, they knew you and understood...that was good...Didn't treat you as a number or a name on a chart.

Personal strength arising from a combination of increased self awareness, spiritual appraisal and reappraisal contributed to coping.

You learn a lot of things...you learn you can't judge others because you never know what you or somebody can do or go through until you have to do it.

Despite individual differences, women dealt with the illness and treatment consistently. The major strategies used were: 1) seeking support, strength and relief from family, friends, nurses, physicians, or religious faith; 2) cognitive mechanisms, such as blocking, repressing, avoiding, and denying behaviours; and 3) focusing on the positive or modifying the situation when possible.

Discussion

Having breast cancer changed the lives of all the subjects. Although most women experienced a feeling of "renewed sense of self", there was also a prevailing sense that "one would never get back to where they had been". Feelings, perceptions, values, and physical being changed in someway: "When you are told you have cancer, your life changes forever...Forever."

Changes in attitudes, priorities, and relationships occurred early in the illness. Several women, especially at mid-treatment, reported less concern with material possessions and a greater appreciation of time, life and relationships.

You look at things...Life is more precious...before you took it all for granted...trees and flowers, even children and things...everyday things...but now it's like you're not going to be here forever.

You change...you don't take things for granted anymore...you appreciate things more and you find life is more fast...time is going by too fast.

By treatment follow-up all except one woman described a new outlook on life and a re-evaluation of life's priorities.

Ah priorities...I reflect and I think of all the years and I joke...I think over the years I neglected myself...not so much physically but emotionally...I should have sat back and relaxed more...I think that was probably one of the things I would change.

I think my attitude is a little different...it kind of hits you in the face...I mean life is pretty precious to be taken from you.

The woman who did not see herself as different did express a desire to help others as a result of her own illness experience.

When an illness like cancer is experienced, meanings undergo significant modifications. A new perspective on life gradually unfolds. All women expressed the notion that one can not really understand what a person with cancer is actually dealing with until it affects the self.

You can't really imagine unless you go through it...somebody will be thinking cancer is like ordinary stuff until you yourself are affected...now you more or less really see the other side of it...once you have been through it.

Through the processes of primary and secondary appraisal (Lazarus & Folkman, 1984), these women reflected upon their past and gradually began to assimilate the experience of diagnosis and treatment of breast cancer. They viewed things differently - considered treatment options, questioned decisions, and supports.

Summary of the Findings

Creation of meaning was influenced by beliefs, history, and social, cultural, and experiential factors. As a new self evolved meanings changed. The challenge was to "get on with living" and "function to the best of one's ability" following the profound impact of the illness breast cancer and its treatment, amidst the always underlying and sometimes looming presence of uncertainty. Direct

confrontation with death lead to heightened self awareness. All women acknowledged that they became stronger in various ways throughout the illness and treatment.

While several meanings of the illness remained prominent from initial treatment to follow-up, others varied over time. Fears of death, loss, and harm to the self were prominent at the time of diagnosis and early treatment. Adverse treatment side effects dominated meaning at mid-treatment and continued to treatment follow-up. Perceptions of loss, especially body image, remained significant across time.

Uncertainty continuously impacted meaning, only the degree of extensiveness varied. By treatment follow-up uncertainty about the future dominated meaning. Ways of coping with breast cancer, the uncertainties, and treatment encompassed greater emotion focused, rather than problem focused strategies. Perceptions of the role of nurses and physicians in facilitating coping were particularly salient.

CHAPTER 6

DISCUSSION OF THE FINDINGS

Lazarus and Folkman's (1984) cognitive-phenomenological theory of stress, appraisal and coping and relevant literature guided conceptualization of the research problem. According to Lazarus and Folkman (1984) cognitive appraisal and coping are two processes which mediate between the person and environment in any stressful encounter. Through cognitive appraisal a person evaluates a situation on the basis of potential harmful effects. The two components of cognitive appraisal - primary and secondary appraisal - converge to shape the meaning of every encounter. Beliefs about control, feelings about an illness and attitudes toward treatment influence primary and secondary appraisal processes.

This study was designed to: (1) identify the key factors shaping meanings of illness and treatment for women experiencing breast cancer for the first time, (2) assess how beliefs about control, feelings about the illness, and attitudes toward chemotherapy affected meanings given to illness and treatment, and, (3) determine if meanings changed over time.

The study examined cognitive appraisal of the experience of breast cancer and treatment along with the concepts of control, feelings and attitudes at three points

in the illness trajectory. The findings of the study are discussed in relation to the conceptual framework with reference to the relevant literature.

Factors Shaping Meanings of Illness and Treatment

According to Lazarus and Folkman (1987; 1984) appraisal of a persistent event is not static. Illness meanings for women comprising the study sample were continuously evolving over time. This was demonstrated by findings from the qualitative data and by subject scores on the Meaning of Illness Questionnaire Self-Report (MIQ-SR), the Cancer Meaning Questionnaire (CMQ), and the Multidimensional Health Locus of Control (MHLC) scales.

Feelings/attitudes. Results from this study indicated that Lazarus & Folkman's (1984) theory was suitable for understanding how women appraise meanings of an event such as a breast cancer illness and its treatment. Through secondary appraisal women identified coping behaviours to deal with breast cancer and the uncertainties associated with illness and treatment. The theory provided a useful framework for interpreting the influence of personal and environmental factors on appraisals of meaning.

Results indicated that there were specific factors shaping meanings of illness and treatment for women with breast cancer and that these meanings changed over time. Because meanings changed the factors impacting meanings also

changed. Furthermore, beliefs about control, feelings about the illness and attitudes toward chemotherapy affected meanings.

When the factors of the MIQ-SR were examined individually it was apparent that the illness breast cancer was most stressful and worrisome at initial treatment. Negative appraisal of coping resources and life changes were common. Family relationships, interrupted careers, and the ability to carry out usual daily activities were profoundly impacted. The negative impact of the illness on day-to-day functioning experienced by the women in the study population is supported by research findings in the literature (Bloom et al., 1987; Frank-Stromborg et al., 1984; and Krause, 1993).

As time went by, meanings of cancer and treatment became difficult to discriminate between. The quantitative data from the MIQ-SR indicated that by mid-treatment subjects viewed their illness as more harmful, disfiguring, disabling, deteriorating and life threatening. Qualitative data indicated that by mid-treatment the many treatment side effects and concerns seemed to be the most powerful forces shaping meaning. The adverse effects of chemotherapy were not only debilitating but also seen as having devastating effects on all body systems. The observed trend towards increased perceptions of a greater negative impact as the

adverse effects of chemotherapy increased is well supported in the literature (Bloom et al., 1987; Love et al., 1989; Loveys & Klaich, 1991; Moch, 1990; Nerenz et al., 1982; Todres & Woktiuk, 1974). Continuing with a form of treatment that interfered with every aspect of living was frustrating and depressing. Thoughts of discontinuing treatment because of adverse side effects have been documented in other studies (Andrykowski et al., 1988; Love et al., 1989; Redd et al., 1982; Wilcox et al., 1982). Prevalence of negative illness demands is also reported in studies focusing on coping with cancer in general and breast cancer in particular (Dodd, 1988; Dodd, Ahmed, Lindsey & Piper, 1985; Dodd, Dibble & Thomas, 1992; Jarrett, Ramirez, Richards & Weinman, 1992; Kesselring et al., 1985; and Myerowitz, 1980;).

Despite the adverse effects many women felt positive about the outcomes of breast cancer. Chemotherapy was perceived as a protective barrier against the cancer, and hope for a good outcome. As one woman stated, "to me chemo means life". However with the completion of chemotherapy came new fears. For many women the protective barrier against cancer had been removed. These women described themselves as being left without the "safety net" of treatment. Women felt that as long as they were receiving chemotherapy, the cancer could not recur. This finding is

consistent with that of Ward et al. (1992). Assessment of psychological and physical distress and planned interventions to help buffer the negative impact must occur from the onset of treatment. It is, more importantly, an ongoing process. There is a continuing need for nurses to help patients cope with side effects during and after treatment is completed.

Hope for a good outcome was overshadowed by negative feelings about treatment. Negative feelings about both the effects of chemotherapy treatment and illness outcomes persisted at follow-up. These stresses, however, were associated by some women with positive life changes. Coping resources were considered to be greater than at either initial or mid-treatment. Nerenz et al. (1982) also found higher coping efforts with the last treatment as opposed to the first chemotherapy treatment.

Responses to the interview questions supported stressful appraisals of harm, loss, and threat. Fear of death, fear of losing control over one's health and life events, perceptions of harm/threat, challenge, loss, altered body image, and uncertainty about quality of life and illness outcomes emerged to shape the meanings of illness for all women. All women stated that the initial reaction to the diagnosis of breast cancer was one of shock and disbelief. Concerns over life and death also took

precedence at this time. This collaborates the findings of Wiseman and Worden (1976-1977). These authors found that for the first three months after diagnosis most patients were concerned about dying. Concerns about health, family, finances, work, and friends were of secondary importance.

Initial fears of death, illness as life threatening, and direct confrontation with death are consistent with the reported literature (Dodd, Dibble & Thomas, 1992; Dodd, Ahmed, Lindsey & Piper, 1985; Dodd, Chen, Lindsey & Piper, 1985; Frank-Stromborg et al., 1984; Kesselring et al., 1986; Krause, 1993; 1987; Loveys & Klaich, 1991; Milton, 1973; Packard, Haberman, Woods & Yates, 1991; Suominen, 1992). The profound impact of breast cancer on a woman was supported by Fallowfield and Clarke (1991). According to Lazarus and Folkman (1984) harm/loss refers to damage that has already been sustained, whereas threat is anticipated harm or loss.

Besides the fears and the adverse treatment effects many of these women viewed breast cancer as synonymous with breast loss. Subjects were faced with changing the minds picture of their body to one with a unilateral breast. The emotional trauma of losing a breast was far reaching. Perceptions of loss were critical meaning of illness themes from diagnosis through follow-up. Loss was physical, psychological, or both, especially for those who had a

modified radical mastectomy (66.7%). Accompanying the permanent physical loss of the breast was altered body image and lowered self-esteem. Negative body image changes were consistent with those of Stromborg & Wright (1984) and Penman et al. (1987).

The strong relationship between attitudes toward mastectomy and self-esteem is consistent with findings of Feather and Wainstock (1989). Loss of a breast involves several significant features: (a) cultural - the breast may be perceived as the 'primary source' of a woman's identification with a feminine role (Bard & Sutherland, 1952); (b) loss of the breast threatens outward physical appearance, sexual attractiveness, and relationships with men; and (c) finally, it may threaten the individual's personal body image, and wholeness of body (Rossier, 1981).

PHLC beliefs were associated with positive attitudes towards chemotherapy and positive feelings about the illness at initial treatment, and positive attitudes toward chemotherapy at mid-treatment. Only at treatment follow-up were perceptions of internal control associated with attitudes toward treatment and feelings about the illness. Locus of control beliefs may be associated with altered body image perceptions. Penman et al. (1987) reported that women who view life outcomes as less under their personal control and more under the control of powerful others, tend to have

a poorer body image.

Challenge is to perceive opportunities for growth, mastery or gain (Lazarus & Folkman, 1984). The qualitative data reinforced the MIQ-SR findings that most women were hopeful about their prognosis and generally optimistic about life. Those who described the illness as a challenge and had moderately positive attitudes, a sense of hope and feelings of personal control over the course of the illness had less negative feelings, less uncertainty about the illness and treatment, more faith in a positive outcome, and greater trust in powerful others. Burgess et al. (1988) also found that subjects who viewed breast cancer as a challenge had higher internal locus of control scores, lower psychological morbidity and more positive coping responses. Perceptions of optimism and challenge have been documented in other studies (Brandt, 1987; Moch, 1990).

Uncertainty

According to Lazarus and Folkman (1984) when a harm/loss situation occurs, it always involves threat because of the implications for future loss. Because of the continuing possibility of recurrence, there was always that element of the unknown and a threat of future losses. The qualitative data findings of this study support the assumption that perceptions of uncertainty influence the degree of stress experienced in response to an illness.

Secondly, meanings of illness were shaped across diagnosis, treatment, and follow-up by the lingering fear and uncertainty of recurrence of the illness.

Uncertainty was appraised as life and death issues, unpredictability of recurrence, being unsure of supportive networks, and doubt about treatment decisions. Uncertainty regarding the duration of an illness or its outcome has been reported as the greatest single psychological stressor for the patient with a life-threatening illness (Koocher, 1984; Mishel, 1993). Previous research findings also suggest that uncertainty increases a person's sense of threat and danger (Bradon, 1990; Christman, et al., 1988; Hilton, 1989, 1988, 1987; Mishel, 1993, 1984, 1981).

Subjects also questioned the reliability of support systems. Not feeling sure about significant others or being able to depend on them generated uncertainty about the future. When family members were perceived as supportive positive feelings resulted, confidence was restored and optimism for a good outcome predominated. Conversely, perceptions of non-support resulted in negative feelings and reduced confidence and hope. These findings correspond with those of Arpin et al. (1987), Kesselring et al. (1986), Woods, Lewis and Elliston (1989) and Northouse (1981)

It has been proposed that a major function of social support is to provide the patient with an opportunity to

clarify her situation through discussion and interaction with others (Mishel & Braden, 1987). Appropriate interaction with significant others during treatment could have helped these women interpret events in a manner more conducive to reducing perceptions of lack of control and lack of support. The availability of a stable core of others to help identify strengths and positive aspects of the situation may have lessened the unpredictability of the outcome. For a small number of women in this study that support was not always sensed or understood. The association between uncertainty, control, and disruption in family relationships is consistent with the findings of Mishel et al. (1984).

All women expressed uncertainty about the future and treatment outcomes. Fear of recurrence was a constant threat. Perception of cancer as death influenced uncertainty, conversely uncertainty about the outcomes of treatment influenced perceptions of death. Subjects were also more uncertain/unclear about treatment outcomes. They were asking, will chemotherapy work, is the cancer gone, will I be cured, what happens if its somewhere else. In short, not knowing if an event is going to occur can lead to a long, drawn-out process of appraisal and reappraisal generating conflicting thoughts, feelings, and behaviours which in turn create feelings of helplessness, confusion and

greater uncertainty.

Negative feelings and uncertainty about treatment progressively increased with time. So much so, that by treatment follow-up subjects expressed the least certainty about both the effects of chemotherapy treatment and illness outcomes. Negative feelings of uncertainty about the future and fear of recurrence have also been reported in the literature (Loveys & Klaich, 1991; Mishel et al., 1984; Moch, 1990; Northouse, 1981; Schain & Fetting, 1992). Feelings of uncertainty were also expressed in terms of lack of closure to the illness and reduced quality of life. These findings are consistent with those of Hilton (1987) and Mishel (1993).

Uncertainty and threat of recurrence were affected by prior knowledge and experience. Although the situation of breast cancer was new to all women, at least 60 percent knew of relatives who had died of cancer. Some women had friends who were alive but were having side effects from therapies. Others had acquaintances who had recurrences from breast cancer. Historical and experiential influences on appraisal of meaning is consistent with reported literature (Fallowfield, Baum & Maguire, 1987; Hilton, 1987; Lipowski, 1970; Love et al., 1989; Mages & Mendelsohn, 1979).

Beliefs about causes of cancer influenced uncertainty about the controllability and predictability. Because cause

could not be attributed to any one agent or event it was difficult to predict the likelihood of occurrence or recurrence. Mean factor scores indicated that subjects neither expected the illness nor felt that they contributed to its occurrence. Uncertainty weakened the sense of mastery or control over a situation. Most of the women said that they could deal with situations when they knew what to expect but when things were uncertain they found themselves having great difficulty. These findings are consistent with those of Burgess et al. (1988), Hilton (1988) and Watson et al. (1990).

In terms of perceptions of control of recurrence, the women mentioned such things as treatments, faith in God, and having faith and confidence in their doctors. These beliefs in powerful others are consistent with an attitude that the problem will be handled by the powerful other. Dealing with control and experiencing uncertainty with cancer is consistent with the literature (Hilton, 1989, 1988, 1987; Loveys & Klaich, 1991; Mishel, 1993; Mishel & Sorenson, 1991; Mishel, Padilla, Grant & Sorenson, 1991; Watson et al., 1990).

Perceptions of Control

Losing control of one's life and body is probably the biggest threat to a cancer patient. This experience can lead to diminished personal competence and loss of self-

esteem (Feather & Wainstock, 1989). Lazarus and Folkman (1984) suggest that sense of control influences appraisal of the meaning of illness. The extent to which people feel confident about being able to control the environment or feeling vulnerable to harm influences the degree of threat or challenge appraisals (Lazarus & Folkman, 1984).

Situational appraisals of control, or belief about control in a specific encounter are part of secondary appraisal (Lazarus & Folkman, 1984). Here demands of the situation are evaluated in relation to coping resources and options. Subjects who appraised adequate coping resources felt a greater sense of internal control. Subjects experiencing moderate stress yet had adequate coping resources were much more certain and optimistic about the illness, its outcome, and treatment.

At initial treatment subjects not only felt an internal sense of control but also held strong beliefs in control by powerful other persons. Wallston and Wallston (1978) state that a person with strong beliefs in external control by powerful others might be expected to continue taking medication in the event of unpleasant effects if there is high trust in the physician or powerful others. In this sense PHLC may be treated as being similar to "internality". In fact, Wallston (1990) suggests PHLC be treated the same as internal locus of control when dealing with patients with

a potentially long term illness. This strong belief in powerful others was absent at follow-up with subjects experiencing a greater sense of internal control.

The low mean scores on chance health locus of control suggest these women were less likely to view health or illness as being externally controlled by chance factor. These results support Wallston & Wallston's (1982) contention that PHLC and CHLC belief scores are usually high in samples of chronic patients, whereas IHLC belief scores parallel those of healthy adults.

Because at mid-treatment negative treatment side effects were more pronounced, it is reasonable to expect that harmful effects were occurring in relation to uncontrollable factors. Qualitative findings suggested that perceptions of limited control over physical functioning were associated with increased perceptions of psychosocial problems within the family. For example, several women felt that because they were halfway through treatment their families perceived them as "back to normal". Intrapersonal conflict arose when the woman felt that she was unable to physically carry out the functions expected of her but family members thought that she looked well enough to do these things. Similar findings have been reported in the literature (Mishel et al., 1984; Penman et al., 1987).

Lazarus and Folkman (1984) state that appraisal of

control can shift as an encounter unfolds. Change can come about as a result of new information and/or as the result of coping efforts. The relationship between situational control appraisals and appraisals of threat and challenge is complex. For women in this study, the potential for controlling the cancer through chemotherapy was balanced against insults to physical and psychological well-being, that is, nausea, fatigue, hair loss and depression.

Feelings of loss of control over one's health were significant concerns expressed in the interviews. When health promoting behaviours were perceived as ineffective, personal control over health and illness was challenged. This finding was similar to that of Loveys and Klaich (1991). It also caused some women to doubt the negative results of tests such as mammography. Hilton (1987) described similar findings.

Loss of control over life events was associated with having to accept limitations imposed by the illness and treatment, of giving up activities, and simply "not being able to do the things I used to do". Similar to Hilton's (1987) findings, beliefs about cancer, its causes, and controllability, together with beliefs about life and what controls life, were influential in the women's perception of their own cancer situation. Although the majority had no idea why they got cancer, several identified possible

reasons such as cigarette smoking, high fat diet, and early menopause. Locus of control beliefs as a foundation for understanding appraisal of illness meanings, from a conceptual point of view, is similar to Lewis (1982) and Thompson's (1981) framework for understanding health related behaviour.

Findings related to the influence of beliefs of control and feelings of uncertainty on the cognitive appraisal of illness meaning are in agreement with Lazarus and Folkman (1984). These authors assert that uncertainty influences perceptions of events as stressful, and beliefs about personal control over outcomes. The influence of uncertainty on perceptions of stressfulness is supported by Christman (1990) and Mishel et al. (1984). Feelings of uncertainty and perceptions of control as significant factors influencing primary and secondary appraisals of illness are also consistent with findings from other studies (Burgess et al., 1988; Hilton, 1988).

Coping with Breast Cancer

Coping is defined as constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Lazarus and Folkman, 1984). Adaptational outcomes are ultimately shaped by the effectiveness of coping efforts (Lazarus & Folkman, 1987).

Coping with changing meanings over time was imperative for all women in the present study.

Sharing feelings and seeking support provided strength and relief. These strategies emerged as the primary means of coping with illness and treatment. Subjects preferred to have support from those closest to them unless they were seeking information. Although most wanted active family involvement some needed to deal with the illness and make decisions on their own. This is consistent with the findings of Frank-Stromborg et al., (1984); Hilton (1988); Lindsey, Ahmed, Dodd (1985); Northouse (1981); and Woods, Lewis and Elliston (1989).

Seeking information from reading and talking with others, both friends and professionals helped women to understand their situation. Information with personal relevancy was most instrumental in modifying uncertainty. This finding is consistent with the literature (Brandt, 1987; Dodd, Dibble & Thomas, 1992; Fallowfield, Baum & Maguire, 1987; Krause, 1993, 1987).

Feelings of alienation from family and friends were more pronounced at mid-treatment because significant others were focusing on "wellness" rather than "sick-role behaviour." There was a sense that feelings could not be shared, cancer was in the past, so why talk about it. Even at treatment follow-up talking with others was not always an

effective coping strategy. They had withstood the experience of breast cancer - the insult to the self, the adversity of treatment - and were now reappraising the situation and critically evaluating the commitment of others.

Sharing experiences and comparing their situations with others who also had breast cancer enhanced coping by mid-treatment. However, a process of filtering information similar to that found by Mishel (1993) and Krause (1993) was used to manage uncertainty. Information was selected or filtered so that only supportive information was acknowledged. A process of downward or positive comparison was used in elevating their situation and viewing others as in worse circumstances. Subjects preferred to compare themselves with patients who had recovered from cancer. These findings are comparable to those of Krause (1993) and Fallowfield, Baum and Maguire (1987).

The experience of cancer strengthened all women's faith. Recourse to religious faith and beliefs was greatest at mid-treatment. At this period in the illness and treatment cycle the negative impact of illness was peaking, perceptions of internal control were lowest, and uncertainty was intensified. Appraisal of religious and spiritual beliefs were a strong source of support. The role of religious help in dealing with stressful situations is

reported in the literature (Brandt, 1987; Herth, 1989; Hilton, 1987; Krause, 1993; Mickley, Soeken & Belcher, 1992; Northouse, 1989).

Secondary to seeking support, strength, and relief from others many women demonstrated the minimizing strategies used by Mages and Mendelsohn (1979) and Hilton (1988). In order to live with fear of recurrence and progression of their disease, it was necessary for them to put the illness out of their minds while remaining sufficiently aware of realities to continue appropriate treatment and follow-up. Blocking, repressing, avoiding, denying, and humour were frequently used. Humour as a coping strategy corresponds with findings of Krause (1993) and Hilton (1988). Positive thinking, a psychological resource (Lazarus & Folkman, 1984), was important for many women. Attempts to focus on the positive wavered throughout the treatment cycle and was probably the lowest at mid treatment.

Most of the women described themselves as being hopeful about their prognosis and generally optimistic about life. Despite concern about the possibility of recurrence, the women usually reported a positive outlook on the future and a positive outcome for their cancer. This finding correlates with the cancer literature (Brandt, 1987; Frank-Stromborg & Wright, 1984; Frank-Stromborg et al., 1984; 1984; Hilton, 1988; Lanham & DiGiannantonio, 1988; Longman &

Young-Graham, 1986; Moch, 1990).

Crockford, Holloway and Walker (1993) suggest that a cheerful and optimistic attitude can discourage the expression of negative attitudes, and too great a readiness to provide reassurance may mean that it is given before the nature of the patients' worries have been clarified. While subjects valued a positive attitude by clinic nurses, health providers must be careful not to miss crucial verbal and non-verbal cues indicative of underlying problems.

Nursing support through caring and information giving were prominent throughout diagnosis, treatment, and follow-up. Perceptions that nurses were available to answer questions and provide emotional support, direction, and understanding within a positive framework facilitated the coping process. Nurses were recognized as being able to understand the subjects' feelings and experiences from a woman's perspective, that is, identification from the unique position of being a woman.

Problem-focused coping (Lazarus & Folkman, 1984) or attempts at modifying the situation were useful for some women. Modifying the situation included active involvement in decision making which provided a sense of empowerment and improved locus of control through internal resources. Confronting problems as they arose and moving toward their resolution also helped to reinforce the sense of control

impaired by the illness and treatment situation. Active attempts to modify the situation are comparable with findings of Hilton (1988) and Mages and Mendelsohn (1979).

In summary, factors shaping meanings of illness and treatment for women experiencing breast cancer were substantiated by quantitative and qualitative data. Meanings changed from initial treatment to mid-treatment to follow-up. Beliefs about control, feelings about the illness, and attitudes toward chemotherapy, along with perceptions of uncertainty significantly influenced appraisal of meaning.

CHAPTER 7

LIMITATIONS, IMPLICATIONS AND CONCLUSIONS

This chapter presents the limitations of this research study and the conclusions drawn from the results.

Implications for nursing practice, nursing theory and nursing research are discussed.

Limitations of the Study

Study findings are subject to many of the limitations of previous studies. The use of a small convenience sample precludes generalization of the findings to the target population. It could be argued that the qualitative component partially compensated for the small sample size. The indepth interviews at three time periods certainly enhanced the quality of the data by providing useful insights into how the women defined illness meanings, control and uncertainty, experienced changes in feelings, attitudes, control and meanings over time, and coped with the illness and treatment.

Another possible limitation was the timing of the first interview. Because diagnosis and surgery normally occur one or two months prior to chemotherapy it might be more realistic to schedule the first interview closer to surgery. One possible drawback is the high anxiety levels following surgery.

Reliability and validity problems were also detected

with the MIQ-SR. Although most subjects found the MIQ-SR easy to complete, some encountered difficulties with questions 23, 24, and 25, which measure feelings of control (see Appendix H). For example, in response to question 23 ("In terms of this illness to what extent do you feel you have to accept it?") many women stated, "Do I have a choice?" "How can I not accept the fact that I have breast cancer?" Conceptually these questions were difficult to answer, are excluded from the factor structure of the MIQ-SR, and treated as individual items in scoring the questionnaire.

The factor structure of the MIQ-SR is relatively complex. Some factors include several related but different concepts. For example, factor four is a measure of challenge, uncertainty, hope, control, and motivation. The results indicated that certain items within a particular factor did not elicit responses consistent with other items.

The MHLC scales (see Appendix H) were generally perceived as easy to complete. Study subjects had some difficulty responding to items such as "My good health is largely a matter of good fortune."

Implications of the Study

The findings of this study have implications for nursing practice, theory, and research.

Nursing Practice

Each woman with breast cancer interprets the illness in terms of personal beliefs, goals and values. The results of this study suggest that women with breast cancer and receiving chemotherapy may appraise the meanings of illness and treatment differently at initial treatment, mid-treatment, and treatment follow-up. Nurses need to acknowledge within and between subject differences at different points in the treatment cycle in order to help women develop effective coping strategies to promote both short-term and long-term adjustment.

The women in this study were grateful for the opportunity to talk about their feelings and experiences. Women described the experience of talking with a non-judgemental health professional as therapeutic and recommended this for everyone with breast cancer. Ongoing dialogue with the patient will elicit information on feelings and attitudes toward cancer and its treatment. Provision of relevant and effective care is dependent upon supporting patients in expressing how they are experiencing and coping with the illness and treatment. Meaningful care results when nurses are able to work with the patient's own understanding of her situation. Knowing what is of utmost importance to these women, their doubts and uncertainties, is a prerequisite to effective nursing care.

The women in this study reported increased richness in relationships with others, finding new meaning through the experience, and developing new perspectives on their world. One overriding theme from the interview data was growth during the illness experience. Growth demands expression, validation, and encouragement. Higher demands for meaningful living challenges nurses to not restrict their efforts to alleviating physical problems but to place equal emphasis on promoting emotional, psychological and social well-being.

Many women in this study identified problems fulfilling work, family, and social roles. More emphasis should be placed on the importance of minimizing role disruptions and managing problematic role changes. Altered relationships with significant others and uncertainty about support suggest that nurses need to assess family functioning and, where possible, include family members from the onset. Nursing actions should focus on supporting and reassuring family members who may need to ventilate their problems and concerns. The involvement of significant others, hopefully, would help facilitate greater understanding and communication between these women and their support systems.

Patients with nebulous relationships with significant others, or who lack this kind of support, especially need the nurse's attention and support. Relationships with a

supportive nurse and an understanding physician are very important. The nurse could serve as an empathic listener and understanding supporter, and help these women identify and use alternate resources such as cancer support groups and self-help groups. For those with or without strong interpersonal supports, contacts through support groups could provide these women with greater opportunities for sharing feelings and concerns, positive interactions, and much needed sources of aid, affection, and affirmation from women who have undergone a similar experience.

The findings also suggest that negative or unfavourable attitudes toward an illness should be used rather than disease severity for identifying subjects requiring referral to psychosocial services. Greater clinical efforts are needed to help patients with unfavourable views of their illness to achieve a more optimistic, hopeful, and satisfied outlook. As well, subjects with a favourable and hopeful outlook, should be encouraged to maintain hope.

The negative impact on body image was another important finding of this study. One of nursing's goals should be to promote a positive body image and increased self-esteem. The woman's perceived self and ideal self should be explored for important clues to level of body image and self-esteem functioning. Realistic expectations and goals are important prerequisites to attaining a positive body image and healthy

readjustment to life.

Women in this study experienced stress related to the uncertainties of illness and treatment. Nurses can and should do more to deal with such thoughts, feelings, and beliefs. Nurses need to be aware of what constitutes appraisal in order to assess whether uncertainties can be reduced or alleviated through further knowledge or clarification. As nurses we need to be more sensitive to patients uncertainties and perceptions of threat, and explore alternatives for best handling the stress of the situation. It is necessary to encourage the patient to have hope for a good outcome, but at the same time help her to acknowledge uncertainty without being fearful of it.

Study findings demonstrated that beliefs about being in control are associated with positive perceptions of the illness and less uncertainty. Some subjects actively engaged in activities believed to decrease recurrence. Exercise, healthy eating and lifestyle changes were used to promote health. Such self-help behaviours may reinforce feelings of control. Self-help groups that are also helpful in promoting and maintaining a sense of control. Women with breast cancer should also be educated to engage in regular breast self examination, as an effective means of promoting early detection and treatment. As patient educators, nurses are in a particularly important position (because of their

access to clients in all settings) to provide information on breast self examination, and health promotion strategies, such as healthy life style behaviours.

Nurses can promote patients control by helping them become more aware of alternatives and their consequences, and by recommending ways to more adequately control stressful factors in the environment. A sense of powerlessness may be reduced by having the person identify stressors and effective strategies to deal with them. However, it is important to respect differences in control preferences. Nurses must support those who want to be more involved in decision making and those for whom decision making would be too overwhelming. It is important not to push control on anyone not ready to assume such responsibility for it may serve to heighten stress.

The frequency with which nurses were identified as sources of verbal and written information suggests nurses are accepted and recognized in this role. Nurses occupy a key position in fostering information flow and evaluating individual reactions and understandings. Ideally information about the disease, planned treatments, and possible secondary effects should be given on two or more occasions with ample time for questions. Because the time between diagnosis and surgery is highly stressful, a slow thoughtful approach to information provision is necessary.

Further, nurses must support whatever decision the individual reaches if they are confident that it was an informed choice.

Coping strategies varied among individuals and within individuals over time. As health care professionals nurses must understand the coping process in order to respect each woman's preference and style. Nurses must listen to concerns and provide information in a way that recognizes individual differences in preference for treatment information and that these differences may represent equally adaptive coping styles. The professional person needs to be aware that the need to teach does not supersede the patients need to learn. Nurses can also advocate on behalf of patients who want information but are reluctant to speak up. Patients can be reminded to ask questions on rounds or during clinic visits. Most of all, patients must be supported in their search for information and their right to know. As patient advocates and coordinators of care, nurses can encourage other health care providers to continuously provide patients and their families with information about the disease, care and treatment.

Nursing Theory

Lazarus and Folkman's (1984) cognitive-phenomenological theory of stress, appraisal and coping provided a useful framework for this study. The theory is also useful for

nursing practice because it provides a framework for understanding how stressful events such as breast cancer and its treatment are appraised and how people cope with and adjust to illness. Furthermore, it also accounts for the influence of perceptions of control and feelings of uncertainty on the appraisal process. Successful adaptation involves a process of appraisal and reappraisal which directs individuals to choose the most effective coping strategies. Knowledge of these processes is crucial to determining the needs of women with breast cancer and developing effective interventions to facilitate healthy responses to cancer and treatment.

Nursing Research

This investigation has generated the following recommendations for future nursing research:

1. Replicate the study with a larger more representative sample of women with breast cancer. With increased sample size, there will be greater confidence in the generalizability of the results.
2. Further research is needed to determine the degree to which women appraise their breast cancer situation as a loss, threat, and/or challenge.
3. Perceptions of control and feelings of uncertainty accounted for a large amount of variance in cognitive appraisal of illness and treatment. More studies are

needed to support the relationships identified in this study with a larger population of women with breast cancer as well as other populations with various cancers.

4. Loss and its impact on body image was a major theme for women with breast cancer. A study could be conducted to examine the extent to which perceptions of loss and altered sense of self impact the quality of life for women with breast cancer.

5. Information giving, especially by nurses, was an important tool used by study participants to help them cope with breast cancer and treatment. A study could be conducted to determine the efficacy of a structured teaching program in meeting the informational needs of women with breast cancer and in generating more positive coping outcomes.

6. Sharing experiences with others was an important means of reducing uncertainty. Research is needed to determine the influence of social support on coping strategies to deal with uncertainty.

7. The high stress associated with diagnosis and treatment choice may interfere with patients' ability to absorb the information provided. Research is needed to determine how nurses provide information to patients about illness and treatment at the initial stage of

illness when they are most anxious and fearful.

8. Meanings of illness and treatment evolved within an experiential context. Future research should be undertaken to obtain information about the influence of others on patients perceptions and interpretations.

9. Structured instruments were not comprehensive enough to capture changes in meanings over time.

Therefore, it is recommended that a triangulation of methods or qualitative data be used to investigate meanings of illness.

Conclusions

The purpose of this research was to investigate factors shaping meanings of illness and treatment for women experiencing breast cancer for the first time, to ascertain how beliefs about control and feelings of uncertainty affected meanings, and to determine if meanings, control, and uncertainty changed over time. Despite the limitations of the present study, the following conclusions are drawn from the results.

A description of factors guiding perceptions of illness and treatment at varying stages of the illness along with knowledge about the influence of perceptions of control and feelings of uncertainty on these meanings would be helpful in planning effective and comprehensive nursing interventions and improve the quality of life women

experience.

Although the relationship was not statistically significant quantitative data findings indicated that factors shaping meanings varied from initial treatment to follow-up. Failure to obtain the expected significant changes in meanings over time may be explained, in part, by the small sample size and large individual and within group variability. Qualitative data validated changes in meaning factors over time. Women with breast cancer have a number of perceptions and fears that are different at initial treatment, mid-treatment and follow-up.

Quantitative and qualitative data indicated that beliefs about control and feelings of uncertainty significantly contributed to the cognitive appraisal of illness and treatment. Positive meanings were associated with perceptions of internal control along with decreased feelings of uncertainty. Conversely, negative meanings were associated with perceptions of external locus of control and increased feelings of uncertainty.

The importance of information surfaced as a recurrent theme. Information helped with understanding the illness, treatment, and the long-term adjustments required in lifestyle and coping with the uncertainty of recurrence. This information was central to patients' cognitive control.

Desire for control whether actual or potential,

informational or predictable, prevailed in a number of ways. It was expressed as: (1) loss of control over one's health, such as feeling powerless in altering the disease process, and uncertainty of illness outcomes following treatment, and, (2) perceived weakening of supports, for example, questioning continued acceptance by significant others following physical alterations and understanding the psychological trauma experienced by family and friends.

What was perceived to be absent was the ability to influence or shape health by engaging in illness prevention or health promotion behaviours. Perceptions of "actually" having control of one's health were dampened by the uncertainty of recurrence. The meaning of control here is the desire for predictability. Predictability may be enhanced through informational control - a form of cognitive control.

However, as many of the respondents noted, information about illness outcomes and long term effects were lacking, that is, most felt inadequate in making an informed choice about treatment regimes despite the provision of sufficient information immediately following diagnosis; no one could tell them about the chances for recurrence or about future outcomes. The absence of feelings of having good control over treatment choices left some of these women with the nagging question of "what if...?"

In conclusion, the results of the study have specific implications for nursing practice, theory and research, and have wide-ranging implications for future nursing research studies in the area of breast cancer.

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Appendix A

Letter Seeking Agency Approval

1992

Director, Newfoundland Cancer Clinic

Dear ,

This letter requests permission to conduct a nursing research study at the Newfoundland Cancer Clinic. I am a graduate student, School of Nursing, Memorial University of Newfoundland. The proposed study is part of the requirement for the degree of Master of Nursing and is under the supervision of Dr. Christine Way.

The purpose of the study is to investigate changes that occur in illness meanings in a sample of women experiencing breast cancer for the first time and receiving chemotherapy treatment.

Permission is sought to interview patients with breast cancer at the Newfoundland Cancer Clinic. A time line for data collection is attached. Each interview will last approximately 45 minutes. Participation in the study will be entirely voluntary and confidentiality will be ensured. It is anticipated that the information from this study will contribute to the knowledge base guiding patient care. Knowledge of the time periods and situations where interventions are most critical is significant to health care providers in general and nurses in particular.

The time commitment anticipated for clinic personnel will be minimal. The chemotherapy nurse coordinator will be asked to approach patients who meet the study's criteria to obtain permission for their names to be released to me. I will be responsible for: approaching patients who have agreed to be contacted; providing an explanation of the study; obtaining a written consent indicating willingness to participate in the study; and carrying out the data collection. I anticipate that data collection will require approximately three to six months.

Enclosed is a copy of my research protocol, including instruments and consent form which have been approved by the Human Investigation Committee of Memorial University of Newfoundland.

The name of your institution will be confidential and will not be identified in any discussion or written report.

I will be pleased to meet with you to clarify the institution's role in the study. Findings will be shared with the clinic upon completion of the study. Should you wish to contact me by telephone, I may be reached at my home number 364-2717 or at my work number 737-6486.

Thank you for your consideration of my request. I look forward to a reply at your earliest convenience.

Sincerely,

Pamela Baker, B.N., R.N.

Enclosure

Appendix B
Letter to Oncologist

1992

Dr.
Newfoundland Cancer Clinic
St. John's, Newfoundland

Dear Dr. ,

I am writing to request your assistance in conducting a nursing research study at the Newfoundland Cancer Clinic using a sample of patients with breast cancer. I am a graduate student, School of Nursing, Memorial University of Newfoundland. The study is part of the requirement for the degree of Master of Nursing and is under the supervision of Dr. Christine Way.

The purpose of the study is to investigate changes that occur in illness meanings in a sample of women experiencing breast cancer for the first time and receiving chemotherapy treatment.

Patients with breast cancer will be interviewed in the Newfoundland Cancer Clinic following diagnosis and prior to or during the first chemotherapy treatment, mid-way through therapy and six weeks following completion of treatment. Each interview will last approximately 45 minutes. Participation in the study will be entirely voluntary. Confidentiality of the participants will be preserved. It is anticipated that information obtained during this study will contribute to the knowledge base guiding patient care. Knowledge of the time periods and situations where interventions are most critical is significant to health care providers in general and nurses in particular.

The time commitment anticipated for clinic personnel will be minimal. The chemotherapy nurse coordinator will be asked to approach patients who meet the study's criteria to obtain permission for their names to be released to me. I will be responsible for: approaching patients who have agreed to be contacted; providing an explanation of the study; obtaining a written consent, indicating willingness to participate in the study; and carrying out all data collection. I anticipate that data collection will require approximately three to six months.

Enclosed is a copy of my research protocol, including instruments and consent form which have been approved by the Human Investigation Committee of Memorial University of Newfoundland. Should you require additional information or wish to meet with me, you may contact me by telephone. I may be reached at my home number 364-2717 or at my work number 737-6486.

Thank you for considering my request. I look forward to a reply at your earliest convenience.

Sincerely,

Pamela M. Baker, B.N., R.N.

Enclosure

Appendix C
Letter to Hospital

1992

Chief of Staff
Hospital
St. John's, Newfoundland

Dear ,

I am a graduate student, School of Nursing, Memorial University of Newfoundland. The Human Investigation Committee of the Faculty of Medicine, Memorial University of Newfoundland has granted approval for a nursing research study "Illness Meanings and Perceptions of Control and Uncertainty in Women with Breast Cancer." The proposed study is part of the requirement for the degree of Master of Nursing and is under the supervision of Dr. Christine Way.

The purpose of the study is to investigate changes that occur in illness meanings in a sample of sixty women experiencing breast cancer for the first time and receiving chemotherapy treatment.

Permission has been requested to conduct the study in the Newfoundland Cancer Clinic. A time line for data collection is attached. In the event that a patient requires hospitalization during either of the data collection periods, permission is sought to interview patients in the General Hospital. Each interview will last approximately forty-five minutes. Participation in the study will be entirely voluntary and confidentiality will be ensured. It is anticipated that the information from this study will contribute to the knowledge base guiding patient care. Knowledge of the time periods and situations where interventions are most critical is significant to health care providers in general and nurses in particular.

No commitment of time is anticipated for hospital personnel. I will be responsible for: approaching patients who have agreed to be contacted; providing explanation of the study; obtaining a written consent to participate in the study; and carrying out the data collection.

Enclosed is a copy of my research protocol, including instruments and consent form which have been approved by the Human Investigation Committee of Memorial University of Newfoundland.

The name of your agency will be confidential and will not be identified in any discussion or written report.

Should you require additional information or wish to meet with me you may contact me at 364-2717 or 737-6486.

Thank you for your consideration of my request. I look forward to a reply at your earliest convenience.

Sincerely,

Pamela M. Baker, B.N., R.N.

Enclosure

Appendix D

Letter to Nursing Manager

1992

Nursing Manager
Newfoundland Cancer Clinic
St. John's, Newfoundland

Dear ,

I am writing to request your assistance in order to conduct a nursing research study at the Newfoundland Cancer Clinic. I am a graduate student, School of Nursing, Memorial University of Newfoundland. The proposed study is part of the requirement for the Degree of Master of Nursing and is under the supervision of Dr. Christine Way.

The purpose of the study is to investigate changes that occur in illness meanings in a sample of women experiencing breast cancer for the first time and receiving chemotherapy treatment.

Patients with breast cancer will be interviewed in the Newfoundland Cancer Clinic following diagnosis and prior to or during the first chemotherapy treatment, mid-way through therapy and six weeks following completion of treatment. Each interview will be carried out at a time that is convenient for the patient. It will last approximately 45 minutes.

Your assistance and cooperation is requested in order to identify suitable patients for the study. In order that confidentiality be assured, I would like you to approach patients who meet selection criteria and ask whether I may visit in order to provide a thorough explanation of the study. I am enclosing a list of patient selection criteria, as well as guidelines to assist you in requesting permission to release the patient's name to me. I will meet with you, or your delegate, once a week in order to obtain the names of patients who have agreed to release of names to me. I will be responsible for approaching patients, explaining the study, and if interested in participating, obtaining an informed signed consent. I will also be responsible for all the data collection. I expect that data collection will require approximately three to six months.

It is anticipated that the information obtained in this study will contribute to the knowledge base guiding patient care. Knowledge of the time periods and situations where

interventions are most critical is significant to health care providers in general and nurses in particular. I will be pleased to share the findings with you and your nursing staff upon completion of the study.

I will make an appointment to meet with you prior to commencing the study, so that I may provide any further information which you may require. Should you wish additional information please contact me at my home number 364-2717 or at 737-6486.

Thank you for considering my request. I look forward to meeting you at your earliest convenience.

Sincerely,

Pamela M. Baker, B.N., R.N.

Enclosure

Appendix E

Selection Criteria to be Utilized by Nursing Manager

All participants of the study must meet the following criteria:

1. A first diagnosis of breast cancer.
2. Discharged from hospital and referred to the Newfoundland Cancer Clinic.
3. Scheduled to receive and/or receiving chemotherapy.
4. Nineteen years of age or over.
5. Able to understand, read and speak English.
6. Physically and mentally competent to participate in the study.

Appendix F

Initial Permission Form

Nursing Manager's Guidelines to Request Permission to
Release Patient's Name to Investigator

Please explain about the study being carried out in this clinic by Mrs. Pamela Baker, a registered nurse in the Master of Nursing Program at Memorial University. She would like to interview people like yourself who are receiving chemotherapy and ask questions about your feelings regarding your illness and treatment. The findings from this study are expected to help you and other patients better adjust to the chemotherapy experience.

Mrs. Baker would like to meet with you and explain the study and answer any questions you may have. I would like to emphasize that you are not in anyway obligated to participate in Mrs. Baker's study and your decision will not influence the care you receive at the clinic.

Would you be willing to have Mrs. Baker contact you so that she may explain the study in greater detail?
Thank you.

Appendix G

FACULTY OF MEDICINE
MEMORIAL UNIVERSITY OF NEWFOUNDLAND
ST. JOHN'S, NEWFOUNDLAND A1B 3V6

CONSENT TO PARTICIPATE IN BIO-MEDICAL RESEARCH

RESEARCH STUDY TITLE: Illness meanings and perceptions of
 control and uncertainty in women
 with breast cancer.

INVESTIGATOR: Pamela Baker Telephone: 364-2717

You have been asked to participate in a research study. Participation in this study is entirely voluntary. You may decide not to participate or may withdraw from the study at any time without affecting your normal treatment.

Confidentiality of information concerning participants will be maintained by the investigator. The investigator will be available during the study at all times should you have any problems or questions about the study.

Purpose of study

This study is being conducted to obtain information about the feelings and experiences that patients have in relation to their illness and treatment. Results of the study will assist nurses and other health care providers to help patients who are receiving chemotherapy.

Description of procedures and tests

Your participation will entail placing a check mark for your responses to statements on two questionnaires. You will be asked some questions about the history of your illness and how you are adjusting. Permission is requested to audiotape this portion of the interview and to obtain information regarding other diagnosed medical conditions and current medications from your clinic chart.

You may refuse to answer any specific questions. Your name will not be recorded with your answers and you will not be personally identified in any report of the study.

At the end of the study all questionnaires and audiotapes will be destroyed.

Duration of subjects participation

Length of the study will be from the time of your first visit to the Newfoundland Cancer Clinic to six weeks following completion of your chemotherapy treatment. Your participation will consist of two or three interviews, each lasting approximately 45 minutes. The interviews will be at the time of your first or second visit to the clinic, midway through your treatment cycle, and six weeks after you have completed treatment. The interviews will take place, while you are in the clinic, at a time that is convenient for you.

Foreseeable risks, discomforts, or inconveniences

There are no expected risks. The inconvenience is in giving 45 minutes of your time to the investigator and placing check marks on the two questionnaires.

Benefits which the subject may receive

You may not benefit directly from the study. However, the opportunity to share your experiences with a health care professional may be of help to you.

Alternative procedures or treatment for those not entering the study.

The decision to take part in the study is yours. Your decision, will not in any way, affect the care you receive. Should you decide at any time to withdraw from the study, you are free to do so. Patients not entering the study will receive treatment as usual.

"I, _____, the undersigned, agree to my participation in the research study described above."

Any questions have been answered and I understand what is involved in the study. I realize that participation is voluntary and that there is no guarantee that I will benefit from my involvement. I acknowledge that a copy of this form has been offered to me.

(Signature of Participant)

(Date)

(Signature of Witness, optional)

To be signed by investigator:

To the best of my ability I have fully explained to the subject the nature of this research study. I have invited questions and provided answers. I believe that the subject fully understands the implications and voluntary nature of the study.

(Signature of Investigator)

(Date)

Phone Number _____

Appendix H

ID Code _____

ILLNESS MEANINGS AND PERCEPTIONS OF
CONTROL AND UNCERTAINTY IN
WOMEN WITH BREAST CANCER

PATIENT QUESTIONNAIRE

INTERVIEW SCHEDULEINTRODUCTION

The purpose of this interview is to gather information about how patients feel about their illness and treatment.

The interview consists of four sections. I will read the purpose of each section and the directions for the section. Should you not understand the directions that I ask, please feel free to ask me to explain.

Thank you for participating in this study.

Pamela M. Baker
Graduate Student
School of Nursing
Memorial University of Newfoundland

ID Code _____
 Section _____

SECTION A

MEANING IN ILLNESS QUESTIONNAIRE - SR (1992)

The purpose of the following section is to ask you a few specific questions about your illness. Please circle the number that best describes your response.

0	1	2	3	4	5	6	
<u>Not at all</u>		<u>Somewhat</u>			<u>Definitely yes</u>		

Has this illness negatively affected:

- | | | | | | | | | |
|---|---|---|---|---|---|---|---|-------|
| 1. How you live day to day? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 2. How you get along with friends? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 3. How you get along with your family? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 4. Your job, school or daily work activities? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |

Would you describe this illness as:

- | | | | | | | | | |
|-----------------|---|---|---|---|---|---|---|-------|
| 5. Harmful? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 6. Threatening? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 7. A loss? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 8. A challenge? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |

Do you see this illness as something that:

- | | | | | | | | | |
|------------------------|---|---|---|---|---|---|---|-------|
| 9. Will go away? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 10. Will stay forever? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 11. Will come and go? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |

ID Code _____
 Section _____

Do you see this illness as:

- | | | | | | | | | |
|---|---|---|---|---|---|---|---|-------|
| 12. Disabling - causing a loss of physical activity or strength? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 13. Disfiguring - causing an appearance change for the worse? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 14. Deteriorating - getting worse? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 15. Would you rate the experience of this illness as stressful or worrying? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 16. Did you expect this illness before the doctor told you? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 17. Do you think you played a part in the occurrence of this illness? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 18. Are you certain about how things will turn out, such as effectiveness of treatment? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 19. Do you believe it is likely that this illness will reoccur, or a second illness like it will occur? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 20. Do you think things will turn out well? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 21. Are you determined to try to function independently, in spite of this illness? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |

In terms of this illness to what extend do you feel:

- | | | | | | | | | |
|--|---|---|---|---|---|---|---|-------|
| 22. You could change or do something about it? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 23. You have to accept it? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |

ID Code _____
 Section _____

- | | | | | | | | | |
|---|---|---|---|---|---|---|---|-------|
| 24. You need to know more before
you can act? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 25. You have to hold back from
doing what you want? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 26. You have changed, for the
better, what you care about? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 27. Do you believe you have a lot
of say regarding the things
you care about? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 28. Do you feel you have the
energy and stamina to get
through this? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 29. Are you pleased with your
outlook on things? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 30. Are you pleased with the way
you are handling things? | 0 | 1 | 2 | 3 | 4 | 5 | 6 | _____ |

Used with the permission of Jacqueline Roberts.

ID Code _____
 Section _____

Section B

Multidimensional Health Locus of Control Scale - Form A

The purpose of this section is to determine the way in which different people view certain important health-related issues. Each item is a belief statement 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 circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly 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.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think I want you to believe.

1	2	3	4	5	6					
Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree					
<hr/>										
1.	If I get sick, it is my own behavior which determines how soon I get well again.			1	2	3	4	5	6	_____
2.	No matter what I do, If I am going to get sick, I will get sick.			1	2	3	4	5	6	_____
3.	Having regular contact with my physician is the best way for me to avoid illness.			1	2	3	4	5	6	_____
4.	Most things that affect my health happen to me by accident.			1	2	3	4	5	6	_____

ID Code _____
 Section _____

5. Whenever I don't feel well, I should consult a medically trained professional. 1 2 3 4 5 6 _____
6. I am in control of my health. 1 2 3 4 5 6 _____
7. My family has a lot to do with my becoming sick or staying healthy. 1 2 3 4 5 6 _____
8. When I get sick, I am to blame. 1 2 3 4 5 6 _____
9. Luck plays a big part in determining how soon I will recover from an illness. 1 2 3 4 5 6 _____
10. Health professionals control my health. 1 2 3 4 5 6 _____
11. My good health is largely a matter of good fortune. 1 2 3 4 5 6 _____
12. The main thing which affects my health is what I myself do. 1 2 3 4 5 6 _____
13. If I take care of myself, I can avoid illness. 1 2 3 4 5 6 _____
14. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me. 1 2 3 4 5 6 _____
15. No matter what I do, I'm likely to get sick. 1 2 3 4 5 6 _____
16. If it's meant to be, I will stay healthy. 1 2 3 4 5 6 _____
17. If I take the right actions, I can stay healthy. 1 2 3 4 5 6 _____
18. Regarding my health, I can only do what my doctor tells me to do. 1 2 3 4 5 6 _____

Used with the permission of Kenneth A. Wallston.

ID Code _____
 Section _____

Section B

Multidimensional Health Locus of Control Scale - Form B

The purpose of this section is to determine the way in which different people view certain important health-related issues. Each item is a belief statement 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 circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly 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.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think I want you to believe.

1	2	3	4	5	6			
Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree			
1.	If I become sick, I have the power to make myself well again.	1	2	3	4	5	6	_____
2.	Often I feel that no matter what I do, if I am going to get sick, I will get sick.	1	2	3	4	5	6	_____
3.	If I see an excellent doctor regularly, I am less likely to have health problems.	1	2	3	4	5	6	_____
4.	It seems that my health is greatly influenced by accidental happenings.	1	2	3	4	5	6	_____

ID Code _____
 Section _____

- | | | | | | | | |
|---|---|---|---|---|---|---|-------|
| 5. I can only maintain my health by consulting health professionals. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 6. I am directly responsible for my health. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 7. Other people play a big part in whether I stay healthy or become sick. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 8. Whatever goes wrong with my health is my own fault. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 9. When I am sick, I just have to let nature run its course. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 10. Health professionals keep me healthy. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 11. When I stay healthy, I'm just plain lucky. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 12. My physical well-being depends on how well I take care of myself. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 13. When I feel ill, I know it is because I have not been taking care of myself. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 14. The type of care I receive from other people is what is responsible for how well I recover from an illness. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 15. Even when I take care of myself, it's easy to get sick. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 16. When I become ill, it's a matter of fate. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 17. I can pretty much stay healthy by taking good care of myself. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |
| 18. Following doctor's orders to the letter is the best way for me to stay healthy. | 1 | 2 | 3 | 4 | 5 | 6 | _____ |

ID Code _____
Section _____**Section C - Part 1****Cancer Meaning Questionnaire**

The purpose of this section is to determine how you feel about this illness and chemotherapy, as well as your family's reaction to your illness. There are no right or wrong answers. Your responses simply indicate your personal feelings. I will ask you six questions. I will also ask you to rate ten words as to how they describe your feelings.

1. What does having this illness
mean to you? _____
2. What has caused the most uncertainty
for you during this illness? _____
3. How useful have past approaches been in
helping you cope with any uncertainty
generated by this illness? _____
4. What meaning does chemotherapy have for you? _____
5. How would you describe your family's reaction
to your illness and treatment? _____
6. How can nurses be most helpful for you at this
time? _____

ID Code _____
Section _____

Section C - Part 2

Comments

1. _____

2. _____

3. _____

4. _____

5. _____

6. _____

ID Code _____
 Section _____

This is a questionnaire designed to determine your feelings about this illness, anticipated outcomes and chemotherapy. Each item is a word which describes your feelings. Beside each item is a scale which ranges from 1 to 10. For each item please circle the number that best represents your feelings at the present time. The more positive you feel about the illness and its outcome or about chemotherapy the higher will be the number you circle. The more negative you feel about the illness and its outcome, and chemotherapy, the lower will be the number you circle.

How would you rate the following in terms of your feelings about this illness and anticipated outcomes?

- | | | | |
|--------------------|----------------------|--------------|-------|
| 7. Bad | 1 2 3 4 5 6 7 8 9 10 | Good | _____ |
| 8. Negative | 1 2 3 4 5 6 7 8 9 10 | Positive | _____ |
| 9. Uncertain | 1 2 3 4 5 6 7 8 9 10 | Certain | _____ |
| 10. Hopeless | 1 2 3 4 5 6 7 8 9 10 | Hopeful | _____ |
| 11. Uncontrollable | 1 2 3 4 5 6 7 8 9 10 | Controllable | _____ |

How would you rate the following in terms of your feelings about chemotherapy at the present time?

- | | | | |
|----------------------|----------------------|-------------|-------|
| 12. Highly Stressful | 1 2 3 4 5 6 7 8 9 10 | Stress Free | _____ |
| 13. Hopeless | 1 2 3 4 5 6 7 8 9 10 | Hopeful | _____ |
| 14. Uncertain | 1 2 3 4 5 6 7 8 9 10 | Certain | _____ |
| 15. Weakens | 1 2 3 4 5 6 7 8 9 10 | Strengthens | _____ |
| 16. Painful | 1 2 3 4 5 6 7 8 9 10 | Painless | _____ |

ID Code _____
Section _____Section D
Personal Profile Sheet

The following questions are designed to help me collect general information about the people who are participating in the study. I will read each question.

- I. What is your marital status?
1. single
 2. married
 3. widow
 4. divorced
 5. separated
 6. other
- II. What is your age: _____
- III. Number of children: _____ Age: _____
- IV. Place of residence: _____
- V. What level of education did you complete?
1. less than high school.
 2. some high school.
 3. high school graduate.
 4. some university or college.
 5. university or college graduate.
 6. some post graduate courses.
 7. master's degree or higher.
- VI. What is your current occupational status?
- _____
- VII. Have you experienced any disruption in your work routine?
(eg. loss of time). _____
- VIII. How long has it been since you were first diagnosed with cancer?
- _____

ID Code _____
Section _____

IX. What are your supports?

Family _____

Other _____

Information to be obtained from chart:

X. Time interval since hospitalization. _____

1. three days
2. four days to one week
3. one week to two weeks
4. two weeks to one month
5. more than one month

XI. Length of hospitalization? _____

1. four days to one week
2. one week to two weeks
3. two weeks to one month
4. more than one month

XII. Did you have surgery? Yes _____ No _____

If yes, describe the type of surgery.

XIII. Type of chemotherapy treatment?

XIV. Medical diagnoses other than Cancer?

ID Code _____
Section _____

XV. Current medications?

Thank you for your cooperation!



Office of Research and Graduate Studies (Medicine)
Faculty of Medicine, The Health Sciences Centre

Appendix I

March 5, 1992.

Reference #1026

Ms. Pamela Baker,
Graduate Student,
General Hospital,
School of Nursing,
Southcott Hall,
Forest Road, St. John's,
A1A 1E5.

Dear Ms. Baker:

This will acknowledge, with thanks, the revised consent form for your research study entitled "Illness Meanings and Perceptions of Control and Uncertainty in Women with Breast Cancer." This consent form is now approved as it contains the modifications requested by the Human Investigation Committee.

Yours sincerely,

Sandra Kelly,
Admin. Staff Specialist &
Secretary, HIC Committee.

SK/ts



NEWFOUNDLAND CANCER TREATMENT AND RESEARCH FOUNDATION

NEWFOUNDLAND CANCER CLINIC

Health Sciences Centre, Prince Philip Drive
St. John's, Newfoundland A1B 3V6 (709) 737-6480

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March 25th., 1992

Pamela Baker, B.N., R.N.
10 Cowan Avenue
St. John's, Nfld.
A1E 3N5

Appendix J

Dear Ms. Baker:

Sorry for the delay in replying to your letter dated Feb. 26th., 1992. Your letter of application, research protocol including instruments and consent form had been forwarded on to our Research Committee Members for review as per clinic policy. I am now pleased to inform you approval has been granted as per outlined in your letter of request.

You understand this is confidential information and the Foundation's rules of confidentiality will apply. I understand you have been in contact with Vivien Wass and she has agreed to assist you by approaching patients who meet the study's criteria and obtaining permission for their names to be released to you.

Yours sincerely,

Alan Kwan, M.D.
F.R.C.S., (C), F.A.C.S.
Medical Director
Nfld. Cancer Treatment
Research Foundation



To: Fellow Health Researcher Appendix K
From: Kenneth A. Wallston, Ph.D.

Thank you for your interest in the Health Locus of Control Scales. Please excuse this form response, but I have so many inquiries requiring similar replies that I have found this to be an efficient means of disseminating information.

You have my permission to utilize Form A or B of the MHLC scales in any health related research you are doing. My only request is that you keep me informed of any results you obtain using the scales. In that way I hope to continue to serve as a clearinghouse for information about the scales.

We have recently developed Form C of the MHLC scales, an instrument which can easily be made specific to any existing medically-related condition which your subjects might have (e.g., diabetes, cancer, high blood pressure, migraine headaches, arthritis, chemical dependencies, etc.) We have used Form C as an "Arthritis Locus of Control Scale" and are generally pleased with its psychometric properties. If you think such an instrument would be helpful in your research and if you are willing to share your data back with us, we would be pleased to make it available to you.

If you wish us to send you additional material, please complete and return the enclosed form. For most items there is a small charge to cover duplication and postage.

If you have more specific questions, don't hesitate to contact me. Please remember to send me information on any use you make of these scales. I have included a usage questionnaire to facilitate your doing so. I look forward to hearing from you.

P.S. I have enclosed a copy of a brief article I just wrote on the importance of placing measures of Health Locus of Control in a Theoretical Context. I hope you find it interesting and stimulating.

8/90



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Appendix L

April 9, 1991

Pamela M. Baker
Assistant Director
General Hospital School of Nursing
Southcott Hall, Forest Road
St. John's, Newfoundland A1A 1ER

Dear Ms. Baker:

Re: Meaning of Illness Questionnaire

In response to your inquiry of March 25, 1991, I am enclosing our latest draft version of the above named questionnaire. Since it is currently under revision, I have enclosed the corresponding factor scales. There is no charge.

Good luck on your study. I would be pleased to be forwarded the results on its completion.

Sincerely,

Jacqueline Roberts, Reg. N., M. Sc.
Assistant Professor
School of Nursing
McMaster University

JR/hh

Encls.



THE GENERAL HOSPITAL

THE HEALTH SCIENCES CENTRE
St. John's, Newfoundland, Canada A1B 3V6

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OPERATED BY
THE GENERAL HOSPITAL
CORPORATION

Appendix M

Telephone: (709) 737-8300
Office: (709) 737-

1992 05 12

TO: Ms. Pamela Baker

FROM: Executive Director

SUBJECT: Illness Meanings and Perceptions of Control and
Uncertainty in Women with Breast Cancer.

This is to inform you that the Board of Directors on recommendation of the Medical Advisory Committee recently approved the above investigation being conducted within the Hospital.

D.R. KEATS
Executive Director

DRK/sh

Appendix N

Factor Structure Meaning of Illness Questionnaire

Factor I - Impact

1. Has this illness negatively affected how you live day to day?
2. Has this illness negatively affected getting along with friends?
3. Has this illness negatively affected how you get along with your family?
4. Has this illness negatively affected your job/school?

Factor II - Type of Stress, Attitude of Harm, Loss, Threat, Functional Context

5. Would you describe this illness as something that is harmful?
6. Would you describe this illness as something that is threatening?
7. Would you describe this illness as a loss?
12. Do you see this illness as disabling?
13. Do you see this illness as disfiguring?
14. Do you see this illness as deteriorating?

Factor III - Degrees of Stress, Change in Commitments, Secondary Appraisal

15. Would you rate the experience of this illness as stressful or worrying?
26. Do you feel you have changed for the better what you care about since this illness?
28. Do you feel you have energy and stamina to get through this?
29. Are you pleased with your outlook on things?
30. Are you pleased with the way you are handling things?

Factor IV -Challenge, Positive Attitude, Motivation, Hope

8. Would you describe this illness as a challenge?
20. Do you think things will turn out well?
21. Are you determined to try to function independently in spite of this illness?
22. In terms of this illness, to what extent do you feel you could change or do something about it?
27. Do you have a lot of say regarding the things you care about?

Factor V - Non-Anticipated Vulnerability

16. Was this illness expected before the doctor told you?
17. Do you think you played a part in the occurrence of this illness?
19. Do you believe it is likely that this illness will reoccur?

Appendix O

Summary of Meaning of Illness Questionnaire

Question		Time			Change	
#	Text	1	2	3	T ₂ -T ₁	T ₃ -T ₂
FACTOR I						
1R	Has this illness negatively affected how you live day to day?	3.077	2.308	2.692	-0.769	+0.384
2R	Has this illness neg. affected how you get along with friends?	5.077	4.385	4.538	-0.692	+0.153
3R	Has this illness neg. affected how you get along with your family?	4.385	3.846	3.692	-0.539	-0.154
4	Has this illness neg. affected your job, school or daily work activities?	3.231	2.615	3.769	-0.616	+1.154
Factor II						
5R	Would you describe this illness as harmful?	3.231	2.077	2.692	-1.154	+0.615
6R	Would you describe this illness as threatening?	2.077	2.846	2.077	+0.769	-0.769
7R	Would you describe this illness as a loss?	3.462	2.231	2.923	-1.231	+0.692
12R	Do you see this illness as disabling - causing a loss of physical activity or strength?	3.615	2.308	2.923	-1.307	+0.615
13R	Do you see this illness as disfiguring - causing an appearance change for the worse?	4.308	3.462	3.615	-0.846	+0.153
14R	Do you see this illness as deteriorating - getting worse?	4.846	4.692	4.923	-0.154	+0.308

Factor III						
15R	Would you rate the experience of this illness as stressful or worrying?	0.923	1.615	1.692	+0.692	+0.077
26	In terms of this illness, to what extent have you changed for the better, what you care about?	3.615	4.769	4.308	+1.154	-0.461
28	In terms of this illness to what extent do you feel you have the energy and stamina to get through this?	5.154	5.308	5.385	+0.154	+0.077
29	In terms of this illness, to what extent are you pleased with your outlook on things?	5.077	5.308	5.462	+0.231	+0.154
30	In terms of this illness, to what extent are you pleased with the way you are handling things?	5.538	5.231	5.231	-0.307	0.000
FACTOR IV						
8	Would you describe this illness as a challenge?	4.538	4.308	5.154	-0.275	+0.846
20	Do you think things will turn out well?	5.077	5.000	4.692	-0.077	-0.308
21	Are you determined to try to function independently, in spite of this illness?	5.846	5.923	6.000	+0.077	+0.077
22	In terms of this illness, to what extent do you feel you could change or do something about it?	1.846	1.846	2.308	0.000	+0.462
27	In terms of this illness, to what extent do you believe you have a lot of say regarding the things you care about?	4.154	4.462	4.462	+0.308	0.000
FACTOR V						
16R	Did you expect this illness before the doctor told you?	3.846	3.846	4.154	0.000	+0.308
17R	Do you think you played a part in the occurrence of the illness?	5.769	5.000	5.538	-0.769	+0.538
19R	Do you believe it is likely that this illness will reoccur, or a second illness like it will occur?	2.615	2.923	3.077	+0.308	-0.154

Question		Time			Change	
#	Individual Items	1	2	3	T_2-T_1	T_3-T_2
9	Do you see this illness as something that will go away?	4.308	4.231	3.846	-0.077	-0.385
10R	Do you see this illness as something that will stay forever?	5.154	4.538	3.231	-0.616	-1.307
11R	Do you see this illness as something that will come and go?	3.538	3.923	3.154	+0.385	-0.769
18	Are you certain about how things will turn out, such as effectiveness of treatment?	3.385	3.231	3.154	-0.154	-0.077
23R	In terms of this illness, to what extent do you feel you have to accept it?	0.231	0.538	0.538	+0.307	0.000
24R	In terms of this illness, to what extent do you feel you need to know more before you can act?	4.538	4.077	3.692	-0.461	-0.385
25R	In terms of this illness, to what extent do you feel you have to hold back from doing what you want to do?	3.769	3.385	3.846	-0.384	+0.461

Note (R) Reverse Score

Appendix P

Summary of Multidimensional Health Locus of Control Scales

Question		Time			Change	
#	Text	1	2	3	T ₂ -T ₁	T ₃ -T ₂
INTERNAL ITEMS						
1	If I get sick, it is my own behaviour which determines how soon I get well again.	5.538	4.308	4.462	-1.230	+0.154
6	I am in control of my health.	4.769	5.154	4.154	+0.385	-1.000
8	When I get sick, I am to blame.	1.385	1.846	2.077	+0.461	+0.231
12	The main thing which affects my health is what I myself do	4.769	5.462	4.077	+0.693	-1.385
13	If I take care of myself, I can avoid illness.	3.692	2.769	3.615	-0.923	+0.846
17	If I take the right actions, I can stay healthy	4.308	4.692	4.538	+0.384	-0.154
CHANCE ITEMS						
2	No matter what I do, if I am going to get sick, I will get sick	4.077	4.308	3.692	+0.231	-0.616
4	Most things that affect my health happen to me by accident.	3.538	2.846	2.385	-0.692	-0.461
9	Luck plays a big part in determining how soon I will recover from an illness.	1.769	3.923	2.385	+2.154	-1.538
11	My good health is largely a matter of good fortune.	2.692	3.000	2.293	+0.308	-0.077
15	No matter what I do, I'm likely to get sick.	2.923	3.846	2.846	+0.923	-1.000
16	If it's meant to be, I will stay healthy.	4.154	3.231	2.846	-0.923	-0.385

Question		Time			Change	
#	Text	1	2	3	T_2-T_1	T_3-T_2
POWERFUL OTHERS						
3	Having regular contact with my physician is the best way for me to avoid illness.	4.385	3.385	4.231	-1.000	+0.846
5	Whenever I don't feel well, I should consult a medically trained professional.	4.077	3.154	4.154	-0.923	+1.000
7	My family has a lot to do with my becoming sick or staying healthy.	2.769	2.692	2.538	-0.077	-0.154
10	Health professionals control my health	4.000	3.692	3.077	-0.308	-0.615
14	When I recover from an illness, it is usually because other people (ie. doctors, nurses, family, friends, etc.) have been taking good care of me.	4.231	3.769	2.846	-0.462	-0.923
18	Regarding my health, I can only do what the doctor tells me to do.	4.000	4.615	4.538	+0.615	-0.077

Appendix Q

Summary of Cancer Meaning Questionnaire 1
 Feelings About Illness and Anticipated Outcome

Question		Time			Change	
#	Text	1	2	3	T_2-T_1	T_3-T_2
10	Hopeless = 1 Hopeful = 10	8.538	9.000	8.308	+0.462	-0.692
8	Negative = 1 Positive = 10	8.154	8.615	7.846	+0.461	-0.769
7	Bad = 1 Good = 10	7.692	8.000	7.846	+0.308	-0.154
11	Uncontrollable = 1 . . . Controllable = 10	7.385	8.615	6.846	+1.230	-1.769
9	Uncertain = 1 Certain = 10	6.692	7.769	6.692	+1.077	-1.077

Appendix R

Summary of Cancer Meaning Questionnaire 2

Attitudes Toward Chemotherapy At The Present Time

Question		Time			Change	
#	Text	1	2	3	$T_2 - T_1$	$T_3 - T_2$
13	Hopeless = 1 Hopeful = 10	8.692	8.615	8.308	-0.077	-0.307
14	Uncertain = 1 Certain = 10	7.538	8.154	7.231	+0.616	-0.923
16	Painful = 1 Painless = 10	7.000	6.308	5.462	-0.692	-0.846
15	Weakens = 1 Strengthens = 10	6.692	5.385	5.692	-1.307	+0.307
12	Highly Stressful = 1 . . Stress Free = 10	6.615	4.846	4.923	-1.769	+0.077

