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# The Possibility of Breast Cancer Recurrence: Coping with Perceived Threats

by

Suzanne Marie Johnson Vickberg

A dissertation submitted to the graduate faculty in Psychology in partial fulfillment of the requirements for the degree of Doctor of Philosophy, the City University of New York

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# Abstract

The Possibility of Breast Cancer Recurrence: Coping with Perceived Threats

by

Suzanne Marie Johnson Vickberg

Advisor: Tracey A. Revenson, Ph.D.

Previous research has identified fears about recurrence as the number one concern of women with breast cancer. The current study is an in depth-examination of women's fears about the possibility of breast cancer recurrence. First, a pilot study was conducted in which sixteen women participated in semi-structured interviews about their thoughts and feelings regarding the possibility of breast cancer recurrence. Then, one-hundred-sixty-nine women with breast cancer completed a questionnaire assessing fears about recurrence, perceived risk of recurrence, perceived control over recurrence, ongoing consequences of their initial diagnosis (i.e., physical and psychosocial effects of the breast cancer), overall psychological adjustment, strategies used to cope with fears about recurrence, and influential life circumstances.

There was a wide range in terms of how much women feared the possibility of recurrence. Fears about death and health (including physical health, emotional health, and further treatment) were most common. Ongoing consequences of the initial diagnosis were the strongest predictors of fears about recurrence, mediating the influence of age, chemotherapy, mastectomy, and perceived risk. Moreover, fears about recurrence were associated with psychological adjustment, even after controlling for background variables, perceived risk, perceived control, and ongoing consequences of the initial diagnosis. Coping played a limited role in adjustment processes. The use of denial as a strategy for coping with fears about recurrence was associated with increased distress while the use of positive reappraisal was associated with increased well-being. Acceptance moderated the relationship of fears about recurrence to reduced well-being - seeming to work as a buffer, particularly when fears revolved around death or health. Finally, women reported many life circumstances (both positive and negative) that they felt influenced their experience with breast cancer and their thoughts about the possibility of recurrence. These circumstances were also associated with psychological adjustment.

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# CHAPTER ONE: INTRODUCTION

The incidence of breast cancer in American women has increased steadily over the past 50 years, culminating in the present 1 in 8 lifetime risk for developing the disease (American Cancer Society, 1999). As scientists struggle to improve methods of prevention, early detection, and treatment, rising numbers of women are living with breast cancer for longer periods of time. In response to this trend, clinical researchers have increasingly focused on quality of life issues and psychosocial adjustment to the disease. Research has found that although approximately 20-30% of women with breast cancer experience significant psychological distress, this distress is substantially reduced in the year following diagnosis, and the majority of women with breast cancer are well adjusted (Carver et al., 1993; Glanz & Lerman, 1992; Goldberg et al., 1992; Irvine, Brown, Crooks, Roberts, & Browne, 1991; Leinster, Aschcroft, Slade, & Dewey, 1989; Omne-Ponten & Sjoden, 1994; Schain, Wellisch, Pasnau, & Landsverk, 1985; Stanton & Snider, 1993).

Despite the evidence that women adjust well to breast cancer, one particular difficulty appears to be shared by an overwhelming majority of women with the disease. From 60 to 99% of women with breast cancer are plagued by ongoing fears that their disease will recur (Metzger, Rogers, & Bauman, 1983; Meyer & Aspegren, 1989; Noguchi et al., 1993; Peters-Golden, 1982; Pistrang & Barker, 1992; Polinsky, 1994; Schover et al., 1995; Sneeuw et al., 1992). The words of one breast cancer survivor illustrate the anxiety caused by this possibility: *"This is what cancer is about to me, living with possible recurrence.*

*Cancer is not about two months of treatment and a couple of minor surgeries... I think the hardest thing for women like me who have found their cancers early and kept their breasts is to believe we are going to get away with all this. Am I* really *going to be OK?"* (Kahane, 1995). Further evidence suggests that fears about breast cancer recurrence, unlike overall psychological distress, do not necessarily dissipate over time. For example, one study found that five years after diagnosis approximately 70% of breast cancer survivors still feared the possibility of recurrence (Mast, 1998). In reality, 57% of women survive to 15 years after diagnosis (American Cancer Society, 1999). Moreover, fears about recurrence are associated with psychological distress among cancer patients and survivors (Metzger et al., 1983; Sneeuw et al., 1992; Timko & Janoff-Bulman, 1985). Together these findings suggest that a more thorough investigation of women's fears about breast cancer recurrence is warranted.

There have been some attempts to determine socio-demographic and treatment characteristics that may influence fears about the possibility of recurrence. In general, the variables that have been examined are those that have been found to predict psychosocial and physical effects of the initial breast cancer diagnosis. Some studies have suggested that fears about recurrence may be associated with the more physically and psychologically aversive treatment protocols such as chemotherapy, or mastectomy as opposed to breast conserving surgery (BCS) (Bartelink, VanDam, & VanDongen, 1985; Kemeny, Wellisch, & Schain, 1988; Lasry et al., 1987; Moyer, 1997; Schover et al., 1995).

However, many other studies have not found these differences (Curran et al., 1998; De Haes, Van Oostrom, & Welvaart, 1986; Ganz, Coscarelli Schag, Polinsky, Heinrich, & Flack, 1987; Mast, 1998; Meyer & Aspegren, 1989). A few studies have examined time since diagnosis as a predictor of fears about recurrence, investigating whether such fears dissipate over time. Although an inverse relationship was identified in at least one study (Lampic et al., 1994), others have found no relation (Mast, 1998; Meyer & Aspegren, 1989; Sneeuw et al., 1992). The most consistent predictor of fears about recurrence is age, with several studies showing that younger women have stronger fears (Curran et al., 1998; Mast, 1998; Metzger et al., 1983; Schover et al., 1995; Walker, 1997), a finding that may be due to multiple factors such as the generally more aggressive nature of breast cancer among younger women, or a sense that a cancer diagnosis early in the life cycle is particularly unexpected or "off schedule".

Although prior research has provided some important information regarding women's fears about breast cancer recurrence, several issues remain in question. First, it is not clear what women fear a recurrence of breast cancer would mean for their lives. What potential effects (e.g., death, further treatment, sexuality issues) do they worry about? Second, we know very little about how women's fears might relate to other factors such as perceived risk of recurrence, perceived control over recurrence, or the ongoing physical and psychosocial effects of the initial diagnosis and treatment. Third, it is not known whether the content of women's fears -- what they fear -- has any bearing on the relationship of those fears to psychological adjustment. For example, are fears about body image as upsetting as fears about further treatment? Finally, little is known about the strategies women use to cope with their fears about recurrence, or the role coping strategies play in the relationship between fears about recurrence and psychological adjustment.

The present research is an in-depth investigation of women's fears about the possibility of breast cancer recurrence. It examines each of the unresolved issues described above. Although these issues have not been addressed in prior empirical investigations with breast cancer survivors, several lines of theory and previous research provide important clues as to the psychological processes involved. I begin with a justification for expecting that women's fears about recurrence would be diverse, encompassing various life domains. I then go on to describe relevant theoretical and empirical work on appraisal, psychological adjustment, and coping. I complete the chapter by outlining the research questions and providing an overview of the research procedures and the chapters that follow.

## Recurrence Poses Multiple Threats

Our expectancies regarding future events are shaped by our past experiences (Fiske & Taylor, 1984; Kirsch, 1999). Thus, women's fears about the possibility of breast cancer recurrence are likely shaped by their previous experiences with breast cancer. Research has documented numerous psychosocial and physical effects of breast cancer, including: emotional difficulties (Ganz et al., 1987; Parle, Jones, & Maguire, 1996), problems associated with sexuality (Andersen & Jochimsen, 1985; Feather & Wainstock, 1989; Kurtz, Wyatt, & Kurtz, 1995; Margolis, Goodman, & Rubin, 1990; Schover et al., 1995; Sneeuw et al., 1992), negative changes in body image (Derogatis, 1986; Glanz & Lerman, 1992; Kasper, 1995; Kemeny et al., 1988; Margolis et al., 1990; Moyer, 1997; Schover, 1994), challenges to one's sense of femininity (Meyer & Aspegren, 1989; Penman et al., 1986; Wellisch et al., 1989), insurance and financial difficulties (Ganz et al., 1987; Polinsky, 1994), pain and suffering (Arathuzik, 1991a; Arathuzik, 1991b; Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992; Pistrang & Barker, 1992), threats to one's self-esteem or self-concept (Charmaz, 1983; Fife, 1994; Ganz et al., 1987; Taylor, 1983), disruptions in daily activities (Ganz et al., 1987; Parle et al., 1996), barriers to carrying out responsibilities, fulfilling important roles, and setting and/or reaching goals (Kahane, 1995; Meyerowitz, Chaiken, & Clark, 1988; Polinsky, 1994), challenges to one's beliefs about the world (Taylor, 1983), and problems with interpersonal relationships (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Lichtman & Taylor, 1986; Pistrang & Barker, 1992). Because the consequences of breast cancer are so numerous and varied, one would expect women's fears about recurrence to be similarly complex. This study addresses what it is about recurrence that women fear, and examines the extent to which ongoing effects of the initial diagnosis (i.e., lingering physical and psychosocial effects) shape women's fears about recurrence.

## Fear of Recurrence: A Specific Approach to Appraisal

Although it is clear why women's fears about recurrence are likely to be multi-faceted, one might ask why it is important to know the content of their fears.

The answer to this question is two-fold. First, there are obvious clinical benefits to understanding a patient's concerns for her future. Addressing those concerns necessitates knowing their nature. But investigating fears about recurrence also serves a more theoretical purpose. In our efforts to understand how people cope with. and adjust to life-threatening illness, one goal has been to determine how a person's perception of the illness relates to other psychological processes. Using Lazarus and Folkman's (1984) terms, it is important to assess how a person's appraisal of the illness influences her coping and adjustment processes.

Lazarus and Folkman have defined appraisal as "the process of categorizing an encounter, and its various facets, with respect to its significance for well-being (p.31)." Appraisal has two components, primary and secondary appraisal (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Lazarus & Folkman, 1984). In primary appraisal an individual evaluates the significance of an event based on her perception of whether it is benign or whether it poses a loss/harm, a threat (i.e., the potential for future loss/harm), or a challenge. Secondary appraisal involves assessing whether one's resources for coping with the stressor are adequate. This process is ongoing and intertwined with the process of primary appraisal. Lazarus and Folkman propose that one's appraisal of a stressor influences their efforts to cope and, subsequently, their psychological adjustment -- in a dynamic, cyclical process. Examining fears about recurrence as they relate to coping and adjustment will provide a test of Lazarus and Folkman's model.

However, in several ways, focusing on fear of recurrence represents a specific approach to the concept of primary appraisal.[1] First, examining fear of recurrence puts the focus on threat appraisals. By zeroing in on threat, much greater attention can be paid to thoroughly assessing and understanding these appraisals and their relation to coping and psychological adjustment. Because recurrence is a possibility for all women diagnosed with breast cancer, and an event that the majority of women with breast cancer fear, it is appropriate in this instance to limit the investigation to threat appraisals.

Second, in response to Somerfield's plea for research that examines coping in the context of specific, rather than global stressors, the current study focuses specifically on women's appraisals of the possibility of recurrence rather than their more general appraisals of breast cancer. Prior research has asked participants to appraise general stressors such as cancer (Stanton & Snider, 1993) or to appraise what they perceive to be the most stressful aspect of that general stressor (Dunkel-Schetter et al., 1992). These approaches have provided useful information regarding the relations among appraisal, coping, and psychological adjustment, but each has its limitations. When participants are asked to appraise a general stressor, we know little about which aspects of the stressor they find to be threatening, harmful or challenging. In the case of breast cancer, are they appraising the threat of death, the side effects of chemotherapy, or the financial strain posed by cancer and its treatment? On the other hand, when participants are asked to appraise one specific aspect they have found to be most stressful, it is difficult to make comparisons across individuals. This study seeks to address these limitations by asking all participants to appraise the same, specific stressor -- the possibility of breast cancer recurrence -- and to go even further by specifying what particular threats they perceive recurrence to pose.

Parle and Maguire (1995) have called for research that acknowledges the multi-faceted nature of cancer and its associated stressors. The possibility that individuals may use different strategies to cope with different aspects of a multi-faceted stressor has often been ignored in coping research (see the discussion below for exceptions). The current study seeks to address this issue by identifying what it is about the possibility of recurrence that women with breast cancer fear. Although the possibility of recurrence is a more specific stressor than, say cancer, it is still likely to be multi-faceted. When a woman with breast cancer asks herself: "What would a recurrence of breast cancer mean for myself and my life?", the answer is likely to include multiple possible threats. This study aims to understand not only the extent to which women fear this possibility, but also how the nature of these fears relates to coping and adjustment to the disease.

## Prior Research on Appraisal

The importance of appraisal as a predictor of coping and adjustment has been highlighted in past research on women with breast cancer (Arathuzik, 1991a; Hilton, 1989; Stanton & Snider, 1993) and individuals facing various other illnesses and stressful life events (McCrae, 1984; Moneyham et al., 1997; Stein, Folkman, Trabasso, & Richards, 1997). In general, this work demonstrates that threat, harm/loss, and challenge appraisals are related to different types of coping, and that appraisals of threat, in particular, are associated with increased psychological distress. More specific investigations of the nature of perceived threats or "what is at stake" in a given situation have been less consistent. For example, some studies have found that the nature of a threat is an important predictor of the coping strategies employed (Folkman et al., 1986; Mattlin, Wethington, & Kessler, 1990; Pearlin & Schooler, 1978), although not all studies have found this relationship (Dunkel-Schetter et al., 1992).

In this study the focal stressor (i.e., fears about the possibility of breast cancer recurrence) is the same across participants, so that coping and psychological adjustment can be examined in relation to appraisals of a particular threat. At the same time, the multi-faceted nature of the stressor is taken into consideration by assessing participant appraisals of "what would be at stake", should the cancer recur (i.e., the content of women's fears about recurrence). Thus, the study provides an opportunity to further understand how the nature of a stressor (as it is perceived) relates to the strategies one uses to manage the stressor, as well as to psychological adjustment.

Although the nature or content of women's fears is the primary focus here, it is important to acknowledge other potentially related components of appraisal. Prior research suggests that perceived risk of recurrence and perceived control over recurrence should be considered in any effort to understand women's fears about the possibility of recurrence. These variables are referred to here as <u>initial appraisal variables</u> because they are conceptualized as potential predictors of fears about recurrence (the primary appraisal variable).

One might expect perceived risk to be the strongest predictor of women's fears about recurrence. It would be logical to assume that women who feel more susceptible to recurrence would be more fearful about the possibility. However, although perceived risk of developing breast cancer has been addressed (Aiken, Fenaughty, West, Johnson, & Luckett, 1995; McCaul, Branstetter, Schroeder, & Glasgow, 1996), perceived risk of recurrence has rarely been studied and its relationship to fear of recurrence is unknown. One study that assessed perceived susceptibility to recurrence found it to be positively related to psychological distress (Timko & Janoff-Bulman, 1985). The current study examines perceived risk as a possible correlate of women's fears about recurrence, and of psychological adjustment.

Perceived control over breast cancer recurrence should also be related to women's fears. Perceptions regarding the controllability of a stressor have been found to be related to the strategies used in coping with that stressor (Aldwin & Revenson, 1987; Thompson, 1981; Thompson & Collins, 1995). For example, an early study found that problem-focused strategies were more likely to be used to cope with a stressor that was appraised as controllable, while emotion-focused strategies were more likely to be applied to uncontrollable stressors (Folkman & Lazarus, 1980).

Although little personal control over recurrence is actually feasible, prior research has shown that more than 50% of women with breast cancer perceive some control over recurrence (Taylor, Lichtman, & Wood, 1984). One might expect women to fear recurrence more if they feel they have no control over the possibility, but this idea has not been previously examined. Perceived controllability of recurrence has been shown to be related to psychological adjustment among cancer patients (Taylor et al., 1984; Timko & Janoff-Bulman, 1985), although not all studies have found this relationship (Malcarne, Compas, Epping-Jordan, & Howell, 1995). This study examines the association of women's perceptions of control over recurrence to their fears about that possibility, and to psychological adjustment.

## Psychological Adjustment

Prior research has demonstrated a consistent relationship between fears about recurrence and psychological adjustment among women with breast cancer (Metzger et al., 1983; Sneeuw et al., 1992; Timko & Janoff-Bulman, 1985). Moreover, several background variables (age, time since diagnosis, chemotherapy, surgery) have been associated both with fears about recurrence and psychological adjustment. Age and time since diagnosis tend to be inversely related to fears and positively related to adjustment, whereas chemotherapy has been associated with increased fears and decreased adjustment (Carver et al., 1993; Ganz et al., 1993; Jamison, Wellisch, & Pasnau, 1978; Levy et al., 1992; Schover et al., 1995; Stanton & Snider, 1993). Results regarding surgery have been more equivocal, but mastectomy (as opposed to BCS) has sometimes been associated with increased fears and decreased adjustment (Glanz & Lerman, 1992; Kemeny et al., 1988; Leinster et al., 1989; Levy et al., 1992; Margolis et al., 1990; Moyer, 1997). Although these background variables are known to be associated both with fears about recurrence and psychological adjustment, the studies examining the relationship between fears and adjustment do not control for them. What is not known is whether the association between fears about recurrence and psychological adjustment remains when these other factors are taken into consideration. One goal of this study is to assess the relationship of fears about recurrence to adjustment, after controlling for these, and other factors.

Psychological adjustment is a broad term that often includes both distress (e.g., depression and anxiety) and well-being (e.g., positive affect), although in most studies of illness only the former is assessed. Recent trends in psychology have highlighted the importance of accounting for both aspects of psychological adjustment. O'Leary and Ickovics (1995) have suggested that it is critical to acknowledge women's strengths in the face of adversity rather than focusing solely on their weaknesses. Moreover, efforts to focus on positive aspects of health recently have become more common in psychological research (Ryff & Singer, 1998). From a clinical vantage point, one might expect that the primary and most direct outcome of living with ongoing fears about recurrence would be feelings of anxiety, depression, and hopelessness. Indeed, research has demonstrated this relationship (Kahane, 1995; Metzger et al., 1983; Sneeuw et al., 1992; Timko & Janoff-Bulman, 1985). However, recognizing women's strengths means focusing on positive aspects of well-being, such as personal growth or strengthened social ties, as well as on distress. In more qualitative work, women with breast cancer describe positive outcomes of their experience (Kahane, 1995; Taylor, 1983). Moreover, different variables predict indicators of positive and negative adjustment among cancer patients (Fromm, Andrykowski, &

Hunt, 1996). Thus, the current study investigates how fears about breast cancer recurrence relate to both positive and negative adjustment, labeled psychological well-being and psychological distress, respectively.

## Coping

Although an association between fears about recurrence and psychological adjustment has been established, it is not known what role coping might play in that relationship. Coping is conceptualized as efforts (successful or not) aimed at managing a stressor (in this case, fears about the possibility of a recurrence). Lazarus and Folkman (1984) define coping as: "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (p.141)". In their Stress and Coping Model, coping serves as a mediator between one's appraisal of a stressor and psychological adjustment. That is, one's appraisal of a stressor influences coping efforts, which subsequently impact psychological adjustment. The relationship of appraisal and adjustment is indirect, working through coping.

Many studies have examined coping with breast cancer, but none have addressed coping with fears about recurrence. As with other stressors, women with breast cancer use a wide range of coping techniques -- cognitive, behavioral, problem-focused, and emotion-focused strategies, involving approach and avoidance of the stressor (Arathuzik, 1991*a*; Carver et al., 1993; Jarrett, Ramirez, Richards, & Weinman, 1992; Manne et al., 1994; Thomas & Marks, 1995; Stanton & Snider, 1993). The strategies of cognitive reappraisal, seeking social support, and avoidance consistently have been identified as among the most common strategies for coping with breast cancer. Reappraisal and support have generally been associated with improved adjustment and avoidance with poorer adjustment.

A primary limitation of these studies is their failure to identify a specific coping target. Breast cancer is not a singular stressor, but has numerous possible consequences. Thus, when we ask women to report their efforts toward coping with breast cancer (in general), it is impossible to know what aspects of the overall experience they are coping with. Even asking women how they cope with a more focused event, such as chemotherapy or cancer related pain, is limited. A woman undergoing chemotherapy may have to deal with excessive fatigue, fears about the long-term physical effects of this treatment, or sexual difficulties resulting from induced menopause. Likewise, the pain caused by a woman's cancer may prevent her from completing daily activities or may heighten fears about the progression of her illness. This study will add to the literature by examining women's efforts to cope with a particular aspect of their breast cancer – fears about the possibility of recurrence.

Fear of recurrence is a unique stressor for two reasons, in addition to its specificity. First, most empirical studies of coping assess efforts to manage a life event that has occurred or a chronic strain that is ongoing (e.g., illness, divorce, death of a loved one, work stress). Coping with fear of recurrence, on the other hand, is an attempt to manage an emotion; according to Lazarus & Folkman's paradigm, cognitive or emotion-focused strategies (as opposed to behavioral or problem-focused) may be most effective.

Many studies have examined emotion-focused coping (Stanton, Danoff-Burg, Cameron, & Ellis, 1994), but this research most often addresses efforts to cope with current stressors. Fear about recurrence, on the other hand, relates to a possible future event, which is the second characteristic making it a unique stressor. Although there has been some work on anticipatory or proactive coping (Aspinwall & Taylor, 1997; Breznitz, 1983; Folkman & Lazarus, 1985; Peacock & Wong, 1996; Raffety, Smith, & Ptacek, 1997) this research tends to focus on known future events (e.g., an upcoming exam or the imminent death of a loved one) rather than possible future events.

The current study examines three cognitive coping strategies -- acceptance, denial, and positive reframing. These strategies were chosen because they represent diverse ways in which an individual may attempt to manage an emotion (i.e., fear) about the possibility of a future event (i.e., breast cancer recurrence).

As defined here, using acceptance as a coping strategy involves accepting that the stressor exists or "learning to live with it" (as opposed to accepting responsibility for the stressor, a definition used in some studies (Folkman et al., 1986)). This type of acceptance is usually conceptualized as a functional or beneficial coping response (Carver, Scheier, & Weintraub, 1989), and research with breast cancer patients has found it to be related to improved adjustment (Arathuzik, 1991a; Carver et al., 1993). But we do not know whether it is beneficial to accept something that may never occur. At this point it is unclear what role acceptance might play in the association between fears about recurrence and psychological adjustment.

Denial is the "opposite" of acceptance. It is the refusal or inability to acknowledge that the stressor exists. In the case of fears about recurrence, one might deny the possibility of recurrence, or accept the possibility, but deny feeling fear. There is some controversy over whether denial is a maladaptive or beneficial coping strategy. Evidence suggests that it may be helpful immediately after an event occurs, but detrimental if used continually (Carver et al.. 1989). It may also be difficult to determine when denial is occurring (Achte, Salokari, Lindfors, Vauhkonen, & Lehvonen, 1988; Orr & Meyer, 1990). If a person is unconsciously denying the existence of a stressor (or of related fear), they may not be able to report using denial as a coping strategy. However, research participants do report using denial, indicating that it sometimes occurs on a conscious level. Studies of women with breast cancer have found the use of denial to be associated with decreased adjustment (Carver et al., 1993; Thomas & Marks, 1995), but it is not known whether denial is a likely or helpful strategy for coping with fears about recurrence.

Positive reframing involves a cognitive attempt to change the meaning of a stressor, to view it in a more positive light. For example, a woman undergoing chemotherapy may think of the accompanying nausea as evidence that the treatment is working (rather than evidence that the drugs are harming her body). Positive reframing has been identified as one of the most common strategies for coping with breast cancer (Carver et al., 1993; Jarrett et al., 1992; Manne et al., 1994; Thomas & Marks, 1995) and has been related to greater psychological adjustment (Carver et al., 1993; Dunkel-Schetter et al., 1992; Stanton & Snider, 1993). What is unclear at this time, is whether individuals are likely to use positive reframing in anticipation of an event (as opposed to during or after an event). Moreover, it is unknown whether this strategy is helpful for coping with an event that may never occur.

This study examines the role of these three cognitive coping strategies in the relationship between fears about recurrence and psychological adjustment. Lazarus and Folkman's model suggests that coping should mediate the relationship between fear of recurrence (appraisal) and psychological adjustment (Lazarus & Folkman, 1984). That is, the effect of fear on adjustment should work through coping. Another alternative is that coping may moderate, rather than mediate, the relationship between fear and adjustment. This possibility is suggested by theories positing other influences on coping, such as disposition or concurrent life events (Carver et al., 1993; Carver & Scheier, 1994; Pearlin, 1991). In this case, appraisal would not necessarily influence coping, but coping may affect (buffer) the relationship of appraisal and adjustment. For example, a coping strategy such as denial may be associated with lesser distress when fears of recurrence are high, but not when fears of recurrence are low. A third possibility is that coping may be related to fear of recurrence and/or to psychological adjustment directly (i.e., as a main effect) but not play any role in the relationship between fear and adjustment. Each of these possibilities will be examined.

## Research Questions

This study addresses the following research questions:

- To what extent do women with breast cancer fear the possibility of recurrence, and what is the content or nature of these fears?
- How are background variables, initial appraisal variables, and ongoing consequences of the initial diagnosis related to women's fears about recurrence?
- What is the relationship of women's fears about recurrence to their overall psychological adjustment, after controlling for background variables, initial appraisal variables, and ongoing consequences of the initial diagnosis?
- What role does coping play in the relationship between fears about recurrence and overall psychological adjustment?

## Overview of the Dissertation

The research was conducted in two phases. A pilot study was conducted to verify the relevance of the research questions, gain a richer understanding of women's thoughts and feelings about the possibility of recurrence, and test a structured measure, developed by the investigator, of fears about recurrence. A small sample of women participated in semi-structured interviews focusing on the effects of breast cancer, their fears about the possibility of breast cancer recurrence, and their efforts to cope with those fears. Methods and results of the pilot study are presented in Chapter 2.

For the main study, a larger sample of women completed a structured written questionnaire. The goal of this study was to address the research questions in a more systematic way, by using standardized assessment tools and multivariate statistics. Several open-ended questions also allowed women to express their thoughts and experiences in a more personal way. Methods for the main study are presented in Chapter 3. Results pertaining to the four research questions above are presented in Chapters 4 (intensity, nature, and correlates of fears about recurrence) and 5 (coping with fears about recurrence). Chapter 6 explores an issue whose importance became apparent during the pilot study and was subsequently addressed in the main study: locating breast cancer and the possibility of recurrence in the context of women lives. A discussion of the study findings is presented in Chapter 7.

# CHAPTER TWO: THE PILOT STUDY

The purpose of conducting a pilot study was three-fold. The first goal was to verify the relevance of the research questions. Although the questions came out of prior research and theory, the pilot study provided an opportunity to assess their importance directly, with a group of women who had breast cancer. The second goal was to learn how women with breast cancer describe their fears regarding the possibility of recurrence. Prior research has used Likert-scale and forced-response questions to determine women's level of fear regarding recurrence. Although useful for determining that fear of recurrence is wide-spread among women with breast cancer, these methods have not provided a very rich understanding of these fears or how they are experienced by the women who report them. This pilot study was designed to elicit more in-depth information about women's thoughts and feelings regarding the possibility of breast cancer recurrence, and the implications that these fears have for their lives. The third goal of this pilot study was to test a structured paper-and-pencil measure assessing the content or nature of women's fears about the possibility of recurrence. A preliminary version of the Concerns about Recurrence Scale (CARS, described below) was completed by each woman who participated in the pilot study. The study was approved by the Institutional Review Boards at both Mount Sinai School of Medicine and The Graduate Center of the City University of New York.

## Eligibility Requirements and Recruitment Procedures

I used the patient lists of three participating physicians (one surgeon and two radiation oncologists at the Mount Sinai Medical Center) to identify potential participants. I made an effort to recruit women who represented the diversity of women receiving treatment for breast cancer. These women varied in age, time since diagnosis, ethnicity, cancer stage, surgery type and whether or not they had chemotherapy. Women were eligible for the study if they met the following criteria: 1) diagnosed with a primary breast cancer at least one year and no more than five years previously; 2) diagnosed with stage I or II breast cancer; 3) received surgery for breast cancer; 4) no recurrence of breast cancer; 5) not currently undergoing active treatment for breast cancer (with the exception that women who were taking Tamoxifen could be entered in the study); 6) treated, at least in part, at Mount Sinai; 7) aged 18 or older; 8) English speaking; and 9) agreed to audio-taping of the interview.

These eligibility criteria aimed to maintain a moderate level of homogeneity in the sample while allowing for some diversity on key medical and socio-demographic variables. The sample was limited to those women diagnosed less than five years previously, in order to increase the chances that the breast cancer experience would still be salient and easily recalled. Only women with stage I or stage II breast cancer were included because the likelihood of a recurrence rises with more advanced disease (American Cancer Society, 1999), as do women's perceptions of the risk of recurrence (Schover et al., 1995). Likewise, because a primary focus of the study was the threats posed by recurrence, women who were in active treatment (and who likely had active disease) were not included. Other eligibility requirements represented practical and ethical concerns.

I sent recruitment letters to 56 women. These letters described the research and informed women that they would soon receive a phone call regarding the study. Approximately two weeks after the letters were sent I called each women to describe the study, answer questions, obtain verbal consent, and schedule in-person interviews with those women who wished to take part in the study.

## Sample

Four of the 56 recruitment letters were returned due to incorrect addresses, although phone calls were made to all 56 women. Eleven women were never reached (multiple phone calls were made to each individual), two were confirmed to be deceased, 12 were ineligible (the majority because they did not speak English), 11 refused to participate in the study (in most cases women stated they did not have time or were not interested), and 20 women agreed to be interviewed. Seventeen women completed the interview (three of the women who agreed were not interviewed due to scheduling difficulties). Thus, 55% of potential participants (i.e., those who were eligible and could be contacted) completed the interview. One woman was found to be ineligible (due to cancer stage) after the interview began -- her responses were not included in thematic content analyses. Table 1 displays socio-demographic and medical variables for the final pilot sample (n = 16).

I conducted analyses to test for differences among those who participated in the study (n =17), those who refused (n = 11), and others who did not complete the study (n = 26, including those who: could not be contacted, could not be scheduled, or were ineligible).[2] No significant differences were found regarding time since diagnosis, disease stage, or ethnicity. There was a significant difference in terms of age, with refusers (mean age = 70.64) being older than those who completed the study (mean age = 57.23) and those who did not complete the study for some other reason (mean age = 58.67), $F(2,51) = 4.72$, $p < .05$. Because the interviews took place at the Mount Sinai Medical Center, it is probable that some older women felt the traveling that was required to participate would be too difficult. Indeed, several of the women who did not complete the interview were in their 80's. However, the study sample did include two women in their mid 70's. It should also be noted that four potential participants were Asian but none completed the interview (one refused, one could not be contacted, and two were ineligible because they did not speak English).

## Interview Procedures

I interviewed each woman in an office on the Sinai campus. The interview room was located in a non-patient-care building so that no woman would have attended medical appointments where the interview took place.[3] Before the interview began, we discussed the primary components of informed consent and the woman read the consent form. We both signed the consent form and I obtained verbal consent to audio-tape the interview. The interview was semi-structured, so that my questions followed from the woman's responses.[4] However, I determined the general focus of the interview, beginning by asking the woman to tell her "story" about her breast cancer diagnosis and treatment. The interview then covered all of the following issues, although not necessarily in the same order: 1) the ways in which breast cancer had impacted the woman's life; 2) fears about recurrence and worries about how a recurrence might affect her life; 3) particular situations that "triggered" such fears; and 4) strategies used to cope with any fears about the possibility of recurrence.

After the semi-structured portion of the interview, each woman completed a preliminary version of the Concerns about Recurrence Scale (CARS), a paper-and-pencil measure constructed to assess the content or nature of women's fears about the possibility of breast cancer recurrence (see description of CARS scale construction below). In order to gain a better understanding of each woman's interpretations regarding the questionnaire items and response options, I discussed each questionnaire response with her, asking her to explain why she chose the numerical rating that she did. Each participant received $20 for completing the interview.

## Data Analysis Procedures

The semi-structured interview protocol was designed to allow women to personalize their answers and to relate their subjective experience. However, in order for such information to be useful it was necessary to categorize responses in a meaningful way. Categorizing or identifying themes within and across participant responses allowed me to draw conclusions about women's experiences with breast cancer and their thoughts and feelings regarding the possibility of breast cancer recurrence. Coding and analyzing the pilot data was completed in several steps.

First, each audio-tape was transcribed by a paid transcriber. After transcription was completed, I read each transcript, while listening to the audio-taped interview. This process allowed me to carefully check for errors and to take "notes" about my overall impressions of the interview and the respondent's answers to the interview questions. Through reading and note-taking I was able to get an overall sense of the sample as a whole, to identify some preliminary coding categories for participant responses to the four topic areas mentioned above, and to determine whether there were other important issues to be addressed. I then read all transcripts a second time, without the audio-tapes. At this point, I identified relevant passages (i.e., those focusing on previously identified themes) for later content coding. I then read the transcripts a final time, for the purpose of solidifying coding schemes and coding participant responses (See Appendix A for the full coding scheme).

## Pilot Study Results

Table 2 displays several demographic and medical characteristics for each woman in the pilot study and demonstrates the diverse combinations of characteristics in the sample. For example, among the black women in the sample, three had chemotherapy and three did not. Among those black women who had chemotherapy, two had breast conserving surgery and one had a mastectomy. Among the black women who had chemotherapy and breast conserving surgery, one was diagnosed four years prior to the study, while the other had been diagnosed one and a half years prior.

In the description of the results that follows, participant responses are identified by a code made up of the ethnicity (W, B, or H) and age of the participant. For example, W56 is a 56-year-old White woman, listed first in Table 2. Because there were two 57-year-old black women in the sample, the one listed first in the table is referred to as B57a and the one listed second, as B57b. The reader may refer to Table 2 to get a sense, albeit limited, of the characteristics of the women who are quoted.

## Consequences of Breast Cancer

Although the focus of this pilot study was on concerns about breast cancer recurrence, it was important to understand how women felt the initial diagnosis influenced their lives, as expectancies regarding future events are shaped by past experiences (Fiske & Taylor, 1984; Kirsch, 1999). However, because other studies have examined the psychosocial and physical sequelae of breast cancer in depth, the issue receives only cursory attention here.

Some women reported that breast cancer had little effect on their lives, while others felt it had a strong influence. For a general sense of the consequences reported by these women, responses were divided into three categories: general physical consequences; general psychosocial consequences; and self-relationship consequences.

Ten women described experiencing physical consequences of breast cancer. For some women the physical effects were ongoing, while for others such effects had occurred at the time of the cancer treatment and were no longer bothering them. The most common physical complaint was pain. In all cases, the pain was a result of the cancer treatment (surgery, chemotherapy or radiation) rather than the cancer itself. Lymphadema -- a chronic and often debilitating condition in which the arm swells as a result of removing the lymph nodes -- was a problem for three women. Changes in appearance, such as hair loss, were also described by three women. Other physical effects, each reported by only one or two women, were headaches, nausea, gynecological problems (as a result of taking Tamoxifen), weight gain, memory loss, reduced range of motion, and induced menopause.

Eleven women described psychological consequences of breast cancer. Five identified fear as one effect of the disease, but the focus of these fears was varied. Women feared recurrence, death, losing their breast(s), health complications from treatment, and the potential for health problems (e.g., breast cancer) of family members. Two women described depression as a result of the disease. Other reported psychological effects were anxiety, changes in priorities, changes in ability to plan for the future, and looking at life differently.

Five women described consequences of breast cancer that related to the self or to relationships with others. Four women described difficulties in relationships with friends and/or family that they felt resulted from the breast cancer. Two of these women described situations in which friendships had dissolved when they revealed that they had been diagnosed with cancer. Other problems were lack of sexual desire, reduced confidence about finding a partner, suffering of family members, and feeling less self-worth.

## Fears about Breast Cancer Recurrence

Based on prior research it was expected that women would express strong fears about recurrence. Perhaps one of the most surprising findings of the pilot interview was the broad variation in the extent to which women thought or worried about recurrence. Although a few women appeared to worry a lot about the possibility, the majority expressed more moderate amounts of fear, with some women reporting that they thought or worried about the possibility of recurrence very little or not at all. If taken at face value, the responses of these women suggest that the possibility of recurrence is not a primary concern for most of them. However, using women's narratives to determine the extent to which they fear recurrence is a difficult task -- women could not be categorized neatly by levels of fear. In some cases women who said they didn't think much about recurrence went on to indicate that they had made life changes based on that fear. Other women used euphemisms to express fears about recurrence (e.g., "I hope it doesn't happen", "I wonder how I'll do", or "I don't want to go through this again"). In several instances women indicated that they try not to think about recurrence, which could mean they were not worried, or, that they were using cognitive strategies to cope with their fears.

With these complexities in mind, I attempted to group women who appeared to have similar experiences with fear of recurrence. Categorization was accomplished by synthesizing women's direct answers to the question "How much do you worry?", their spontaneous expressions of fear or the absence of fear, and more subtle indicators such as the extent to which their responses focused on recurrence as opposed to issues such as other life events, and the role that the possibility of recurrence played in thoughts about the future. Quotes illustrating the thoughts expressed by women in each group were chosen to illustrate the diversity of women's experiences, even within seemingly similar groups of women.

One group consisted of those women who indicated relatively strong fears of recurrence. Their fear was expressed by statements such as:

*"... sometime I wonder if it's all out of my body ... I figure if you get one spot who knows. maybe it comes some place else you know. I figure once you're diagnosed with it. its there (B57a)."*

*"Yeah well now. is right away I'm scared now ... everything I haved. right away I think this is cancer (L63)."*

*"Well I have to hope its not gonna be soon ... but one day I think its gonna come back. Cause most of the people, once you have, you know cancer, so then later you die from cancer (L52)."*

One similarity of the women in this group was that each felt she had a particular reason to fear recurrence. B57a was currently in the process of diagnostic testing to determine whether her cancer had recurred, and L68 had been told by one physician that she had a recurrence and then told by another physician she did not. L63 had a lump on the side of her face that she felt was suspicious, although physicians had told her it was nothing to worry about. (This participant even asked me to look at the lump and indicate whether I thought it was a tumor). L52 reported that she had been suicidal during chemotherapy and indicated she would likely return to that state if (or when) she had a recurrence requiring chemotherapy. W55 indicated that she had intimate knowledge of the possibility of recurrence, as she was a scientist working at a cancer hospital. Although she stated that she did not really think her own cancer would return, she went on to explain that she no longer makes long-term plans or sets long-term goals because of the possibility of recurrence.

Six women expressed some fear of recurrence, but indicated that the fear was more subtle, or not a central focus of their lives. For example:

Interviewer: "Do you think about the possibility of the cancer coming back?"
*Patient: "Maybe in some recess in my mind, but not...I'm trying to live more for the moment and you know there is these thoughts lurking that, um, I'm doing these things but am I going to be around to need that, or enjoy them or whatever (W40)."*

*"I don't worry about it every day. I mean I worry because two of my, two of them* (tumors) *were aggressive so I worry about that... (B38)"*

*"Everyday I get up and I think about recurrence ... I'm thankful each day that I feel well (B58)."*

One of the most striking characteristics of this group of women was their tendency to focus on other issues or life events that distracted them from thinking about breast cancer and/or the possibility of recurrence. Several women were dealing with other illnesses - their own or those of people in their social networks. B56 had a heart attack two years prior to her breast cancer diagnosis and said that concerns about her heart were more central than fears about breast cancer. W74 was taking care of her husband who had become somewhat disabled as a result of his cancer. In comparison, her breast cancer did not seem to be a significant threat, as evidenced by statements such as: *"I try not to think too much about it* (recurrence)*...like I said my husband's not well. He went through a big surgery in '94, and he still...he just didn't come out of it."* B74 described several health problems of her own and those of her five grown children, which occupied her thoughts. Likewise, B58 spoke of dealing with sarcoidosis, a chronic and potentially debilitating disease. W40 described multiple life strains -- concerns about her job being terminated, a failing relationship, and disappointment connected to her dwindling hopes of ever having a child. All of these appeared to be more prominent issues than the concern of recurrence. When asked if these issues distracted her from thinking about the possibility of recurrence she replied: *"Yeah, these other things have distracted me probably because they're really in your face. Yeah, I don't know if that's a good thing or...the boyfriend thing is very upsetting and it, it hits to the core."*

Five women reported little to no fear about the possibility of breast cancer recurrence. The following statements illustrate their feelings:

*"I just consider myself blessed because I feel, you know I feel confident that it's not going to come back... (B57a)"*

*"I really don't dwell on it. I really don't. I didn't want to become obsessed with cancer in the way my sister was... (L69)"*

I: "Do you worry about a recurrence?" *P: "Not a lot. I tend to be a worrier in general but I must say I don't, and I think that's only because my prognosis is good... (W49)"*

Again, some of the women in this group reported health problems that appeared to be more prominent in their thoughts than the possibility of breast cancer recurrence. W56 was extremely concerned with symptoms of early-stage lymphadema, for which she had been unable to get treatment. She spoke very little about the possibility of recurrence. W66, who had multiple chronic health problems stated: *"...the other thing* (severe intestinal problems), *as I said, is still going on and it distracts me from my bosom."* The three other women in this category explained their lack of concern by describing a tendency to compare their own prognosis and treatment protocol to other individuals with cancer. For example, B57b compared her experience to that of her two sisters, both of whom died of cancer, and gave the following reasons for her lack of fear: *"maybe because I didn't have chemotherapy...maybe because I didn't suffer, I wasn't in pain..."* She went so far as to say that sometimes she had difficulty believing she had ever had cancer.

Although women reporting little fear did not appear to be preoccupied with thoughts about recurrence, they did describe particular situations in which they had been distressed about the possibility. For example, B57b stated that the letter introducing the current study, which mentioned the possibility of recurrence, had upset her -- although all of her other statements indicated she never thought about recurrence. Likewise, W49 indicated that she was not particularly concerned about recurrence, but told of becoming extremely upset when she looked at a graph illustrating 10-year survival rates among early stage breast cancer patients. These occurrences highlight the difficulty of determining the extent to which women fear recurrence, even when they were asked directly to describe their feelings.

One factor that sets this study apart from other research on women's fears about breast cancer recurrence is its focus on the content of women's fears; what the possibility of recurrence means to women with breast cancer. One woman stated this clearly and succinctly: *"I think the diagnosis in the abstract means nothing, it's how it affects your life that means something... (W49)"*

Prior studies have not asked about the nature of women's fears, assuming that fears about recurrence revolve around the possibility of death. Responses of the women in this sample indicate that death was a major concern, but that other concerns were also prominent.

Twelve of the sixteen women mentioned death as one possible consequence of recurrence. Half of these women identified death as a fear or concern. For example, I: "Are there certain things you're afraid of...if the cancer were to come back, what do you think that would mean for you?" P: *"It might mean I'd die. That's what it might mean. I'm not ready to go yet (W74)."* Three of the women mentioning death stated that it was not a concern for them. One woman said: *"I'm not afraid of the death itself, I'm not. I'm afraid how I would leave people behind (W55)."* In all three cases these women identified something that they were more concerned about: leaving others behind, pain, and quality of life. Three other women referred to death only indirectly, making statements about "being around" in the future. For example, *"When you have children, you know, that's what you want...you want to be around for your children (B58)."*

Fearing death did not preclude other fears for the women in this study. Only one woman (L63) spoke of death as the sole concern related to recurrence. The second most common fear was chemotherapy. The statements made about chemotherapy were some of the most emphatic in the interviews: *"That's what I'm afraid, I'll be older, more weak, and I don't want to take the chemo. Oh my god. No. No. They have to find something else (L52)."* A few women even questioned whether they would undergo chemotherapy a second time: *"Chemo. I don't know if I could handle chemo again (B57a)."* All six women who mentioned fears about chemotherapy had undergone that treatment after their initial diagnosis. Among women who had experienced the treatment previously, the fear of chemotherapy was as common as the fear of death.

Although death and chemotherapy were the most common concerns, several other fears were identified. Five women worried that a recurrence of breast cancer would be difficult to cope with emotionally. They talked about the possibility that a recurrence would cause them to be depressed, scared, anxious, or to "freak out". Other women spoke of not being able to predict how they would react emotionally to a recurrence. Five women commented that they feared the pain that could be associated with a recurrence. One woman said: *"I'm only afraid of the pain. If I got some medication for the pain, I don't care (L52)".* Four women worried that a recurrence would mean more advanced, metastasized, or untreatable disease, for example, *"I know that it will not be, I mean if it comes back it usually is not treatable, successfully (W55)."* Although these fears may be another indirect way to acknowledge the possibility of death, they may also represent other concerns such as pain, and suffering through treatments without benefit. Causing family members to suffer or leaving them behind was a concern for four women. The loss of the breast (or losing feeling in the breast) was also mentioned by only four women. One woman said: *"I hope I don't have to lose my breast because I was lucky this time ... I kept the breast (W74)."* Although it is a complication associated with treatment (i.e., Tamoxifen) more than recurrence of breast cancer, it is of note that four women mentioned gynecological cancers as a concern. Other fears, mentioned by only one woman each, were further surgery, being out of work, being more on guard for the rest of one's life, losing hair, having to make more difficult treatment decisions, and ruling out motherhood.

## Triggers of Fears about Recurrence

When asked what was likely to trigger their fears about recurrence, women's responses were as varied as the fears themselves. The most common trigger for fears about recurrence was being around others with cancer or hearing people talk about breast cancer (mentioned by 12 women). Some of these women spoke of being upset upon hearing about other women who were diagnosed or who had died from breast cancer. For example, "*So this is the things that upset me. when I hear from someone else what happened to them, I always think it could happen to me (B57a).*" Others talked about seeing TV programs that made them think about recurrence or being upset by talking with other breast cancer patients who told their own stories (sometimes of recurrence) and discussed the dangers or limitations of particular treatments (such as Tamoxifen). One woman's experience talking to another survivor about Tamoxifen upset her greatly: "*... she says that's very bad, it's very dangerous, you could get uterine cancer taking...when you take Tamoxifen. She scared the heebie-jeebies out of me (W74).*" A related experience was seeing that many women in support groups and clinics had mastectomies rather than breast conserving surgery. More than one woman worried that she had made the wrong choice in selecting to have the more conservative treatment. One of these women said: *"...whenever I went back to the check-ups and that kind of thing, or treatment, it seemed like everyone had their breast removed ... I begin to get concerned that maybe I, I didn't do the right thing you know (B58)."* Finally, one women reported that the introductory letter for the current study had upset her, as it made her focus on the possibility of a recurrence.

Seven women reported that their fears were triggered in situations where identifying a recurrence was possible. For example, several women spoke about feeling anxious when they had a doctor appointment or went for a mammogram. One participant got very upset at her last mammogram appointment: *"They left me waiting in the room...room for like half an hour and I was starting to really freak out. I was like, can you please get this over with because I'm about to go crazy here (W40)."* Other women were worried whenever they had a physical symptom such as lump anywhere on their body, or feelings of fatigue. One woman said: *"One day I touch here something very hard and right away I sit down. I say 'Oh my god I have another tumor here' so I put nervous you know (L63)."* Two women were clearly worried about recurrence as a result of being told by physicians that there was reason for suspicion (based on diagnostic tests).

Three women said their fears about recurrence were triggered by physical reminders of the initial breast cancer. For one woman, this trigger involved seeing her partially reconstructed breast. For others, feeling pain or noticing swelling in the breast brought back reminders of the cancer and triggered worries about recurrence. When asked whether anything in particular made her worry about recurrence one woman said, "*...it* (her breast) *always hurts and it's ... I think it's always going to be swollen and it's a little different color so it's always, so what does that song, it's always there to re... always there to remind me (W66).*" One woman said that taking Tamoxifen everyday reminded her of the concern about recurrence. She stated: "*Well I'm still not through it ... because I'm on medication for it every day it reminds me twice a day. Tamoxifen (W74).*"

Two women described situations in which future-oriented activities made them think about the possibility of recurrence. For example, after making a big purchase or getting involved in a long-term project these women wondered whether they would be around to enjoy or need those things: "*... why did I buy this. why did I buy that? I won't be wearing this...I won't be wearing that ... I might be ill before I wear it or whatever (B58).*"

Finally, two women indicated that their mood could trigger thoughts about recurrence. One woman stated that getting depressed about other things reminded her of the cancer and all the bad things that had happened to her. Another woman said that when she was in a good mood, thoughts of the cancer could come along and spoil it.

## Coping with Fears About Recurrence

Women used a range of strategies to cope with their fears about recurrence. The most common coping strategy was the use of social support, reported by seven women. Some women went to support groups or sought support from other cancer survivors. Other women turned to friends or family for support, or used professional sources of support such as therapists and social workers. Three women described ways in which support was not helpful. For example, "*Someone send a woman who had the same breast cancer diagnosis, 15 years ago ... I felt very depressed when she was coming to me, talking to me about her problem. On one hand I mean to me I was surprised with myself because I should have felt good because she survived for 15 years and she's telling me that, in a way you'll be okay, but no. I didn't want to go through somebody's problems and somebody's life, umm, it wasn't helpful to me (W55).*"

Six women reported what are classified as cognitive strategies. Some women spoke of trying not to think about or focus on the possibility of recurrence (avoidance). This strategy was described succinctly by one participant: "*I am trying to just not worry too much (W40).*" Others said they told themselves that there would be new and better treatments in the future and tried to believe that their doctors were knowledgeable enough to prevent a recurrence. For example: I: "Are there other ways that you try to deal with your fears? P: "*Umm well, trying to think that I have a lot of faith in my doctors, and I had gone to Dr. (X) for many many years, and she's got a very good reputation (L69)*". Still others used the strategy of hoping their cancer would not recur or telling themselves that it would not recur. One woman said she thought of recurrence sometimes, but then she started thinking good thoughts: "*You know like it's not going to happen to me, it's not coming back, the only way to come back if I worry it back. I'm not worrying it* *back you know (B56)."* Finally, accepting that one cannot do anything about the possibility of recurrence was a coping strategy described by more than one woman.

It is difficult to ascertain how many women were actually using cognitive strategies to cope with their fears about recurrence. One could ask the question: If a woman is successfully using denial, minimization or cognitive distraction to cope with her fears, would she necessarily be able to report using those strategies? If she were successfully coping through these strategies wouldn't she, by definition, have few fears about recurrence? This difficulty is present in any research attempting to assess the use of cognitive coping strategies. In this study, it leads one to wonder about the women who indicated little fear of recurrence. To what extent is their absence of fear the result of successfully using cognitive coping strategies? Indeed, several of these women reported using such strategies. For example, one woman simply stated that she "buries things" while another said: " *I guess after that* (a recurrence) *forever that you wouldn't be so ready to dismiss anything, not that you're really dismissing it, but I think that's a coping strategy to get on with life (W49)."*

More behavioral strategies also were reported. Behavioral distraction was used by four women who described efforts to keep busy with their daily routine, focus their energies on work, or distract themselves by reading a book or watching TV. One participant said: "*... as long as I'm occupied and have something to do that I like, I really don't think about it that much (B58)."* Three women used problem-focused health behaviors to cope with their fears about recurrence. Health behaviors included going to the doctor for check-ups or mammograms (i.e., "getting clean bill of health"), exercising and eating a healthy diet, and learning about breast cancer. Religion was mentioned by three women women, who said that going to church, praying, or reading the bible eased their fears about recurrence. When asked how she coped with her fears one woman said: *"Pray... Pray or cry. and I go in the bathroom. I, I turned on the water and I sit in there and I pray (L52)."* Finally, as evidenced by the quote above, emotional expression was used by two women to cope with fears about recurrence. Both laughing and crying were included in this category.

It is interesting to note that two of the coping strategies reported -- social support and health behaviors -- are likely to occur in the same environments as the most common triggers of fears about recurrence. For several women in the study, social support was sought out in support groups or through other cancer patients. But hearing others talk about cancer was also the most likely trigger of worries about recurrence. In some cases it was the same women who identified support groups as useful coping strategies and as triggers of their fears. As one woman stated: *"I would recommend it to anybody to go to one of these groups. I'm sure they're all very good...it can be very depressing too, cause then you see them having the second bout and all that can be...but I guess that's just part of it (L69)."*

Practicing health behaviors, particularly going to the doctor for checkups and mammograms, was also identified as both a useful coping strategy and a trigger of fears about recurrence. In the case of physician visits, anticipating the exam and its results were clearly the trigger for fears, while being told one's health remained good served as a coping strategy. The following quotes illustrate the dual characterization of physician visits: *"I'm still worried for now when they have to check me again... Then if they told me nothing is wrong then I'm gonna feel good (L68)." "I'm seeing the doctors ... and it makes you think about it. But it. actually in a way it's good to see them because when I get a clean bill of health at the time I see them I feel better (W74)."*

The semi-structured interviews were useful for eliciting women's spontaneous responses to questions about their fears regarding recurrence. However, a more structured measure is needed to assess the nature of women's fears in a larger sample of women. Although other investigators have assessed the extent to which women are concerned about the possibility of recurrence (Metzger et al., 1983; Meyer & Aspegren, 1989; Noguchi et al., 1993; Peters-Golden, 1982; Pistrang & Barker, 1992; Polinsky, 1994; Schover et al., 1995; Sneeuw et al., 1992), prior research has not assessed the ways in which women perceive this possibility to be threatening. The Concerns about Recurrence Scale (CARS) was constructed for that purpose.

## Construction and Testing of the Concerns about Recurrence Scale

The interviews were used as an opportunity to pilot test the CARS. Twenty-three self-report items were written based on the literature describing physical and psychosocial consequences of breast cancer. Because expectancies regarding future events are shaped by past experiences (Fiske & Taylor, 1984; Kirsch, 1999), the assumption was made that threats posed by the possibility of recurrence would be similar to the consequences resulting from the initial diagnosis of the disease (e.g., threats to: ability to reach future goals, body image, pain and suffering). A five-point Likert Scale (0 = "Not at all", 1 = "A little", 2 = "Moderately", 3 = "A lot", and 4 = "Extremely") was used to indicate the extent to which women felt a recurrence of breast cancer would be threatening in each domain. After completing the measure, women were asked if there were any other ways in which they felt a breast cancer recurrence would be threatening, and whether they felt there were any ways in which a breast cancer recurrence could have positive consequences. However, the first question elicited only a few responses: "would frighten son", "scared of it spreading", "could never trust my body again", and "sense of hope difficult to maintain"; and no one anticipated any positive consequences of a breast cancer recurrence.[5]

After the participant completed the entire measure, I discussed each item rating with her. For example, the woman was asked to describe what she meant if she responded to the item "My sense of sexuality would be threatened by a recurrence of breast cancer" by indicating a "3" ("Moderately"). This process allowed me to get a sense of how the participant interpreted each item, as well as how she interpreted the response categories.

Quantitative analyses cannot be conducted with a sample of 16 women. However, some trends may be noted by examining descriptive statistics (see

Table 3). The items rated as most threatening were: 1) further treatment such as radiation and chemotherapy, 2) further, possibly more extensive surgery, and 3) threats to emotional well-being. Interestingly, threat to life was the fifth most threatening item. The items rated to be least threatening were: 1) threats to spirituality or faith, 2) threats to motherhood roles; and 3) threats to sense of self as a woman.

Sub-scales were created by grouping items into three conceptual categories: physical threats, psychosocial threats, and self and relationship threats. Overall, physical threats were the most common concerns, the mean item-score indicating women were threatened "moderately" to "a lot" (Table 3). Psychosocial threats were the next most common, endorsed at the moderate level. Self and relationships threats were the least common, with Likert ratings indicating women felt "a little" to "moderately" threatened in that domain.

The CARS was discussed with two nurses, two surgeons, and one social worker, all of whom worked closely with breast cancer patients. These medical professionals felt that patients' concerns were adequately represented in the measure. However, suggestions made by the health professionals and the women in the pilot study led to several modifications of the measure for the main study (see Appendix B for the final version of the CARS).

Most importantly, the structure and language of the items was changed. In the original version of the CARS, women were asked how threatened they felt by each potential consequence of a recurrence. However, participant responses suggested that the word "threat" may have been too abstract. Thus, the items were changed to ask women how much they worry about each potential consequence of a recurrence.[6] An item stem with the words, "I worry that a recurrence of breast cancer would:" is displayed prior to the item list (e.g., "Upset me emotionally" or "Cause me pain and suffering").

Second, the central construct -- breast cancer recurrence -- was defined more clearly. Some women interpreted recurrence to mean only a return of the same cancer in the breast where it was originally detected. Other women interpreted recurrence to mean a possible metastasis or spreading of the disease. Still others included a second breast cancer, possibly in the other breast, in their definition of recurrence. In order to be as inclusive as possible, recurrence is defined as follows: "*By recurrence we mean the breast cancer coming back in the same breast or another area of the body, or a new breast cancer in either breast.*" Although this definition is not as narrow as that used by medical professionals (where a recurrence can be in the same breast or another area of the body as long is it originates from the same tumor source), it more accurately represents the nature of women's fears regarding breast cancer in their future.

Finally, several items were added to the measure, and the wording of other items was revised in order to: split a complex item into two simpler items; "backup" an item that was being interpreted in multiple ways; or capture alternative interpretations of an item.[7,8]

### Summary and Conclusions of the Pilot Study

Conducting this pilot study proved to be a useful process, illuminating women's thoughts and feelings about the possibility of recurrence and providing an opportunity to test and improve a structured measure of women's fears. Among the most revealing aspects of the pilot interviews was that women indicated less fear of recurrence than was expected on the basis of the literature. Although the possibility of recurrence was a central concern for a few of the women who participated, most women reported lower levels of fear. However, we should be cautious in concluding that women with breast cancer have little fear of recurrence, considering the relatively small sample and the possibility that those individuals who fear recurrence most may be least likely to participate in research where recurrence is identified as the focus. Instead, the findings of this pilot study should be considered an illustration of the diverse experiences of women with breast cancer and the variability in the extent to which they fear the possibility of recurrence.

Several factors were identified as possible modifiers of women's fears about recurrence. Those women who appeared to have the strongest fear of recurrence also had some particular reason to believe it was likely (e.g., physical symptoms or physician suspicion). Even among those women reporting less fear of recurrence, physical symptoms and physician visits were identified as triggers of fear, a finding that echos prior studies (Easterling & Leventhal, 1989). For many women fear of recurrence appeared to be tempered by other life events and illnesses. However, it is not entirely clear whether these events/illnesses distracted the women from thinking about recurrence or whether the absence of fear about recurrence allowed them to focus on other events/illnesses. Finally, interactions with other people who had cancer appeared to influence women's fears. Some of the women who reported the least fear about recurrence credited their lack of fear to comparisons that they made to other people with cancer. Such "downward comparisons" have been identified as adaptive in prior studies with breast cancer patients (Stanton, Danoff-Burg, Cameron, & Snider, 1999; Taylor, 1983) At the same time, several women indicated that being around, or hearing about, others with cancer triggered or elevated their own fears.

The possibility of death was a central fear for these women, but by no means the only fear. Fears about further treatment, particularly chemotherapy, and emotional difficulties were very salient. In general, the most common fears were physical in nature, while the less common concerns revolved around identity, sexuality, and interpersonal relationships. These results are consistent with a recent study investigating concerns of breast cancer patients (focusing on the initial diagnosis rather than the possibility of recurrence) (Spencer et al., 1999).

The small number of women in the pilot study precludes making broad generalizations of the findings. However, we can be reasonably confident that the range of possible experiences are represented, given the diversity of the sample regarding age, ethnicity, treatment, marital status and time since diagnosis. The findings do suggest issues that warrant further investigation. In particular, both the intensity and the nature of women's fears about recurrence require careful assessment. Although women in this sample appeared to fear recurrence less than expected, determining the extent of their fear was a difficult undertaking.

Moreover, although fear of recurrence spanned several particular concerns (e.g., death, further treatment, emotional well-being), it is not clear if or how the nature of women's fears might relate to other variables such as coping or psychological adjustment. Finally, although previous research has examined stressful life events as a possible exacerbating factor for cancer patients (DuHamel et al., 2000; Grassi, Malacarne, Maestri, & Ramelli, 1997), this pilot study suggests it is important to explore the possibility that such events may distract women from focusing on their breast cancer or the possibility of recurrence. These issues, among others, are examined in the larger study.

# CHAPTER THREE: METHODS

## Recruitment

The study was approved by the Institutional Review Boards at both Mount Sinai School of Medicine and The Graduate Center of the City University of New York. Research participants were recruited through five participating physicians (three surgeons and two radiation oncologists) at Mount Sinai Medical Center. Women were eligible for participation if they met the following criteria: 1) diagnosed with a primary breast cancer one to seven years previously; 2) diagnosed with local or regional breast cancer (Stage I, II, or III); 3) received surgery for breast cancer; 4) no past recurrence of breast cancer; 5) not currently undergoing active treatment for breast cancer (with the exception that women who were taking Tamoxifen could be entered in the study); 6) treated, at least in part, at Mount Sinai; 7) aged 18 or older; and 8) English speaking.

The preceding eligibility criteria aimed to maintain a moderate level of homogeneity in the sample while allowing for between-group comparisons on key medical and socio-demographic variables. Including women diagnosed one to seven years previously allowed for an analysis of the importance of time since diagnosis while still restricting the range. Only women with local or regional breast cancer (Stages I-III) were included because women with metastatic (or stage IV) disease are much less likely to ever reach remission (American Cancer Society, 1999), making recurrence an irrelevant issue. Likewise, because a primary focus of the study was women's fears about recurrence, women who had a previous recurrence or were currently undergoing treatment (indicating the likelihood of active disease) were not included. The other eligibility requirements represented practical and ethical concerns.

Two slightly different recruitment strategies were used. Four of the five physicians used the following procedures to contact their patients: Physicians sent a standard letter to each eligible patient describing the study and their support of it. Patients were instructed to use the postage-paid envelope provided to return the letter to me, the investigaor, if they wanted to receive the study questionnaire. Approximately three weeks later, physicians sent a reminder letter (and a second postage-paid envelope) to any patient who had not yet returned the original letter.

I mailed a packet to each woman who requested the questionnaire, within approximately one week of receiving her letter. Packets included an introductory letter from myself, a questionnaire booklet, and a postage-paid return envelope. If the woman had not returned the questionnaire within approximately three weeks, I sent her a reminder letter. I then mailed a replacement questionnaire packet, approximately three additional weeks later, to any woman who still had not returned the questionnaire.

A slightly different recruitment strategy was used by one physician. He sent the questionnaire packet directly to each eligible patient with a letter explaining the study, describing his collaboration with me, and asking patients to complete the questionnaire. A postage-paid envelope was included so that women could return the completed packets to the physician's office. Procedures for reminder letters and replacement packets remained the same, with all cover letters signed by the physician.

Table 4 presents recruitment statistics and response rates for both recruitment strategies. A conservative estimate of the response rate was computed by dividing the number of completed questionnaires (n = 189) by the number of women (n = 373) who could reasonably be assumed to have received the letter and/or questionnaire and to be English-speaking (i.e., the post office did not return the letter indicating the address was incorrect and no friend or relative contacted me to indicate that the woman had died or did not speak English). Using this formula, the overall response rate was 51%. This estimate is considered to be conservative because it cannot be confirmed that all intended recipients actually received the letter or questionnaire, or were able to understand it. Several returned questionnaires could not be used because the women were later determined to be ineligible. As a result, 169 questionnaires were used for statistical analyses.[9]

There was a significant difference in response rate between the two recruitment strategies (Pearson $\chi^2$ (1) = 18.02, $p < .001$): More women recruited with the second strategy (the questionnaire mailed directly from the physician: 63%) completed the questionnaire than with the first strategy (41%). It is not known whether this difference was because of extra step involved in the first recruitment strategy (returning the letter to request a questionnaire), or because of some characteristic of the surgeon who used the more direct strategy or his relationship with his patients.

A limited amount of background information was available for those women who did not participate in the study. Analyses were conducted to determine whether those 189 women who returned the questionnaire differed in age, time since diagnosis, cancer stage, and ethnicity from the 184 who did not (excluding those women for whom an incorrect address was confirmed, those women who were deceased, and those women who did not speak English). No differences were found regarding cancer stage or time since diagnosis, but there were significant differences for ethnicity (Pearson $\chi^2$ (2) = 27.76, $p < .001$) and age ($t$ (353) = -2.05, $p < .05$). Participation rates were nearly twice as high for White women (59%) as for Black (29%) or Hispanic (28%) women and women who completed the questionnaire were younger (M = 60 years) than those who did not (M = 62 years). Table 5 displays the socio-demographic and medical characteristics of the final sample of 169 women.

## Measures

### Appraisal

Overall fear of recurrence was assessed with four questions designed to determine the extent to which women feared recurrence. Questions assessed frequency, potential for upset, consistency, and intensity of fears about recurrence. Participants used six-point scales with various anchors to answer each of the following questions: "How afraid are you that your breast cancer will recur?" (1 = not at all afraid, 6 = very afraid); "How much time do you spend thinking about the possibility that your breast cancer will recur?" (1 = I don't think about it at all, 6 = I think about it all the time); "How much does the possibility that your breast cancer may recur upset you?" (1 = it does not upset me at all, 6 = it makes me extremely upset); and "How often do you worry about the possibility that your breast cancer may recur?" (1 = I never worry about it, 6 = I worry about it all the time).

Perceived risk of recurrence was assessed with two items modified from those used by Aiken and her colleagues to assess women's perceived risk of developing breast cancer (Aiken et al., 1995): "What do you believe is the chance that your breast cancer will recur?"; and "How susceptible do you feel you are to a recurrence of breast cancer?" Participants responded using six-point scales (1 = no chance or not susceptible at all, 6 = high chance or highly susceptible)

Perceived control over recurrence was assessed with three questions assessing direct and indirect control over cancer: "To what extent do you feel you have control over whether your breast cancer recurs?"; "To what extent do you feel someone else (such as a physician or other person) has control over whether your breast cancer recurs?"; and "To what extent do you believe a recurrence would be due to chance or fate?"[10] These items were rated on six-point Likert Scales (1 = No Control or Not at all Due to Chance or Fate and 6 = Complete Control or Completely Due to Chance or Fate).

A principal components analysis with oblique rotation confirmed that fear, risk, and control represented separate constructs. One control item ("To what extent do you feel that a breast cancer recurrence would be due to chance or fate?") did not load on any of the factors and was not included in the final control index. Although fear and risk were related (r = .43), neither of these constructs was correlated with control. I averaged the four fear items to create an Overall

Fear of Recurrence Index ($\alpha$ = .87), the two risk items to create a Perceived Risk of Recurrence Index ($\alpha$ = .77), and the two control items to create a Perceived Control over Recurrence Index ($\alpha$ = .58).

The nature or content of women's fears about recurrence was assessed with the Concerns about Recurrence Scale (CARS), a measure constructed for this study and described in Chapter 2. Participants used a five-point Likert Scale (0 = "Not at all", 1 = "A little", 2 = "Moderately", 3 = "A lot", and 4 = "Extremely") to indicate the extent to which they worry about each potential threat of recurrence (e.g., interfere with ability to reach future goals, upset me emotionally, cause pain and suffering). An open-ended question at the end of the measure allowed women to indicate any additional worries. To test for item order effects, two versions of the measure were used, but no order effects were found. Psychometric properties and scoring of the CARS are described in Chapter 4.

## Psychological Adjustment

Psychological distress and psychological well-being were assessed with the Mental Health Inventory (MHI) (Veit & Ware, 1983), a 38-item, self-report measure. The MHI was designed for use with non-psychiatric populations and was originally tested with a sample of 5,089 respondents at four sites across the United States. The measure has been used in prior studies with cancer patients (Kornblith et al., 1995; Miller, Manne, Taylor, Keates, & Dougherty, 1996; Ostroff, Woolverton, Berry, & Lesko, 1996). A factor analysis conducted by the measure's authors identified a lower order five-factor solution and a higher order two-factor solution in which the lower-order factors of depression, anxiety, and loss of emotional and behavioral control are combined into a psychological distress factor, and general positive affect and emotional ties are combined into a psychological well-being factor. The current study employed the higher order solution. The correlation between distress and well-being was $r = -.75$, $p < .001$. Internal consistency reliability for both scales was excellent (Distress = .95, Well-being = .94).

### Coping

Three cognitive coping strategies (acceptance, denial, and positive reframing) were assessed with sub-scales from The Brief Cope (Carver, 1997), a self-report measure that assesses the situation-specific use of coping strategies. Participants used a four-point Likert scale (1 = I haven't been doing this at all, 2 = I've been doing this a little bit, 3 = I've been doing this a moderate amount, and 4 = I've been doing this a lot), to indicate the extent to which they currently use each strategy to cope with their fears about the possibility of breast cancer recurrence. Several items were modified to apply to a possible future event (i.e., the possibility of breast cancer recurrence) rather than a present situation. For example, the item "I've been saying to myself 'this isn't real'" was modified to "I've been saying to myself 'the possibility of a recurrence isn't real'". Inter-correlations among the scales were small but significant (acceptance - denial, $r = -.23$, $p < .01$; acceptance - positive reframing, $r = .23$, $p < .01$; denial - positive reframing, $r = .24$, $p < .001$). Internal consistency reliability of the three coping scales was .76 for acceptance, .73 for denial, and .64 for positive reframing.

## Contextual Variables

Background variables (socio-demographic and medical) were assessed in the questionnaire. Cancer stage was obtained from medical charts whenever possible (approximately 90% of cases). When stage could not be located in the chart it was obtained from the participant.

Ongoing consequences of the initial diagnosis were assessed with the Consequences of Breast Cancer Scale (CBCS), a measure designed for this study. Participants used a 5-point Likert Scale (0 = Not at all, 1 = A little, 2 = Moderately, 3 = A lot, and 4 = Extremely) to indicate the extent to which breast cancer was currently affecting their lives (e.g., interferes with ability to reach future goals, upsets me emotionally, causes pain and suffering). The measure was constructed to be parallel to the CARS, so that comparisons could be made between consequences perceived to have resulted from the initial diagnosis and threats perceived to be posed by the possibility of a recurrence. For example, if a woman feels that her initial diagnosis of breast cancer has had negative consequences for her romantic relationships, is she likely to fear that a recurrence would have the same result? Seven items from the CARS could not be included in the CBCS because they were not appropriate for a measure of current or ongoing consequences (e.g., cause me to die, require chemotherapy). An open-ended question at the end of the measure assessed whether women perceived any other consequences to have resulted from breast cancer. Psychometric properties and scoring of the CBCS are described in Chapter 4.

Life Circumstances were assessed with an open-ended writing task.

Women were asked to write about any life experiences (good or bad) that may have influenced the way they thought about breast cancer or the possibility of recurrence. The follow directions were provided:

> *The main focus of this survey is on your experiences with breast cancer. However, we understand that breast cancer is not the only event that is occurring in a woman's life. We are also interested in any other events (good or bad) that you think may have affected how you dealt with your breast cancer or how much you worry about the possibility of recurrence. For example, another health problem or personal situation such as a divorce may make the breast cancer seem less important in comparison, or it may make the cancer and possibility of recurrence even more difficult to deal with. In the same way, a happy event such as the birth of a baby or a new relationship could make the breast cancer and the possibility of recurrence seem more or less difficult to deal with. Please use the space provided to describe any events or situations in your life that may have influenced how you think about your breast cancer and the possibility of recurrence. For any situation or event that you describe, please explain how you think it may have affected your experience with breast cancer or your thoughts about the possibility of recurrence. Please write as much, or as little, as you wish.*

Content coding was used to analyze the written responses. Circumstances were originally coded as positive or negative, and then further divided into content areas (e.g., social support or death of a loved one). A third general category was suggested by the pilot study and the written responses here, distracting negative circumstances. Negative circumstances were coded as distracting if the participant's written comment suggested that the circumstance they described was more distressing or salient than breast cancer or the possibility of recurrence.

## Women's Words about Recurrence

Although not specifically instructed to do so, almost half of the women in the sample wrote about their general thoughts and feelings regarding the possibility of recurrence. These statements were provided in response to the question about life circumstances or in other parts of the questionnaire, such as the open-ended question at the end of the CARS. Because women's words can enrich our understanding of their fears, these responses were content coded and are described in the next chapter.

## Results and Analysis Overview

Results are divided into three chapters. Chapter 4 focuses on fear of recurrence, its correlates, and the relationship of fear to overall psychological adjustment. Chapter 5 addresses the role of coping in the relationship between fear of recurrence and adjustment. Chapter 6 explores how breast cancer and women's fear of recurrence fit into the context of women's lives.

Data analysis began by examining patterns of missing data and distributions of the variables of interest.[11] Transformed scores were used whenever they improved the skewness and/or kurtosis of a variable.[12] Each chapter begins with descriptive statistics and correlational analyses of the primary variables, followed by multivariate analyses.

# CHAPTER FOUR: CONCERNS ABOUT BREAST CANCER RECURRENCE: INTENSITY, NATURE AND CORRELATES OF FEAR

Prior research has identified fear of recurrence as a common concern for breast cancer patients and survivors. This research has focused on the frequency and intensity of fears, without addressing their essence or meaning. In this chapter, I present data that address the content of women's fears, targeting what it is about the possibility of recurrence that women with breast cancer fear. I then examine several potential correlates of these fears, as well as the relationship of fears about recurrence to psychological adjustment. Figure 1 depicts the conceptual model to be tested. Before examining these issues I present descriptive findings about women's overall levels of fear about the possibility of recurrence, as well as their perceptions of risk and control.

## The Possibility of Recurrence: Fear, Risk, and Control

Mean scores indicate moderate to low levels of overall fear, perceived risk, and perceived control regarding the possibility of recurrence (see Table 6). T-tests indicated that women's fears about recurrence were significantly stronger than their perceptions of risk, and that their perceptions of risk were significantly stronger than their perceptions of control ($p$'s < .001). Frequency distributions suggest greater variability among the sample. Although many women did have scores in the moderate range, scores were low for a large percentage of the sample and a small but important percentage had high scores (see Figure 2). These scores are put into context by examining women's written comments about the possibility of recurrence. Many women (n= 82) described their thoughts and feelings about recurrence in response to the open-ended question on life circumstances, or in other areas of the questionnaire. These comments enrich the quantitative findings, further illustrating women's perceptions of the possibility of recurrence. The quotes presented below represent a sample of the diverse comments that women wrote regarding fear, risk, and control of recurrence.

Just under half of the sample (46%) reported little to no fear about the possibility of recurrence (i.e., ratings were on the lower third of the Likert scale). For the most part, the spontaneous written comments of these women reflect this. Many women indicated that breast cancer recurrence was something they rarely thought about:

*"I do not worry at all. I have a very positive attitude and do not even think about breast cancer."*

*"I try to spend as little time as possible worrying about what might happen. My attitude has been - worry when it actually happens (recurrence). I think it would be very upsetting to my life if it did - but worrying is not part of my coping strategy."*

Other women acknowledged <u>thinking</u> about the possibility of recurrence, but indicated that their <u>fear</u> was minimal. For example: *"The five year period which means you are clean and clear looks like a long time ahead. I do not dwell on it* *and make the same plans I normally would - but it is in the back of mind - just occasionally intrusive but does not affect my lifestyle."*

In general, written responses supported womens' Likert ratings indicating little to no fear of recurrence. However, a few written comments suggested that women may have felt more fear than was indicated by their low ratings on the fear scale. For example, one woman with a low fear score simply stated: *"The fear of recurrence is always there."*

Approximately 10% of the sample reported high levels of fear about recurrence (i.e., ratings were on the higher third of the Likert scale). Because there were relatively few women in this group, a limited number of written comments were available for examination, but the comments women did write illuminate their concerns and indicate that the fear of recurrence was central for them.

*"The thought of recurrence is the most frightening thought to me. If it happens, hopefully I'll be able to deal with it. Not looking forward to it to say the least."*

*"Breast cancer is something that is always in back of my mind. It affects my life, the way I think, and it terrorizes me to think it could come back. Recurrence is my biggest fear and to go through chemo again is something I can't imagine. I pray that day will never come."*

*"I try every day to think positive and try to convince myself that a recurrence will never happen. ... I never feel totally free. This disease could recur at anytime and I never feel relaxed."*

Approximately 45% of the sample indicated a moderate level of fear about recurrence (i.e., ratings were in the middle third of the Likert scale), but their spontaneous written comments suggest a range of fear levels. For some women the fear appeared to be subtle, but constant, while for others it was more transient. Several statements indicated active efforts <u>not</u> to focus on recurrence, whereas others suggested that the fear of recurrence interfered with their ability to plan for the future. Several quotes are presented here, to illustrate the diversity of experiences among women who responded with similar Likert ratings of fears about recurrence.

*"I can honestly say that now I monitor and orchestrate my life very carefully because I do have that fear of the recurrence of breast cancer or any other cancer and many times I wonder if and when once again I'll go through that "stop in your tracks" feeling of being told you have cancer."*

*"I am in fear of recurrence but I don't think about it often"*

*"I can't take the future for granted. When I try to look ahead I think 'what's the*

*use, I may not even be here'."*

*"After one year I am going about my life and trying hard not to think about a recurrence. Trying to think positive and be thankful for what I have."*

*"As far as a recurrence, I don't dwell on it or worry - but it is with me always as is the fact that I had breast cancer. It's just there. My favorite word is "hopefully". Hopefully I'm cancer free. Hopefully it won't happen again."*

*"In the beginning I could only feel very nervous. I have calmed down some but I worry a lot about recurrence."*

Women wrote far fewer comments about perceived risk and perceived control. However, examining the responses that were provided does illuminate some of the thought processes that were associated with low and moderate Likert ratings on these indicies. The few women who reported high levels of perceived risk (4% of the sample) or perceived control (4% of the sample) did not provide any written statements regarding these beliefs. The comments of women who reported low levels of perceived risk (64% of the sample) generally supported those ratings. For example, *"I strongly believe that I will not have a breast cancer recurrence since there was no lymph gland involvement and no family history."* Likewise, women perceiving low levels of control over recurrence

(77% of the sample) expressed their beliefs in writing, *"I have no control if cancer should appear again but will face any situation when it occurs."* Several of the women who perceived moderate levels of risk (32% of the sample) wrote comments that further substantiated their Likert ratings: *"I feel I won't have a recurrence, but I am trying to live a rich life just in case."*, but only one of the women with a moderate control score (19% of the sample) wrote anything about her beliefs. Her response indicated an interesting contradiction between beliefs about control and action aimed at control: *"I am a fatalist, so I do not think I can influence the future very much. I get all my checkups on time, trying to do the best I can to avoid a recurrence."*

Despite the general congruence between ratings and written comments, some women, like the one quoted above, wrote about recurrence in a way that seemed to be at odds with their ratings. Another example is provided by the comment written by one woman whose score indicated a low level of perceived control, *"I think that by keeping the immune system healthy I will not get a recurrence of breast cancer."*

Many of the women's written comments about recurrence described factors that modified their fears about this possibility. Specifically, comments addressed comparisons of fears about breast cancer recurrence to fears about other cancer diagnoses, "triggers" of fears, and the likelihood of "beating" a recurrence.

Several women indicated that they had hierarchies of fear and described the place of a possible recurrence in those hierarchies. Often these women compared their (lack of) fear of breast cancer recurrence to fears about other types of cancer. Other women interpreted "recurrence" to mean "local recurrence" and compared their fear regarding that possibility to the possibility of metastatic disease or a new breast cancer.

*"I have a clear hierarchy of concerns. The least is localized recurrence and loss of the breast. Second, is cancer in my other breast, especially if I had to lose the lymph nodes. Third, and the only real great fear is that this cancer escaped into the rest of my body."*

*"I'm not so much worried about a breast cancer recurrence as I am about a lung or stomach or pancreatic etc. type of cancer."*

*"Am I worried about breast cancer? No, not specifically but I don't want lung cancer or colon cancer, either, and so I should have x-rays, pap smears etc."*

The pilot phase of this research identified several triggers for fears about recurrence. However, women's written comments in the main study were overwhelmingly focused on two of these triggers: physical symptoms and physician visits. Among those women identifying physical symptoms as triggers for their fears, most appeared to fear recurrence only when they felt a pain or discovered a "symptom" somewhere in their bodies.

*"I generally don't think that I will have a recurrence. I don't worry much about it. However, whenever something is wrong with my body, I can't help but wonder if there is any cancer connection. I don't dwell on the worry but it does surface in vulnerable moments."*

*"Every pain I have I always feel the cancer has returned."*

*"When other problems occur, the first thought is "is this cancer?" For example, I had a hysterectomy and I worried about cancer. I had a urinary tract infection, but my first thought was cancer."*

Several other women indicated that their fears about recurrence were triggered by physician appointments or anticipated medical tests. Again, the fear of recurrence seemed to be strongest when a physician appointment or medical test was imminent.

*"I strongly believe that I will not have a breast cancer recurrence since there was no lymph gland involvement and no family history. However, I admit that I am apprehensive when I go for a check-up to the surgeon, radiologist or oncologist ."*

*"I'll always be scared taking my blood tests, scans and doctors visits but, in truth, I thought I was going to die 5 years ago and I'm still here. If "it" comes back maybe I'll be just as lucky again."*

*"I also think I overreact when it becomes close to the time of my annual mammogram. My anxiety level becomes very high."*

Several women acknowledged the possibility of recurrence but went on to express their beliefs that they would be able to "beat" a recurrence if it happened.

*"I truly think about recurrence - but because my recovery from this cancer issue was not horrible or disastrous to my life I'm not really afraid that it will change my life any more than it did in 95-96. If it happens - I will get treated and it will be gone - and I will live."*

*"I try not to dwell on these feelings. I tell myself the reality of recurrence is slim and even if it does occur I will beat it again."*

*"I know I'm strong enough to go through it again, I just don't want to have to put my life on hold again and not be able to do or enjoy all we have planned for the future."*

Taken together, the Likert ratings and written comments suggest that women with breast cancer vary widely in how much they fear recurrence, and, to a lesser degree, in how much they perceive themselves to be at risk for recurrence and to have control over recurrence. Physical symptoms and physician visits were likely to trigger fears about recurrence for many women, regardless of how much fear a woman reported. On the other hand, the comments written by some women indicated that they did not view recurrence as a catastrophic event. Indeed, several women expressed the belief that they would be able to "beat" a recurrence if it happened. This finding raises the question: What do women with breast cancer think a recurrence would mean for their lives?

## The Possibility of Recurrence: What Do Women Fear?

The Concerns about Recurrence Scale (CARS) provides a more structured assessment of women's fears about breast cancer recurrence. Means and standard deviations for the 30 CARS items are presented in Table 7 in order of decreasing strength. Among the most common worries were "Require chemotherapy", "Threaten my life", "Threaten my physical health", and "Be more serious than the first diagnosis." Among the least common were "Prevent me from becoming a mother", "Threaten my spirituality or faith", "Hurt my relationships with friends or family", and "Make me feel I am less of a woman".

An exploratory factor analysis was conducted in order to determine the structure of the CARS and to identify meaningful subsets of items[13,14]. Because of heterogeneity among item variances, the generalized least squares method of extraction was used. This method weights items by the reciprocal standard deviation in an effort to equalize the variances (Bollen, 1989). All values below .40 were suppressed and oblique rotation was chosen because it was assumed that factors would be correlated.

The factor analysis resulted in a four factor solution that accounted for 70% of the variance. The factors are displayed in Table 8. The first factor was comprised of eleven items that referred to concern about future treatment (chemotherapy, radiation, and surgery), emotional upset, physical health, carrying out planned activities, and loss of the breast(s). This factor was labeled "Health Worries". The second factor included seven items referring to femininity, sexuality, womanhood, body image, romantic relationships, identity, and spirituality/faith. This factor was labeled "Womanhood Worries". The third factor was labeled "Role Worries". This factor included six items pertaining to roles and responsibilities at work and at home, relationships with friends and family, physical ability to complete daily activities, financial problems, and self-confidence. The final factor, "Death Worries", contained only two items, both pertaining to the possibility that a recurrence of breast cancer could lead to death.[15] Only one item, "[I worry that a recurrence of breast cancer would:] Mean losing my breast(s)" loaded above .40 on more than one factor. This item was included in the sub-scale for which it had the highest loading, Health Worries. Three items did not load above .40 on any of the factors ("Lead me to feel disappointed in my body or feel my body is attacking me"; "Threaten my ability to be a good mother (grandmother, aunt etc.)"; "Prevent me from maintaining a positive attitude"). These items were not included on any sub-scale and will not be discussed further.

Responses to the open-ended question at the end of the CARS were, for the most part, elaborations on the possible consequences described in the items. One additional concern, pain and suffering of loved ones, was suggested by six women.

Scores for the four CARS sub-scales were computed by averaging the items loading >.40 (see Table 8 for alpha coefficients of sub-scales). No total CARS score was computed. Table 9 presents means and standard deviations for the four CARS sub-scales (as well as inter-factor correlations). Women indicated moderate fears about death and about health (a T-test indicated that death worries were significantly stronger that health worries, $p < .01$). Fears regarding roles and womanhood were weaker, with scores on role worries being significantly lower than health worries, and scores on womanhood worries being significantly lower than role worries. However, it is again more useful to examine the percentages of the sample who scored in the low, moderate, and high range for each fear domain (Figure 3).[16]

Approximately 3/4 of the sample reported worrying about the possibility that a recurrence could lead to death, and almost 40% of the sample was very concerned about this possibility. The distribution of fears regarding health was similar, with an even larger percentage worrying that a recurrence would have health consequences (86%), and again, approximately 40% reporting high levels of fear. Women were markedly less concerned about recurrence interfering with their roles and responsibilities, although close to 60% did report these fears at some level (with just 10% indicating high levels of concern). Finally, less than half of the sample indicated worrying that a recurrence would influence their lives in terms of womanhood issues, with less than 10% reporting high levels of fear in this domain.

## Correlates of Fears about Recurrence

Three sets of variables were examined as potential correlates of fears about recurrence. Four background variables (age, time since diagnosis, chemotherapy, and surgery) were examined because prior research suggests that they may be associated with fears about recurrence. Initial appraisal variables – perceived risk and perceived control – were also expected to be related to these fears, based on past research. In line with theories proposing that expectancies about future events are shaped by past experiences, it was hypothesized that ongoing consequences of the initial diagnosis would be associated with fears about recurrence, and that these consequences would mediate the relationship between background variables and fears (see Figure 1). However, there was no conceptual reason to think that ongoing consequences would be related to initial appraisal variables or would mediate the relationship of these variables to fears about recurrence.

The Consequences of Breast Cancer Scale (CBCS) was designed to parallel the CARS; thus, three sub-scales (health consequences, womanhood consequences, and role consequences) were constructed. (There was no death consequences sub-scale. Instead, the one life-threat item was included in the health consequences sub-scale.) Women perceived few ongoing consequences of their initial diagnosis (see Table 10). Indeed, mean scores on the three sub-scales were all below one (when the possible range was 0 to 4). T-tests indicated that health consequences were significantly more common that role or womanhood consequences ($p$'s < .001). Figure 4 displays the percentages of the sample who reported low, moderate and high levels of consequences in each domain. Over half of the sample reported some ongoing consequences in the health domain, although the percentage reporting high levels of health consequences was small (not quite 10%). Less than 20% reported ongoing consequences in terms of roles or womanhood issues, with not even 5% indicating high levels of consequences in these domains.

Hierarchical regression analysis was used to test the conceptual model illustrated in Figure 1 (the final variable in the model – psychological adjustment – was not yet included in the analysis). Table 11 displays bivariate correlations among the potential correlates of fear of recurrence, and Table 12 presents their bivariate correlations with the five fear variables (overall fear, death worries, health worries, role worries, and womanhood worries). Mediation was tested using hierarchical multiple regression (see Table 13). In each regression equation a fear variable was regressed on three sets of predictors: Background variables (age, time since diagnosis, chemotherapy and surgery) were entered in the first step; initial appraisal variables (perceived risk and perceived control) were entered in the second step; and ongoing consequences (health, role, and womanhood) were entered in the final step.

Baron and Kenny (1986) describe three criteria for demonstrating mediation: 1) The predictor must be associated with the mediator; 2) the predictor must be associated with the criterion variable; and 3) the mediator must be associated with the criterion variable, with the association between the predictor and the criterion variable dropping to nonsignificance when the mediator is added to the model. Partial mediation is suggested if the beta weight of the predictor drops substantially with the addition of the mediator, but remains significant. The bivariate correlations in Table 11 provide data to test the first criterion; the hierarchical regression equations in Table 13 provide findings that account for criteria two and three. Step one of the regression analyses demonstrates the association of the predictors (age, time, chemotherapy, and surgery) to the criterion variable (fear). Step three demonstrates the association of the mediators (health, role, and womanhood consequences) to the criterion variable, and the extent to which the association of the predictors to the criterion variable changes (specifically, that the percent of variance explained/beta weights decrease and become non-significant) with the addition of the mediators. Criterion one is accounted for by examining bivariate correlations of single mediators to single predictors.

## Factors Predicting Overall Fear of Recurrence

Age was inversely associated with overall fear of recurrence in the first and second steps of the analysis. In the second step, there was also a trend for surgery (mastectomy was associated with greater fear than BCS) and perceived risk was positively associated with fear of recurrence. When ongoing consequences of the initial diagnosis were added in the third step, age was no longer associated with fear, suggesting mediation. Moreover, the trend for surgery disappeared and the association of risk to fear became weaker (although it remained significant). Health consequences and womanhood consequences were positively related to overall fear, and role consequences were inversely related to fear (trend). Bivariate correlations confirmed the mediating role of consequences by demonstrating that health, role, and womanhood consequences were all inversely related to age (all $p$'s < .01), and health and role consequences were related to mastectomy as opposed to BCS (i.e., women who had mastectomy reported more ongoing consequences) (all $p$'s < .05). The suggestion that consequences partially mediated the relationship of risk to overall fear was also confirmed; health, role, and womanhood consequences were positively associated with risk (all $p$'s < .01).

## Factors Predicting Death Worries

Age was inversely related to death worries in the first and second steps of the analysis. Risk was positively associated with death worries in the second step. When consequences were entered in the third step, age was no longer related to death worries and the relationship between risk and death worries was weakened, although it remained significant. Health consequences were positively associated with death worries and role consequences were inversely related. Bivariate correlations confirmed that the relationship of age to death worries was mediated by consequences; both role and health consequences were inversely related to age ($p$'s < .01). Moreover, the suggestion that the relationship of risk and death worries was partially mediated by consequences was confirmed; role and health consequences were positively related to risk (p's < .01).

## Factors Predicting Health Worries

In the first and second steps of the analysis both age and chemotherapy were significantly related to health worries. Age was inversely related to health worries and those women who had chemotherapy reported more worries about their health than those who did not have chemotherapy. This effect was reduced to a trend in the second step. Risk was also associated with health worries in the second step. However, when consequences were added in the third step, the associations of age, chemotherapy, and risk were all reduced to non-significance, suggesting mediation. Only health consequences were related to health worries. Bivariate correlations confirmed mediation, demonstrating that health consequences were inversely associated with age, positively associated with risk, and associated with undergoing chemotherapy (i.e., those women who had undergone chemotherapy reported more health consequences) (all p's < .01).

## Factors Predicting Role Worries

In the first step of the analysis there were trends for age and chemotherapy to predict role worries. Age was inversely associated with these worries and those women who had chemotherapy reported more worries about their roles. In the second step the trend for chemotherapy remained and a trend for surgery appeared. Those women who had a mastectomy reported more worries about roles than women who had BCS. Risk also was positively associated with role worries in the second step and there was a trend for control (positive relationship). When consequences were added to the analysis in the third step, the associations of chemotherapy, surgery, risk, and control all disappeared. Only health consequences and role consequences predicted role worries. Follow-up analyses confirmed that consequences mediated the relationships of age, chemotherapy, and risk to role worries; health and role consequences were both positively related to risk, and related to mastectomy (i.e., women who had mastectomy reported more consequences than women who had BCS) ($p$'s < .05). Although health consequences were also associated with chemotherapy (i.e., those women undergoing chemotherapy reported more health consequences than those not undergoing chemotherapy) ($p$ <.01), role consequences were not.

### Factors Predicting Womanhood Worries

Age was inversely associated with womanhood worries in the first step and second steps of the analysis. Risk was also positively associated with womanhood worries in the second step. However, the relationships of age and risk to womanhood worries dropped to non-significance when consequences were added in the third step. Only womanhood consequences were positively related to womanhood worries. Follow-up analyses confirmed that consequences mediated the relationships of age and risk to womanhood worries; womanhood consequences were inversely associated with age and positively associated with risk ($p$'s < .05).

### Synopsis

Findings generally support the model illustrated in Figure 1. Younger age, having had a mastectomy, and having undergone chemotherapy were associated with fears about recurrence, but in all cases these effects were mediated by ongoing consequences of the initital diagnosis. It should be noted that a moderate bivariate correlation between age and chemotherapy (-.42, $p < .001$), and a smaller correlation between mastectomy (as opposed to BCS) and chemotherapy (.27, $p < .001$) suggests that the contributions of these variables may have been somewhat masked by multicollinearity. Perceived risk was also associated with greater fear, and this relationship was partially mediated by consequences. These findings suggest that an additional arrow should be added to the model in Figure 1 – from perceived risk of recurrence to ongoing consequences.

## How do Fears of Recurrence Relate to Psychological Adjustment?

T-tests were used to compare women's mean scores on distress (M = 51.42, SD = 18.78) and well-being (M = 63.17, SD = 12.93) to the normative mean scores of a non-clinical community sample (distress M = 47.54, SD = 15.39; well-being M = 59.16, SD = 12.16) published by Veit and Ware (1983). Both t-tests were significant (distress: $t\ (166) = 2.67$, $p < .01$; well-being: $t\ (166) = 4.01$, $p < .001$). Women in this sample were more distressed than the normative sample, but they also reported greater well-being.

Hierarchical regression analysis was used to determine the independent contribution of fears about breast cancer recurrence to psychological adjustment, after controlling for background variables (age, time since diagnosis, surgery, chemotherapy), initial appraisal variables (perceived risk and perceived control), and ongoing consequences of the initial diagnosis (health, roles, and womanhood). It was hypothesized that any relationship between the initial appraisal variables to psychological adjustment would be mediated by fear of recurrence, but that ongoing consequences of the initial diagnosis would be directly associated with adjustment (see Figure 1). Because of multicollinearity among fear domains, separate regression analyses were conducted to examine the contribution of each fear variable to each of the psychological adjustment variables, psychological distress and well-being (i.e., five fear variables X two adjustment variables = 10 regression equations). For each equation, background variables were entered in the first step, initial appraisal variables in the second step, and ongoing consequences in the third step. In the fourth step, one of the fear of recurrence variables was entered.

## Predictors of Psychological Distress

None of the background variables were related to psychological distress on the first step. On the second step, perceived risk was positively associated with distress ($\beta = .259$, $p < .01$), but perceived control was not. On the third step, health consequences ($\beta = .266$) and womanhood consequences ($\beta = .224$) made independent contributions to psychological distress ($p$'s $< .05$) and there was a trend for role consequences ($\beta = .212$, $p = .06$). There was also a trend for age ($\beta = .138$, $p < .09$) to become positively related to distress on this step. Perceived risk no longer made a significant contribution to psychological distress on the third step.

All models were significant on the fourth step, when one of the fear variables was added to the equation. Table 14 presents the final model F-values and adjusted $R^2$, as well as change in adjusted $R^2$ with the addition of the respective fear variable. Table 15 shows the beta weights for each variable in the fourth step. Overall fear, and death, health, and womanhood worries all made significant contributions to psychological distress in their respective equations, and there was also a trend ($p$ = .06) for role worries. The largest change in adjusted $R^2$ (.07) occurred with the addition of the variable measuring overall fear. Of the specific fear domains, womanhood worries and death worries made the largest contribution to distress (.04 and .03 in separate equations). Age was positively related to distress in the fourth step, across all fear variables. Consequences also were significant, but these effects varied depending on the fear variable being examined.[17]

## Predictors of Psychological Well-being

Identical analyses were conducted with psychological well-being as the criterion variable in the regression equations. None of the background variables were related to well-being in the first step. On the second step, perceived risk ($\beta = -.30$, $p < .001$) was inversely related to well-being, as was surgery (trend, $\beta = -.14$, $p = .10$), women who had mastectomy reported lower well-being. On the third step, role consequences ($\beta = -.29$, $p < .05$) were inversely related to well-being, as were womanhood consequences ($\beta = -.24$, $p< .05$). Chemotherapy ($\beta = .17$, $p < .05$) was positively related to well-being on this step and perceived risk ($\beta = -.20$, $p < .05$) was inversely associated with well-being. There was also a trend for perceived control ($\beta = .13$, $p < .10$) to be positively related to well-being on this step.

All models were significant in the fourth step. Table 16 presents the final model F-values and adjusted $R^2$, as well as change in adjusted $R^2$ with the addition of the respective fear variable. Table 17 shows the beta weights for each variable in the fourth step. Overall fear, and death, role, and womanhood worries all made significant independent contributions to psychological well-being in their respective analyses. There was also a trend for health worries to be significant. Again, the largest change in adjusted $R^2$ was associated with overall fear (.05), and sizeable changes were also made with the addition of death worries (.03) and womanhood worries (.02) in their respective equations. Chemotherapy was positively related to well-being in the fourth step, across all fear variables. Role and womanhood consequences were also significant, but these effects varied depending on the fear variable being examined. Perceived risk was inversely associated with well-being across fear domains (but not with overall fear) and there was a trend for perceived control to be positively associated with well-being.[18]

## Summary

Women varied widely in the extent to which they feared the possibility of recurrence. Perceptions of risk and control varied as well, although less broadly. Written comments put Likert scores into context and suggested that the scores were relatively face-valid. Fears revolved primarily around physical health and death issues, although concerns about roles and womanhood issues were also identified. Findings generally fit the conceptual model presented in Figure 1.

Younger age, having undergone chemotherapy, and having had a mastectomy (as opposed to BCS) were related to fears about recurrence, although these associations were accounted for by variability in ongoing consequences of the initial diagnosis. Perceived risk of recurrence was positively associated with fears, but this effect too was partially mediated by consequences. Fears about recurrence were significantly associated with both psychological distress and psychological well-being, even after controlling for background variables, initial appraisal variables, and ongoing consequences of the initial diagnosis. When all of these variables were considered together, age, chemotherapy, risk, control, and consequences also made significant contributions to adjustment.

# CHAPTER FIVE: COPING WITH FEARS ABOUT BREAST CANCER RECURRENCE

A number of studies have examined coping with breast cancer but none have focused on how women cope with fears about recurrence in particular. In this chapter I address the use of acceptance. denial. and positive reframing as strategies for coping with fears about recurrence, and I examine the role of coping in the relationship between fears and psychological adjustment. Three conceptual models are examined, as shown in Figure 5: coping as a mediator, coping as a moderator, and coping as a direct effect.

Mean scores for the acceptance, denial, and positive reframing scales are presented in Table 18, along with the correlations of these scales to fears about recurrence and psychological adjustment.[19] Women reported the highest levels of acceptance as a strategy for coping with their fears about recurrence. T-tests showed that women used this strategy significantly more than denial ($\underline{p} < .001$), which was used significantly more than positive reframing ($\underline{p} < .001$). Although denial was correlated significantly with fears and with distress, there were no other significant correlations between coping and fears or adjustment.

## The Role of Coping

Hierarchical regression analyses were conducted to examine the role of coping in the relationship between fears about recurrence and psychological adjustment. Other study variables were not included in the analyses for two reasons: 1) the role of coping can be more clearly demonstrated in isolation from other variables; and 2) bivariate correlations (see Table 19) showed only one significant relationship between coping and the other variables examined (including background variables, initial appraisal variables, and ongoing consequences). Perceived risk of recurrence was positively associated with using acceptance as a coping strategy.

Because one goal of the analyses was to determine whether the role of coping was dependent on the fear domain being examined, separate regression equations were constructed for each fear variable (overall fear of recurrence; death worries; health worries; role worries; and womanhood worries). The first step of each regression equation included one of the fear variables (seen at the top of each column in Tables 20 and 21). Step 2 included the set of three coping strategies (acceptance, denial, and positive reframing). These first two steps allowed for testing whether coping mediated the relationship between fear and adjustment. The final step tested whether coping moderated the relationship between fear and adjustment. This step included the set of three cross-products of acceptance, denial, and positive reappraisal with the respective fear variable (e.g., the first equation included acceptance X overall fear, denial X overall fear, and positive reframing X overall fear). Fear variables and coping variables were mean-centered to reduce multicollinearity. Separate sets of regression equations were computed for the two outcomes: psychological distress (Table 20) and psychological well-being (Table 21).

The pattern of results was generally consistent across the five fear variables. Findings did not support the role of coping as a mediator of the relationship of fears about recurrence and psychological adjustment. Two significant direct effects for coping appeared across the analyses (i.e., independent of which fear variable was entered): denial was related to increased psychological distress and positive reframing was related to increased psychological well-being. In addition to these direct effects, there was some suggestion of a moderating effect for the strategy of acceptance with the outcome of well-being. (None of the interaction terms were significant for distress). The beta weights for the interaction of fear and acceptance were significant at the .05 level when the fear variable was health worries or womanhood worries and at the .10 level when the fear variable was death worries or role worries. This interaction was not significant when the fear variable was overall fear.

Regression lines were plotted according to the procedures described by Aiken and West (1991). In this procedure two groups are examined: 1) those scoring one standard deviation above the mean on the moderating variable, here acceptance; and 2) those scoring one standard deviation below the mean on the moderating variable. The slope of the line representing the "moderated relationship" (between fear and psychological well-being) is computed separately for each group. Figure 6 displays the regression lines for death, health, role, and womanhood worries. All four graphs show a strong inverse association between fear and well-being among women who used low levels of acceptance in coping with fears about recurrence (all slopes significant at $p < .001$). This group included all women whose acceptance scores were below 2.6 ($n = 29$), one standard deviation below the mean acceptance score of 4.5. Findings were more variable across fear domains for the women who used high levels of acceptance to cope with their fears (acceptance scores higher than 6.4, one standard deviation above the mean acceptance score; n = 21). When the fear variable was death worries or health worries, the inverse association between fear and well-being was not seen among women using high levels of acceptance (i.e., the slopes were not significant). Thus, using acceptance appeared to buffer the effects of experiencing these fears. However, the inverse relationship between fears and well-being was significant ($p < .01$) on the womanhood worries plot, and there was a trend for it to be significant ($p < .10$) on the role worries plot, indicating that the suggested buffering effect was not as strong when fears revolved around womanhood or role issues.

## Summary

Coping played only a limited role in the relationship between women's fears of recurrence and their psychological adjustment. The use of acceptance served as a moderator of fears and well-being, seeming to work as a buffer, particularly when fears revolved around death or health. None of the coping strategies served as mediators. However, both denial and positive reframing were directly related to adjustment; there were positive associations between denial and distress and between positive reframing and well-being. Little is known about who uses which strategies and why. Although a positive relationship between perceived risk and acceptance was identified, no significant bivariate relationships were identified between coping and background variables, perceived control, or ongoing consequences.

# CHAPTER SIX: BREAST CANCER AND THE POSSIBILITY OF RECURRENCE IN THE CONTEXT OF WOMEN'S LIVES

The preceding chapters addressed factors and processes associated with fears about the possibility of breast cancer recurrence. Although fears about recurrence are conceptualized as the focal stressor, it is important to acknowledge that breast cancer occurs in the context of women's lives. That is, there are likely to be other life circumstances (good or bad) that simultaneously influence psychological adjustment and women's experiences with breast cancer and the possibility of recurrence. The importance of exploring this issue was suggested in the pilot study and is illustrated by the words of one woman who took part in the larger study: *"I have had the* *<u>experience</u>* *of trauma several times in my life since childhood, so I believe that my reaction to the diagnosis of breast cancer and its sequelae (surgery treatment etc.) existed and exists in the context of my total life experiences."*

In an open-ended writing task women were asked to describe how their life circumstances (positive or negative) might have influenced their experience with breast cancer and their perceptions of the possibility of recurrence. Only 110 women (65%) responded to the question, and only 84 of the 110 actually described influential life circumstances.[20] Some women described multiple events or situations. In some cases women described how their experience with breast cancer had been influenced by their life circumstances. Other women did not make the impact of the circumstances explicit, but the valence of the impact (positive or negative) was implied. Sometimes women did not indicate any influential experiences in the space provided for that purpose, but wrote about life experiences in other parts of the questionnaire. All of these responses were included in the following analyses. Thus, the quantitative findings in this chapter are considered exploratory and should be interpreted with caution.

Life circumstances were coded as positive or negative and further divided into content areas. Many women described both positive and negative circumstances, with some describing multiple circumstances in each category. Some negative circumstances received an additional code: "distracting circumstance". Distracting circumstances were those negative experiences that women described as more distressing or more salient than breast cancer or the possibility of recurrence. Eighteen women described such circumstances. The following quote from a woman in the study illustrates the importance of considering the complexity of women's lives: *"Just a little about my background and how I dealt with breast cancer so well. In 1963 at the age of 29 I buried my very loving husband and father of our 5 children ages 5 years to 14. In 1981 I buried my only son at the age of 33. In 1984 I had a heart attack, in 1989 I had my right hip replaced because of arthritis and a year later my left hip. 1994 I was operated on because of gallstone and appendix."* Although this quote may represent an extreme situation, it became clear that several women felt other life circumstances were more overwhelming than the cancer, and in some cases made the cancer easier to accept.

Table 22 shows the number of women describing each type of circumstance. In order to provide an illustration of the diversity among women's experiences, three quotes are presented for each theme discussed.

### Positive Circumstances

Fifty-four women (49%) wrote about positive circumstances that made it easier to cope with breast cancer or the possibility of recurrence. Social support was most commonly mentioned as a factor that eased the stress of having cancer (n = 34). The following quotes are representative of women's responses regarding social support:

*"During all the time after the surgery and up to the present day I had a great deal of love and closeness from family and friends."*

*"My peers and supervisors all were very supportive and I had a huge support system made up of family and friends. They all took turns taking me to chemo. staying and going home with me each time. I was very fortunate in the caring and concern that my significant relations showed me. I was made to feel very special and valued."*

*"I am married to an extraordinarily warm man and have two grown sons to whom I am <u>very</u> devoted. I think its mutual. <u>Love</u> keeps my spirits up."*

Related to social support, several women (n = 13) wrote about the positive influence of having children or grandchildren who brought joy to their lives or added incentive to go on. For example, *"Having a college age son and a high school age son helped me focus on the good things in my life and enjoy sharing good times with them."*

*"When I was going through chemotherapy I lost every hair on my body. I would go to the hospital for treatment with a framed picture of my bald granddaughter ... just having her picture by my side gave me strength and courage. I would talk to her picture and tell her someday we would both have hair."*

*"The family support was exceptional and if I thought of giving up I realized what pain I would cause to my children and many friends, it appeared I had no alternative but to go on."*

Twelve women credited the competence or caring of their physicians with making the breast cancer experience easier. The influence of these individuals is illustrated by the following quotes:

*"Having a doctor who makes you feel he cares makes all the difference in the world."*

*"The confidence, compassion, and concern of (my doctor) was a god given gift to me. This faith in my surgeon has been a healing factor not only physically, but emotionally."*

*"My oncologist is very aggressive and I chose him because he gave me hope and strength."*

A few women (n = 7) talked about their faith or religion as an important source of strength and healing. For example:

*"For me, my religious beliefs have been an enormous help. They have leant meaning to the whole experience and have allowed me to move on beyond the cancer and live my life."*

*"My religious faith, and my belief that the way one deals with life's trials is the measure of a person have helped me accept my breast cancer without anger or resentment."*

*"My faith in god has been strengthened and carries me on - even though in the far reaches of my mind is the physical "fear" of any cancer attacking me again."*

Thirteen women spoke of activities that made breast cancer easier to cope with. In some cases it was continuing work, while in others it was volunteering or speaking with other cancer patients. Still other women spoke of fulfilling a dream or beginning a new activity. The following examples illustrate the importance of such involvement:

*"I have been very busy with my work and have really not had time to be sick or to feel sorry for myself etc... having positive work that is important to me, and being emotionally secure and supported, have enabled me not to pay any attention to the real but small possibility of recurrence."*

*"Being a volunteer in the Breast Program at Mount Sinai is very helpful to me - and helping people who are newly diagnosed - or just starting radiation - and who don't know what to expect - has been very gratifying"*

*"My boyfriend and I were talking about getting married the summer before my breast cancer diagnosis. All I could think about was getting rid of the cancer and being healthy again so I put everything on the "back burner". Last summer, we resumed our feelings about getting married, and we are now engaged and planning to get married in June 2000 in Hawaii."*

Finally, a few women (n = 5) spoke of using "alternative treatments" or making healthy lifestyle changes. These health behaviors appeared to provide comfort and have a positive influence on their lives:

*"I teach mind-body techniques to my patients. My illness has been an opportunity to test my beliefs. I rely heavily on complementary techniques to control my health (and follow traditional medical regimes as well). I think my background has*

*helped me tremendously."*

*"I try to spend the end of each day doing visualization, which feels right for me at this time."*

*"I also investigated alternative methods of treatment including meditation, herbs and Traditional Chinese Medicine. I felt that having some knowledge about the workings of the disease and the pros and cons of various treatment allowed me to be an active participant in the care and handling of it."*

Together, these quotes illustrate the potential influence of positive life circumstances on women's experiences with breast cancer. Women's comments suggest that such resources may not only reduce overall distress, but may alleviate the stress associated with breast cancer and the possibility of recurrence. However, life circumstances are not always positive; negative life circumstances may also influence women's ability to cope with and adjust to breast cancer and the possibility of recurrence.

### Negative Circumstances

Sixty-five women (59%) wrote about negative events or life circumstances that were distressing for them. In some cases the negative influence of these experiences was not explicitly stated, but was implied. Some women directly addressed the relation between negative circumstances and their experience with breast cancer, while others simply described the events as generally distressing.

The most commonly described negative circumstance (n = 28) was health problems including other types of cancer, heart attacks, chronic back pain, severe hot flashes, lymphadema, gynecological problems (often leading to hysterectomies) and other chronic, and sometimes debilitating, conditions. The following quotes illustrate women's struggles to cope with their health problems:

"*When the breast cancer in 1996 came about it was only 11 months after my colon cancer. In 1983 I had a hysterectomy as a result of cancer of the uterus ... This* (the occurrence of breast cancer) *made me feel very vulnerable and depressed.*"

"*Probably as a result of my chemo, I developed avascular necrosis on both my hips. This means that I can no longer do brisk walking as I want to do daily - for me this is a sacrifice. I also experience aches and pains in my legs and hips; eventually I will need a hip replacement.*"

"*When a person has multiple health problems combined with breast cancer, this creates a hazardous situation. Doctors <u>must</u> take all of the health problems into consideration! ...* (I am afraid of) *dying on the operating table due to lack of oxygen in the lung. I am only functioning with 1 lung!*"

Nine of these women stated that their other illnesses (or fears about other illnesses) were "distracting" or were more central to their lives than their breast cancer was:

*"In 1996 I had a heart attack. I am much more fearful of having another attack than I am about recurring cancer."*

*"I am currently dealing with the overwhelming fatigue, pain, and loss of muscle power associated with the post-polio syndrome...I certainly do not want a recurrence of breast cancer, but it's the post-polio problem that is overwhelming and affects my emotional status etc."*

*"In December 1995 I was diagnosed with an acoustic neuroma... breast cancer had been relatively easy for me and I was not prepared for the physical disability resulting from the 9 hour operation... Even though this situation was benign and less life-threatening, it altered my quality of life in ways that breast cancer has not."*

It was fairly common (n = 22) for women to write about the death of a loved one. For some women, losing a loved one was a generally distressing experience. For others, particularly when the loved one died of cancer, the death made their own cancer more difficult to deal with.

*"My mother just passed away from a recurrence of ovarian cancer. The cancer*

*questions are very upsetting to answer!"*

*"Unfortunately, over the past five years, I have lost two friends and three acquaintances to breast cancer. It was difficult for me to stay positive."*

*"My mother died of stomach cancer at age 55. This made my cancer more scary, as I knew death could occur, and I wondered if I was genetically inclined toward cancer."*

Among those women writing about the death of a loved one, five reported that this death was more difficult to deal with than their own cancer.

*"My living experience of breast cancer has not affected me as much as when my first husband died of kidney cancer in '72 - I was in great fear and pain during his whole illness - from diagnosis until his death at age 50."*

*"I lost my 26 year-old-son to lung cancer. The pain and emotion was so great that when I was diagnosed with breast cancer (16 years later) it was almost anti-climactic."*

*"Having breast cancer is nothing in comparison to losing a spouse."*

For some women (n = 18) the illness of a loved one caused them distress. A few women mentioned that they were the sole caretaker for an ill relative and that their own cancer experience was influenced by that circumstance. For others, a friend's or relative's cancer recurrence made them fear for their own health.

*"One of my friends (from the support group) has recently been diagnosed with a recurrence. It has caused the fear, which I had pushed to the back of my consciousness, to come to the fore. Now I worry more about my health and future than I did before."*

*"I am the sole caretaker of an aging mother. My only concern regarding a recurrence is if I will be able to take care of her."*

*"Husband has had a heart transplant 3 years ago. Generally he is doing well. When he has a setback I get anxious."*

Five women commented that their loved one's illness affected their thoughts about their own breast cancer. For these women, the loved one's illness appeared to distract them from focusing on their own illness:

*"Second grandchild developed cancer at age 3 ½ - was under treatment with chemo for two years. I think more about him having a recurrence, and how all that*

*chemo and all the x-rays that were done in those 2 years might affect him in the future."*

*"I have a friend who had breast cancer and now has lung cancer with complications...its been a hard month with a lot of "this could be me" and being grateful that it isn't - and watching someone you care about suffer."*

*"I have a child who is a survivor of a different kind of tumor, whose life and well-being feels more relevant than mine and also for whom I need to stay alive...That's why I've dealt with my situation expediently, and grateful for the fact that it was not worse."*

Finally, nine women described difficulties in their family lives that upset them or made it more difficult to cope with their breast cancer. Sometimes a strained relationship was the cause of distress; other times unsupportive family members were the cause. Some women wrote about family situations or events that caused them to worry:

*"My husband lost his job and went into business for himself 3 years before I was diagnosed. This was extremely stressful to me. Although everything has worked out I am still stressed."*

*"I have a teenage daughter. She causes a great deal of stress for my husband and me. I often think about how things would be for her and my husband if I should die and not be here to help. If they would miss me or maybe even better off."*

*"My husband was the biggest disappointment, he wasn't there for me emotionally or physically. That will always hurt me. I can't forgive him for seeing me in such pain and agony, and yet he had nothing to say."*

These comments all illustrate the importance of addressing the context in which breast cancer occurs. Many women are simultaneously facing breast cancer and other difficult circumstances in their lives. For some women, past events continue to be salient and influence their experience with cancer. Positive circumstances also appear to be an important part of the context in which breast cancer occurs. We have seen that the consequences of breast cancer and women's overall fears about recurrence are associated with psychological adjustment. Women's comments suggest that other life circumstances may relate to psychological adjustment as well.

## Exploratory Quantitative Analyses

A more quantitative analysis can clarify the relationship of these life circumstances to psychological adjustment, and fears about the possibility of breast cancer recurrence. All 110 women who responded to the open-ended question about life circumstances were included in the analysis, regardless of whether their response actually addressed life circumstances. This decision was based on the assumption that women who wrote something in response to this question would have been likely to mention any events or situations they felt were influential. However, those who did not write anything in response to the question were more likely to have skipped the question for other reasons (e.g., they felt the exercise was too labor-intensive).

Three dummy-coded variables were constructed: positive circumstances, negative circumstances, and distracting negative circumstances. Each woman received a code for all three variables; a "1" was assigned when the women had described at least one circumstance in that category, and a "0" was assigned when the woman had not described any circumstances in that category. Any particular woman could receive a code of "1" in more than one category. Indeed, several negative circumstances were also coded as distracting circumstances (see Table 22).

The correlations among life circumstance categories as well as the correlations of life circumstances to psychological adjustment and fears about recurrence are presented in Table 23. Positive circumstances were related to decreased psychological distress and increased psychological well-being, whereas negative circumstances were associated with increased distress and decreased well-being.

Three simultaneous regression analyses were conducted in order to determine the independent contributions of positive, negative, and distracting life circumstances to psychological adjustment (i.e., distress and well-being) and fears about recurrence (See Table 24). This analysis allowed me to examine the contribution of distracting circumstances after partialling out the effect of negative circumstances. In both equations predicting adjustment, positive circumstances were associated with better adjustment and negative circumstances were associated with poorer adjustment. In addition, distracting circumstances were associated with better adjustment (significant effect for distress and a trend for well-being). The equation predicting fear of recurrence was not significant, but there was a trend for distracting circumstances to be related to decreased fears about recurrence.

Because all three types of life circumstances were closely related to psychological adjustment, it was important to get a better idea of who was likely to report each type of circumstance. Bivariate correlations among life circumstances and other study variables indicated that distracting circumstances were significantly related to age, time since diagnosis, chemotherapy, and surgery (see Table 25). Older age and longer time since diagnosis were both associated with a greater likelihood of describing a distracting event, whereas chemotherapy and having had a mastectomy were both associated with a lower likelihood of describing a distracting event. Moreover, reporting greater role consequences was associated with a greater likelihood of reporting a negative event and a lower likelihood of reporting a positive or distracting event. Initial appraisal variables were not associated with any category of circumstances.

## Summary

All of the women in this sample have one thing in common, they have all been diagnosed with breast cancer. However, their written comments illustrate that their experience with breast cancer did not occur in a vacuum. The majority of these women wrote about other positive and negative life circumstances that affected their lives. In general, positive circumstances appeared to make facing breast cancer easier, and such circumstances were associated with decreased distress and increased well-being. Negative circumstances, on the other hand, seemed to be more complex. They generally appeared to add to the burden of breast cancer and were associated with increased distress and decreased well-being. However, a sub-sample of women described negative life circumstances that were distracting or were more salient than breast cancer and the possibility of recurrence. These distracting negative circumstances were associated with decreased distress and increased well-being.

# CHAPTER SEVEN: GENERAL DISCUSSION

For women with breast cancer, the future is uncertain. They cannot know whether their cancer will return, and they feel little control over the possibility. These women do not appear hopeless, however, as the majority perceived little risk of recurrence. Few of these women expect to be among the 43% who do not survive breast cancer (American Cancer Society, 1999).[21] But perceptions of low risk do not preclude feeling fearful about the possibility of the cancer returning. More than half of the women participating in this study expressed fears about recurrence. Fears revolved primarily around the possibilities of death, further treatment, emotional difficulties and physical limitations. Women were less concerned about threats to identity, womanhood, roles, or relationships with others.

These findings echo a recent study of women treated for early stage breast cancer in the previous year (Spencer et al., 1999). Asked about their concerns regarding breast cancer, women were most concerned about possible recurrence, death, pain, and overwhelming bills. Lesser concerns were sexuality, femininity, identity, and relationships with others. These convergent findings suggest that breast cancer may not be as unique an illness as is sometimes assumed. It has been argued that the multiple meanings of the breast (i.e., femininity, sexuality, motherhood) makes breast cancer particularly distressing (Kahane, 1995; Yalom, 1997). However, mastectomy is becoming increasingly rare (Moyer, 1997), and breast conserving surgery often spares women from losing their breasts. The major concerns of women with breast cancer –

recurrence, future treatment, death, pain, emotional difficulties, physical illness, and financial problems – are a reality for those with most any cancer, as well as many other chronic or life-threatening illnesses. Thus, although the findings of the current study generalize most clearly to recently treated women with breast cancer, they may also inform us about appraisal, coping and adjustment in the context of other illnesses.

Results are also likely to generalize to women regardless of the time elapsed since diagnosis. Although women in this study were diagnosed with breast cancer between one and seven years previously -- a broad range compared to most studies -- few effects of time were found. Time since diagnosis was not related to fears about recurrence, initial appraisal variables, ongoing consequences of the initial diagnosis, psychological adjustment, or use of coping strategies -- suggesting that these issues may be important throughout the course of the illness and "survivorship".

The following discussion addresses the primary findings of the study, locating them within a framework of broader theory and prior research, as well as suggesting fruitful areas for future studies. First, I relate the findings to theories about expectancies: how they are formed and the possible effects they might have. Second, I discuss the importance of acknowledging the context in which breast cancer occurs, arguing that cancer is not an isolated event but is usually intertwined with women's life circumstances. Third, I address how women's efforts to cope with the possibility of recurrence fit in with larger theories of stress and coping. I end the chapter with a brief discussion of study limitations and some concluding thoughts.

## Expectancy Theories: Connecting Past, Present, and Future

An individual's ability to think about and plan for the future is dependent on their expectations of what the future holds (Maddux, 1999). Thus, it is natural for women to think about what a breast cancer recurrence would mean for their lives. But worrying about the future can also be stressful, as suggested by the association of fears about recurrence to increased distress and decreased well-being, in this sample and others (Metzger et al., 1983; Sneeuw et al., 1992; Timko & Janoff-Bulman, 1985). Because the data are cross-sectional, it cannot be determined whether fears about recurrence _cause_ impaired adjustment. Indeed, other possibilities are equally plausible. For example, generalized depression or anxiety may lead to fears about recurrence, or a third variable, such as a personality trait, may lead to increased fears _and_ impaired adjustment. Longitudinal studies are needed to clarify the causal mechanisms involved. Nonetheless, it seems desirable to help women reduce their fears about recurrence, and findings from this study provide some clues as to how that might be accomplished.

Consistent with prior research, younger age, undergoing chemotherapy, and having a mastectomy as opposed to BCS were related to increased fears about recurrence. Moreover, higher perceived risk of recurrence was associated with greater fear of recurrence. These findings provide clues as to _who_ might be most likely to benefit from intervention. Results further suggest that the associations of these variables to fears about recurrence work through (or are mediated by) the lingering impact of the breast cancer. That is, younger women, those who underwent chemotherapy, those who had a mastectomy, and those who believe themselves to be at greater risk for recurrence were experiencing more ongoing consequences of the initial diagnosis. Those ongoing consequences, in turn, appeared to explain the increased fears of recurrence reported by these women. These findings provide support for theories proposing that expectancies about future events are shaped by past experiences (Fiske & Taylor, 1984; Kirsch, 1999).

Further support for this explanation is indicated by the "domain-specific" relationship of ongoing consequences to fears about the future. Specifically, both death worries and health worries were best predicted by ongoing health consequences; womanhood worries were best predicted by ongoing womanhood consequences; and role worries were predicted by ongoing role consequences (although ongoing health consequences were the best predictor). Overall fear of recurrence, unlike the specific fear domains, was predicted by all three types of consequences, as well as perceived risk of recurrence. It should be noted that the possibility remains that these results are due to a measurement artifact, as parallel CARS and CBCS items were presented in the same questionnaire. Future studies examining consequences and fears at different time-points could strengthen the argument made here.

It stands to reason that reducing women's fears about recurrence might be accomplished by targeting their experiences with the initial breast cancer at the time of diagnosis, during treatment, or at a later date. Cognitive-behavioral therapy may be a particularly useful strategy for this purpose. A recent study found that children's fears about a future bone marrow aspiration (an invasive and painful medical procedure) could be reduced by encouraging them to focus on their successful efforts to cope with past aspirations (Chen, Zeltzer, Crask, & Katz, 1999). A similar cognitive behavioral intervention could work with adult breast cancer patients. Therapy could aim to change women's views of the initial diagnosis and its effects, or it could encourage women to recognize their own strength in dealing with the difficulties they have faced. Either strategy may ease women's worries about the impact of a possible recurrence.

Although we have some clues as to how women's expectancies about recurrence are formed, we know little about how they might influence future experiences. For example, could expectations about particular threats (e.g., pain and suffering or difficulty with fulfilling roles) encourage these problems in the case of a recurrence? Could expectations and fears about recurrence contribute to the chance of recurrence itself?

There are two primary ways in which expectancies about future events can increase the likelihood of their occurring. Kirsch's theory of expectancies proposes that anticipations of automatic responses can cause them to occur (Kirsch, 1999). An example is a medication intended to decrease pain. Even if an individual has received a placebo, their expectation of pain reduction can lead to an actual reduction in pain (placebo effect or self-fulfilling prophesy). In a similar way, a woman's expectations that a recurrence would be painful, or would have negative effects on her body image for example, could contribute to such an effect if the cancer returns.

Another way in which the likelihood of an event is increased by expectancies is that the individual is primed to notice it. Schema theories propose that an individual is more likely to attend to occurrences that fit in with their schema or framework for viewing the world (Fiske & Taylor, 1984). Thus, a woman who expects that a recurrence would interfere with her romantic relationships, for example, may be more likely to notice any tension that occurs between her and her partner(s). Only a prospective study could address these questions.

A second important question is whether expectancies and fears about recurrence could contribute to the return of the cancer. Research has been far from conclusive in terms of this issue. However, there is some indication that stress-inducing emotional states may influence biological processes involved in immune functioning, and that suppressed immune functioning could influence the progression of illnesses such as cancer (Baum & Posluszny, 1999; Levy & Wise, 1987). An extension of this reasoning suggests that fears about breast cancer recurrence could contribute to the return of the cancer. The specific effects of fears about recurrence have not been examined in previous psychoimmunological studies. Future prospective research should address this issue.

Despite the suggested negative impact of fears about recurrence, there are ways in which fears could be a positive factor in women's lives. For example, it has been demonstrated that worry about breast cancer is related to increased screening behaviors (breast self-exam, clinical breast exam, and mammography) among healthy women (Lerman et al., 1991; McCaul, Schroeder, & Reid, 1996).[22] Likewise, fears about recurrence may increase women's commitment to these and other health behaviors (e.g., diet, exercise). Moreover, there is evidence that expecting a recurrence could lead to better adjustment in the case of the cancer returning. Cella and colleagues found that those individuals who were completely surprised by a recurrence evidenced more intrusive thoughts and avoidant symptoms than those who "knew it could happen" (Cella, Mahon, & Donovan, 1990). However, participants reported their expectancies about recurrence retrospectively, so that causality is inconclusive.

## Putting Breast Cancer into Context

The findings discussed thus far highlight connections between women's past, present, and future experiences with breast cancer. But breast cancer does not occur in a vacuum. Women also suggested that other life circumstances (in the past and present) were important. They described both positive and negative circumstances as influential for their psychological adjustment and fears about recurrence. This idea is by no means new; indeed this notion is the basis for a multitude of studies examining the influence of positive (e.g., social support) and negative (e.g., stressful life events) circumstances on the overall adjustment of cancer patients and other populations. What has less often been addressed is participants' understanding of how such circumstances interact with or influence their experience of cancer.

Perhaps the most important finding in this vein is that a small but meaningful group of women described negative life circumstances that appeared to distract them from focusing on their breast cancer or the possibility of recurrence. Not only were these circumstances described as more central concerns than breast cancer or the possibility of recurrence, but they were associated with better psychological adjustment. This finding is at odds with prior "cumulative stress" research, which suggests that negative life circumstances may exacerbate the distress associated with cancer (DuHamel et al., 2000; Grassi et al., 1997) or other stressful events (King, King, Fairbank, Keane, & Adams, 1998; Koopman, Classen, & Spiegel, 1994; Yehuda & McFarlane, 1995). The failure of these studies to identify such distracting events may be due to a limitation of the life events checklists they often employ. Although these measures sometimes allow the participant to indicate the valence of the event (was it experienced as positive or negative?), they do not assess the participant's experience of the event in relation to cancer (or another focal event). Indeed, the group of women describing distracting circumstances would not have been identified in the current study if such a checklist had been employed. Given that the distracting circumstances were described as negative experiences, and yet they were associated with improved adjustment and reduced fears about recurrence, it seems critical to do a more systematic study of women's perceptions of the role such events play.

What remains in question is why the negative experiences of these women seemed to draw their focus away from breast cancer, when many other women reported negative circumstances without such a benefit. There did not seem to be a difference in the kind or magnitude of circumstances described. However, it is possible that the women describing distracting circumstances simply had a less stressful experience with breast cancer. Post hoc analyses found that women who reported a distracting negative event were likely to be older, not to have undergone chemotherapy, to have had BCS rather than mastectomy, and to have been diagnosed less recently than women not reporting such circumstances. Each of these variables has been related to fewer physical and psychosocial effects among women with breast cancer (Glanz & Lerman, 1992; Kahane, 1995; Kaplan, 1992; Coscarelli Schag et al., 1993; Schover, 1994). Maybe breast cancer and the possibility of recurrence simply required less attention from these women, allowing them to focus on other life circumstances.

Another possibility is that the women describing distracting circumstances may have experienced some sort of personal growth or transformation as a result of the breast cancer or their other life experiences. Prior theory and research has suggested that stressful or traumatic occurrences often result in a search for meaning (Park & Folkman, 1997; Tedeschi & Calhoun, 1995; Thompson & Janigian, 1988). This search can lead to benefits such as changes in priorities or increased appreciation of life. It is possible that some women in this sample experienced such a change as a result of their experiences with breast cancer or other difficult life circumstances. Indeed, may women spontaneously wrote comments about reprioritizing or appreciating each day. What cannot be determined is why these women would have experienced such changes – and improved adjustment – while others did not. One possibility is that the more advanced age of these women encouraged such personal growth. Indeed, prior research has found age to be positively associated with perceptions that life is meaningful (Reker, 1992; Reker, Peacock, & Wong, 1987).

## Coping with Fears about Recurrence: A Unique Stressor?

The search for meaning is often conceptualized as a coping strategy (e.g., positive reframing and cognitive reappraisal strategies both involve attempts to find meaning). Although women in this sample reported higher levels of well-being than a normative sample, they reported using very little positive reframing to cope with their fears about the possibility of breast cancer recurrence. Instead, the use of acceptance and denial were more common, but still not frequently used. Based on Lazarus and Folkman's (1984) stress and coping paradigm, it was expected that these coping strategies would mediate the relationship between fears about recurrence (appraisal) and psychological adjustment. There was no evidence of mediation. However, there were direct relationships between coping and adjustment: Denial was associated with increased distress, and positive reframing was associated with increased well-being. Moreover, the use of acceptance moderated (or buffered) the relationship between fears about recurrence and decreased well-being, particularly when fears revolved around death or health.

There are several possible reasons for the limited findings regarding coping. First, the investigation of coping focused on three cognitive strategies. This decision was based on the reasoning that cognitive strategies would be most likely to play a role in coping with fears about a possible future event. However, reports of all three strategies were relatively low and it is possible that other types of strategies (i.e., behavioral or problem-focused) may have had stronger effects. That is, focusing on these three strategies may not have given coping a fair shot and examining a broader range of strategies may have produced different results.

Second, women were instructed to skip the coping measure if they never worried about the possibility of recurrence (one cannot cope with something that does not exist). However, their lack of fear could have been due to successful coping that eradicated any fears. Thus, the "best copers" may have been excluded from the analysis, weakening the results.

Finally, coping processes are both dynamic and reciprocal. Although it is commonly acknowledged that cross-sectional analyses cannot determine the causal direction of relationships between variables, it is often assumed that a "snap-shot" of these processes can be captured. However, finding a consistent pattern at one moment in time may be dependent on all participants being at the same point in the coping process when a cross-sectional analysis is conducted. But this is unlikely, as coping is a dynamic and cyclical process, which individuals experience at different rates. Moreover, the range of time since diagnosis represented in this study makes it unlikely that participants would all be at the same point in the coping process when they completed the questionnaire.

Despite the limited role of coping, findings did partially support the Lazarus and Folkman (1984) paradigm. There was a strong and consistent relationship between appraisal (fears about recurrence) and psychological adjustment. Because the nature of the target stressor was held constant across women (i.e., all women reported efforts to cope with fears about recurrence), their differing perceptions of that stressor were highlighted, demonstrating the importance of assessing appraisals and narrowing the coping target. The intensity of women's fears (or their appraisal of the stressor) was strongly associated with adjustment, even after controlling for background variables, initial appraisal variables, and ongoing consequences. In short, consistent with Lazarus and Folkman's theory, appraisal matters.

Contrary to expectations, the specific content of women's fears (e.g., concerns about death versus concerns about womanhood) did not appear to be an important factor in women's coping efforts. However, there was evidence that the general nature of the threat (i.e., fear of recurrence as the stressor) may have influenced coping. Previous studies have consistently identified positive reframing (or similar strategies, such as positive reappraisal or positive focus) as one of the most commonly used strategies for coping with breast cancer (Arathuzik, 1991a; Carver et al., 1993; Dunkel-Schetter et al., 1992; Jarrett et al., 1992; Manne et al., 1994; Thomas & Marks, 1995). Some of the same studies have found denial to be one of the least commonly used strategies (Carver et al., 1993; Thomas & Marks, 1995). However, findings of the current study were different: positive reframing was rarely used for coping with fears about recurrence. In fact, women used significantly less positive reframing to cope with their fears than they did denial. This finding points to the importance of defining a coping target specifically. It suggests that women may use different strategies to cope with fears about breast cancer recurrence than they do to cope with breast cancer more generally.

A likely explanation for the low levels of positive reframing is that the target stressor in the current study related to a possible future event. It may be particularly difficult to reframe an event before it occurs. Aspinwall and Taylor (1997) propose that strategies such as positive reappraisal are not a likely form of proactive coping, or efforts to cope with a potential future event. Instead, they suggest that active coping efforts aimed at preventing the potential event are more likely. However, because women perceive little control over the possibility of recurrence, such strategies are not likely in this sample. Perhaps the uncertainty associated with the possibility of recurrence prevents women from going any further than simply denying or accepting that it could happen.

The pilot study further substantiates the claim that positive reframing may be unlikely prior to the occurrence of an event. Women were asked to describe any potential benefits that a recurrence could have. Describing possible benefits would have provided evidence that women were engaging in some form of anticipatory positive reframing. However, none of the women in the pilot study could think of any potential benefits of recurrence, although prior research has shown that cancer patients often perceive benefits of their illnesses after diagnosis or treatment (Carter, 1993; Fife, 1994; Fromm et al., 1996; Taylor, 1983; Fife, 1995).

Although contrary to other evidence, there was an indication that women were using some form of anticipatory positive reframing; several women indicated the belief that they could beat a recurrence if it happened. Although not suggesting any benefits of recurrence, these statements do suggest anticipatory positive reframing in the form of threat minimization.

## Study Limitations

As previously noted, the study's primary limitation is that the data are cross-sectional, preventing any inferences about causal relationships between variables. However, when investigating previously unexamined issues, it is often appropriate to first conduct a cross-sectional analysis – identifying associations between variables at one moment in time – before expending the resources required by a longitudinal study.

A second limitation of this study -- as with all studies of cancer patients -- is the possibility that individuals who participate in research may be different, in some meaningful way, from those who do not participate. It is sometimes thought that the most distressed individuals are the least likely to participate in research. If this is true, indicators of psychological distress and fears about recurrence may be underestimated. On the other hand, it has also been suggested that distressed individuals may be more likely to participate in research, as a form of help-seeking (Butler, Koopman, Classen, & Spiegel, 1999; Felton, Revenson, & Hinrichsen, 1984), and that variables such as psychological distress may be overestimated. Because participation in studies of this sort is completely voluntary and psychological information about non-participants is rarely available, this problem is difficult to overcome.

A third limitation is that the sample for the main study was relatively homogenous in terms of ethnicity, possibly restricting the generalizability of the results. This issue is particularly important because the response rates of Black and Hispanic women were substantially lower than that of White women. It is not known if these women were more reluctant to participate in the research, although the availability of the questionnaire only in English may have been a barrier to participation for some individuals. As it has been demonstrated that Hispanic women are more likely to be distressed and to have concerns about breast cancer than either White or Black women (Spencer et al., 1999), they are important subgroup for future investigations.

## Concluding Thoughts

Despite these limitations, this investigation considered many questions that have not been previously addressed and suggests fruitful areas for further research, as well as intervention. Perhaps most importantly, this study reminds us to refrain from making assumptions about women and their experiences with breast cancer. Indeed, several common assumptions are challenged by the results. First, prior research suggests that fear of recurrence is almost universal among women with breast cancer. However, these women represent a wide range in terms of the extent to which they fear recurrence. In fact, almost half of the sample reported that they do not fear recurrence at all, and even fewer women perceived themselves to be at risk of recurrence. This diversity should be highlighted and examined in more detail in the future.

Another common assumption has been that women's primary concerns about breast cancer and recurrence relate exclusively to the possibility of death, or, in other cases, to the interrelated issues of body image, femininity, and sexuality. These women feared death, but they also feared further treatment, emotional upset, and physical debilitation with equal intensity. On the other hand, concerns about body image, femininity, and sexuality were rare in comparison. Researchers and clinicians should recognize the multi-faceted nature of women's fears about recurrence and address them as such.

Third, research is often conducted as if breast cancer is the only, or at least the primary, stressor in a woman's life. However, other difficult circumstances were common among these women, and these circumstances appeared to influence their experiences with breast cancer and their psychological adjustment. It is essential for both researchers and clinicians to view breast cancer in the context in which it occurs – that is, women's complex and challenging lives.

Finally, we most often assume that breast cancer diagnosis and treatment are traumatic experiences that leave women distressed and lacking hope. Indeed, the women in this sample were more distressed than a normative sample. However, they also reported a greater sense of well-being in comparison to that norm. We would be remiss not to acknowledge that women's experiences with breast cancer, like their lives in general, are complex and multidimensional. This notion is illustrated by a final quote from a woman who took part in the study: "*Life is precious, every day, with family, friends, nature, because I have seen loved ones die - - and been afraid for my life when I got the cancer, and know I am mortal. Each day is a gift.*"

## Footnotes

[1] Although the original intention of the current study was to investigate women's perceptions of the "threats" posed by the possibility of recurrence, it was determined in the pilot study that the terms fear and worry were more meaningful to lay-people. In order to be consistent, the more theoretical concept of threat will be referred to as fear or worry, more concrete concepts. Although some might raise the issue that fear and worry connote more emotional states than threat, I would argue that these terms/concepts represent an indication of the extent to which a threat is salient. Moreover, although there may be technical distinctions between the concepts of fear and worry, they are used here interchangeably to describe women's "real life" experiences.

[2] The one deceased patient was not included in this analysis.

[3] It was thought that fears about recurrence might be exaggerated if interviews were conducted in treatment areas of the hospital. Indeed, research has demonstrated that entering areas where treatment took place can trigger conditioned reactions such as anxiety and nausea (Redd & Andersen, 1981).

[4] Although all interviews were conducted in English, an interpreter was present for one interview with a Hispanic participant whose English was not particularly strong.

[5] This result was notable given research indicating that many individuals perceive positive consequences from a cancer diagnosis after it occurs (Kahane, 1995; Taylor, 1983). Because not one of the women mentioned a potential positive consequence of recurrence, this item was removed from the final version of the CARS.

[6] Some women did respond to the items by indicating how worried they were by the possibility of that consequence occurring (i.e., how much potential harm they anticipated in that domain). However, others appeared to be indicating their perception of how possible it was that the consequence would occur, if the breast cancer returned. An example illustrates the difference between these types of responses. Two women responded to the item "I feel threatened by the possibility that a recurrence of breast cancer would require further treatment such as chemotherapy and radiation" with the same rating, a four (Extremely). One women (B38) explained her answer in the following way: *"I don't want to go through that again... I don't want to go through that"*, indicating that she felt threatened by the possibility of further treatment. The other woman (W49) stated *"yeah, well I think it probably in all likelihood it would. So, uh, probably, I can't imagine having a breast cancer recurrence that wouldn't, unless I just have...even if I have a mastectomy. I'm sure they'd recommend chemo or radiation."* Her answer implied that she felt further treatment would be a likely consequence of a

recurrence, not that she necessarily felt threatened by the possibility. Asking women how much they worry about each possible consequence seems to be a better way of assessing their appraisals of how threatening a recurrence would be in each domain.

[7]For example, the item "a recurrence of breast cancer would be a threat to my ability to become a mother or fulfill my motherhood roles" was split into two items for the final version of the CARS ("Prevent me from becoming a mother" and "Threaten my ability to be a good mother (grandmother, aunt etc.)"). Another item ("Cause me to die") was added to the final version of the CARS to "backup" the preliminary item "I feel that a recurrence of breast cancer would be a threat to my life" (revised to "Threaten my life" in the final version). Some women interpreted the life-threat item on the preliminary CARS to mean a threat to one's lifestyle as opposed to a threat to one's continued existence. Adding an item increased the likelihood that the notion of life-threat would be assessed accurately. A final example illustrates the addition of an item for the purpose of capturing an alternative interpretation of a preliminary item. The item "A recurrence of breast cancer would threaten my sense of satisfaction with my body" was interpreted by some women to mean "Make me feel badly about how my body looks or feels", which was the intended meaning of the item and the wording used in the final measure. However, other women interpreted the item to mean "Lead me to be disappointed in my body or feel that my body is attacking me". This item was added in the final version of the CARS, because some women reported feeling threatened by that possibility.

[8]The wording of other items was revised, primarily based on the advice of the health professionals and participant interpretations of the items. For example, an item on the preliminary CARS read: "I feel a recurrence of breast cancer would threaten my ability to reach goals I have set for myself". In several cases, women in the sample stated that they no longer had goals at their age: *"Well what goals? I'm, I'm 68 (H69)"*; *"No, no. At my age I don't have any more goal (W74)"*; *"Well I'm old, how old I ain't got no more goals (H68)"*; and *"Well I don't think I have no goals too much now, at the age I am, I did everything just about what I was going to do (B74)"*. Based on these interpretations and a suggestion from one of the medical professionals, the wording of this item was changed to: "Keep me from doing things I had planned to do". It was felt that this wording could more appropriately apply to all of the women in the sample.

[9]When women did not complete a particular measure sufficiently (defined as completing at least 80% of the items) they were removed from analyses concerning that measure. Appendix C displays the number of questionnaires available for analyses by each individual measure, and by combinations of measures.

[10]Although direct and indirect control have been examined as independent

constructs in some prior studies (Wallston & Wallston, 1982), both were included here to get a general sense of whether women thought breast cancer recurrence was controllable at all, by themselves or by someone else. Perceptions of both direct and indirect control have been associated with improved adjustment among breast cancer patients (Taylor et al., 1984).

[11] In order to maintain sufficient power for statistical analyses, missing data points were substituted in one of the two following ways: mean substitution; or zero substitution. For the measures of Fear, Risk, and Control, as well as the MHI, replacing missing data was done with mean substitution. It should be noted that missing data were not replaced for women who failed to answer more than one of the Fear items, more than one of the Risk items, or more than one of the Control items. Instead, these women were excluded from all analyses involving the measures of Fear, Risk, or Control. Likewise, those women who failed to answer more than 20% of the items on the MHI were excluded from analyses involving that measure.

For the CARS and CBCS, the decision was made to replace all missing data points with "0" (i.e., "not at all"). This decision was based on the reasoning that any item that was not endorsed was not a concern for the participant. Similarly, missing data points on the Brief COPE were replaced with "1" ("I have not been doing this at all"), based on the same reasoning. Missing data points were not replaced if a participant failed to answer more than 20% of the items on the CARS, the CBCS, or the Brief Cope. Instead, women with substantial missing data were excluded from any analyses involving that measure. See Appendix C for a table of sample size for particular measures and combinations of measures.

[12] The following transformed variables were used: LG10 Risk, SQRT Control, LG10 Death Worries, SQRT Health Worries, SQRT Role Worries, SQRT Womanhood Worries, SQRT Health Consequences, SQRT Role Consequences, SQRT Womanhood Consequences, LG10 Distress, LG10 Positive Reframing, and SQRT Denial.

[13] Although there are a variety of "rules of thumb" specifying that the required number of participants for factor analysis depends on the number items in a measure, these rules lack theoretical rational and empirical evidence (Guadagnoli & Velicer, 1988). More important are absolute sample size, number of variables per factor and the size of factor loadings. Guadagnoli and Velicer (1988) indicate that 150 participants should be sufficient if each component has several high loading variables. Moreover they state that components with 4 or more variables that load above .60 can be interpreted whatever the sample size.

[14] Because the mean score for the "Prevent me from becoming a mother" item was only .12 and the item was endorsed by only 8 women, this item was not included in the factor analysis.

[15]Although the Death Worries factor contained only two items, it was retained for conceptual reasons. As fears about recurrence are sometimes assumed to be equivalent to fears of death, one goal of the analyses was to determine whether fears about death related to other variables differently than fears about other issues did.

[16]A cluster analysis was performed to answer the question of whether there were groups of women who shared particular patterns of concerns about breast cancer recurrence. For example, one group of women might have concerns about health and womanhood but not about death or roles. Another group of women might have concerns about health, death, and roles, but not about womanhood. This analysis resulted in groups that differed only in the intensity of their fears. That is, the group with the strongest fears about future health had the strongest fears in all domains. Thus, clusters of women were not created, and continuous scores for the CARS sub-scales were used in all analyses.

[17]A simultaneous regression ($F(14,136) = 7.64$, $\underline{p} < .001$; adjusted $R^2 = .383$) including all fear variables (and controlling for background variables, initial appraisal variables, and ongoing consequences) showed that only overall fear was significantly associated with distress ($\beta = .324$, $\underline{p} < .003$). There was also a trend for womanhood worries ($\beta = .209$, $\underline{p} = .070$).

[18]A simultaneous regression ($F(14,136) = 5.65$, $\underline{p} < .001$; adjusted $R^2 = .302$) including all fear variables (and controlling for background variables, initial appraisal variables, and ongoing consequences) showed that only overall fear was significantly associated with well-being ($\beta = -.295$, $\underline{p} < .05$).

[19]Participants were instructed not to complete the Brief COPE if they <u>never</u> worried about the possibility of recurrence. Thus, the sample was smaller for analyses involving coping (n = 137) than it was for preceding analyses. Women who completed the coping measure reported significantly more overall fear, death worries, and health worries (all $\underline{p}$'s < .01) than those who did not complete the measure. There were no differences between the groups in terms of psychological distress or psychological well-being.

[20]Fifty-nine women chose not to write anything in response to the question about influential experiences or circumstances. These women are not included in any analyses about life circumstances. The assumption cannot necessarily be made that these individuals did not experience any influential events or situations. Instead, it is likely that these individuals either preferred not to write about their experiences, or they did not view their experiences as relevant to breast cancer or the possibility of recurrence. Some women who did write a response used the space to express their thoughts and feelings about breast cancer or the possibility of recurrence, without referring to any other life circumstances. These responses

were discussed in Chapter 4.

[21] Fifty-seven percent women diagnosed with breast cancer survive to 15 years after diagnosis (American Cancer Society, 1999).

[22] There is currently a controversy over whether the relationship between breast cancer worry and screening is u-shaped (inverted) or linear. Some researchers have found that moderate worry is associated with higher likelihood of screening than either low or high levels of worry (Lerman et al., 1991), while others have found that the likelihood of screening rises with increased worry (McCaul, Schroeder et al., 1996). A meta-analytic review of breast cancer risk and mammography was conducted in 1996 (McCaul, Branstetter et al, 1996). Six of the studies included in the review measured worry. However, due to the way that data were presented in these studies, the authors of the review were unable to determine whether the relationship between worry and screening was linear or curvilinear.

Table 1

Sample Characteristics for Pilot Study

| Characteristic | Descriptive Statistic |
|---|---|
| Age | M = 58 years (SD, 10.56) Range = 38 - 74 years |
| Time Since Diagnosis | M = 2.45 years (SD, 1.27) Range = 1.14 - 4.90 years |
| Ethnicity | 6 Black (37.5%)<br>4 Hispanic (25%)<br>6 White (37.5%) |
| Religion | 7 Catholic (44%)<br>4 Protestant (25%)<br>2 Jewish (12.5%)<br>3 Other Religion or Did not Respond (18.5%) |
| Education | 8 High School Diploma or Less (50%)<br>5 Some College Education - College Degree (31.5%)<br>3 Some Post-college Education (18.5%) |
| Employment | 5 Employed Full Time (31%)<br>2 Employed Part Time (13%)<br>5 Retired and/or Receiving Social Security (31%)<br>3 Receiving Disability (19%)<br>1 Receiving Public Assistance (6%) |
| Annual Income[a] | 6 $20,000 or Less (46%)<br>4 $20,000-$39,000 (31%)<br>2 $40,000-$59,000 (15%)<br>1 Over $100,000 (8%) |
| Marital Status | 4 Never Been Married (25%)<br>6 Currently Married (37.5%)<br>6 Separated/Divorced/Widowed (37.5%) |
| Children | 1 Under age 18 (6%)<br>10 Over age 18 (63%)<br>5 No Children (31%) |
| Treatment | 13 Radiation (81%)<br>9 Chemotherapy (56%)<br>14 Tamoxifen (88%)<br>4 Mastectomy (25%)<br>12 Breast Conserving Surgery (75%) |

[a] Percentages are of those women who reported income (81% of the sample).

Table 2

Profiles of Pilot Study Participants

| Ethnicity | Age | Marital Status | Time Since Diagnosis | Stage of Cancer | Chemo-therapy | Type of Surgery |
|---|---|---|---|---|---|---|
| White | 56 | Divorced | 2.5 | 2 | Yes | BCS |
| Black | 57 | Single | 4 | 2 | Yes | BCS |
| Black | 57 | Divorced | 4 | 1 | No | BCS |
| Black | 58 | Married | 1.5 | 2 | Yes | BCS |
| Latina | 69 | Divorced | 3.5 | 1 | Yes | BCS |
| Black | 56 | Married | 2.5 | 1 | No | BCS |
| White | 74 | Married | 1.5 | 1 | No | BCS |
| Latina | 63 | Married | 1 | 2 | Yes | BCS |
| Latina | 52 | Married | 2 | 1 | Yes | BCS |
| White | 66 | Widowed | 1.5 | 2 | No | BCS |
| White | 49 | Married | 1.5 | 1 | No | BCS |
| Black | 38 | Single | 1.5 | 2 | Yes | Mast. |
| Black | 74 | Separated | 2 | 1 | No | Mast. |
| Latina | 68 | Single | 5 | 1 | No | Mast. |
| White | 55 | Divorced | 4.5 | 2 | Yes | Mast. |
| White | 40 | Single | 1 | 2 | Yes | BCS |

Note. BCS = Breast Conserving Surgery; Mast. = Mastectomy.

Table 3

Descriptive Statistics For Preliminary CARS Items

| Item | Mean | S.D. |
|---|---|---|
| I feel threatened by the possibility that a recurrence of breast cancer would require further treatment such as chemotherapy and radiation (PH) | 3.25 | 1.13 |
| I feel threatened by the possibility that a recurrence of breast cancer would require further, more extensive surgery (PH) | 2.94 | 1.06 |
| My emotional well-being would be threatened by a recurrence of breast cancer (PS) | 2.91 | .78 |
| A recurrence of breast cancer would threaten to cause me pain and suffering (PH) | 2.75 | 1.06 |
| I feel that a recurrence of breast cancer would be a threat to my life (PH) | 2.69 | 1.01 |
| A recurrence of breast cancer would be a threat to my physical health (PH) | 2.68 | 1.01 |
| My sense of having control over my life would be threatened by a recurrence of breast cancer (PS) | 2.56 | 1.09 |
| My physical ability to carry out daily activities would be threatened by a recurrence of breast cancer (PH) | 2.19 | 1.11 |
| My ability to maintain a positive attitude would be threatened by a recurrence of breast cancer (PS) | 2.13 | 1.26 |
| A recurrence of breast cancer would pose a financial threat to me (PS) | 2.13 | 1.50 |
| A recurrence of breast cancer would threaten my sense of satisfaction with my body (SR) | 2.06 | 1.48 |

Note. All items rated on a 0-4 Likert Scale. PH = Physical Threats; PS = Psychosocial Threats; SR = Self/Relationship Threats.

Table 3 continued on the next page

Table 3 Continued

Descriptive Statistics For Preliminary CARS Items

| Item | Mean | S.D. |
|---|---|---|
| A recurrence of breast cancer would be a threat to my ability to fulfill important roles and responsibilities (PS) | 2.06 | 1.34 |
| I feel that my ability to plan for the future would be threatened by a recurrence of breast cancer (PS) | 1.88 | 1.41 |
| My sense of sexuality would be threatened by a recurrence of breast cancer (SR) | 1.75 | 1.57 |
| A recurrence of breast cancer would threaten my self-confidence (SR) | 1.63 | 1.45 |
| I feel a recurrence of breast cancer would threaten my ability to reach goals I have set for myself (PS) | 1.50 | 1.37 |
| A recurrence of breast cancer would threaten my sexual or romantic relationship(s) (SR) | 1.44 | 1.59 |
| I feel that a recurrence of breast cancer would threaten my sense of femininity (SR) | 1.31 | 1.40 |
| My sense of who I am or my identity would be threatened by a recurrence of breast cancer (SR) | 1.13 | 1.31 |
| I feel that a recurrence of breast cancer would be threatening to my personal relationships with friends and family (SR) | 1.13 | 1.50 |
| A recurrence of breast cancer would threaten my sense of myself as a woman (SR) | 1.13 | 1.20 |
| A recurrence of breast cancer would threaten my ability to become a mother or fulfill motherhood roles (SR) | .50 | 1.10 |
| I feel that my spirituality or faith would be threatened by a recurrence of breast cancer (PS) | .38 | .72 |

Note. All items rated on a 0-4 Likert Scale. PH = Physical Threats; PS = Psychosocial Threats; SR = Self/Relationship Threats.

**Table 3 continued on the next page**

Table 3 Continued

Descriptive Statistics For Preliminary CARS Items

| Sub-scale | Mean | S.D. |
|---|---|---|
| Physical Threats - Mean Item Score | 2.77 | .71 |
| Psychosocial Threats - Mean Item Score | 1.92 | .92 |
| Self and Relationship Threats - Mean Item Score | 1.42 | 1.12 |

Note. All items rated on a 0-4 Likert Scale.

Table 4

Response Rates for the Two Recruitment Strategies and the Total Sample

| | Physician Letter | Physician Letter and Packet | Total |
|---|---|---|---|
| **Contact Attempted** | **263** | **209** | **472** |
| Incorrect Address Confirmed[a] | 46 | 30 | 76 |
| Patient Deceased[b] | 6 | 10 | 16 |
| Non-English Speaking[c] | 5 | 2 | 7 |
| **Potential Recruits** | **206** | **167** | **373** |
| No Response[d] | 77 | 57 | 134 |
| Packet Requested | 125 (61%) | N.A. | N.A. |
| Active Refusal[e] | 45 | 5 | 50 |
| **Questionnaire Completed** | **84 (41%)** | **105 (63%)** | **189 (51%)** |
| Ineligible Due to Recurrence | 8 | 9 | 17 |
| Ineligible Due to Stage 0 or IV | 1 | 2 | 3 |
| **Total Sample** | **75** | **94** | **169** |

[a] Packet returned by post office; [b] Confirmed by the post office or a friend/relative; [c] Confirmed by participant or a friend/relative; [d] It is not known whether failure to respond indicated a lack of interest, ill health, or some other reason; in fact, it cannot be confirmed that these letters were received by the intended recipients or that those individuals were able to read them (i.e., could read English); [e] indicated by a phone call, returning a blank questionnaire, or failure to return a questionnaire that was requested.

Table 5

Sample Characteristics

| Characteristic | Descriptive Statistic |
|---|---|
| Age | Mean 59 Years (SD 11.41), Range 35-88 Years |
| Time Since Diagnosis | Mean 3 Years (SD 1.42), Range 1-7 Years |
| Marital Status | 13% Never Married<br>52% Married or Equivalent<br>11% Separated or Divorced<br>14% Widowed |
| Main Partner | 59% Yes |
| Children | 76% Yes |
| Children Under 18 | 17% Yes |
| Children Living at Home | 31% Yes |
| Ethnicity | 8 % African American<br>74% White<br>10% Hispanic<br>8% Multi-ethnic or Other Ethnicity |
| Education | 21% Up to High School Diploma<br>17% Some College/Tech. School<br>22% College Degree<br>40% Some Post-College Educ. |
| Annual Income | 16% Less than $20,000<br>19% $20,000 to $39,000<br>13% $40,000 to $59,000<br>14% $60,000 to $79,000<br>16% $80,000 to $139,000<br>22% $140,000 or more |
| Employment | 40% Working Full time<br>18% Working Part time<br>27% Retired<br>8% Homemaker<br>7% Disability |
| Cancer Stage | 63% Local<br>37% Regional |
| Surgery Type | 82% BCS<br>18% Mastectomy |
| Radiation / Chemotherapy | 88% Yes / 54% Yes |

Table 6

Descriptive Statistics for Overall Fear, Perceived Risk, and Perceived Control Indices

| Variable | Mean | S.D. |
|---|---|---|
| Overall Fear | 2.91 | 1.29 |
| Perceived Risk | 2.51 | 1.08 |
| Perceived Control | 2.01 | 1.18 |

Note. Possible Range = 1 - 6.

Table 7

Descriptive Statistics for CARS Items

| | Mean | S.D. |
|---|---|---|
| Require chemotherapy | 2.30 | 1.50 |
| Threaten my life | 2.25 | 1.48 |
| Threaten my physical health | 2.15 | 1.45 |
| Be more serious than the first diagnosis | 2.13 | 1.46 |
| Cause me to die | 2.10 | 1.60 |
| Upset me emotionally | 2.08 | 1.45 |
| Require further surgery | 2.03 | 1.47 |
| Cause pain and suffering | 1.87 | 1.39 |
| Keep me from doing things I had planned to do | 1.74 | 1.52 |
| Mean losing my breast(s) | 1.73 | 1.52 |
| Interfere with my ability to plan for the future | 1.70 | 1.54 |
| Make me feel I don't have control over my life | 1.70 | 1.50 |
| Require radiation treatment | 1.55 | 1.51 |
| Interfere with my ability to carry out daily activities | 1.45 | 1.41 |
| Prevent me from maintaining a positive attitude | 1.38 | 1.39 |
| Keep me from fulfilling important roles (in my job or at home) | 1.34 | 1.43 |
| Cause financial problems for me | 1.21 | 1.49 |
| Lead me to feel disappointed in my body or feel my body is attacking me | 1.20 | 1.45 |
| Keep me from fulfilling my responsibilities (in my job or at home) | 1.18 | 1.37 |
| Make me feel badly about how my body looks or feels | 1.16 | 1.40 |
| Harm my self-confidence | .75 | 1.18 |

Table 7 continued on the next page

Table 7 continued

Descriptive Statistics for CARS Items

| | Mean | S.D. |
|---|---|---|
| Harm my self-confidence | .75 | 1.18 |
| Interfere with my sense of sexuality | .73 | 1.23 |
| Threaten my identity (how I see myself) | .71 | 1.20 |
| Lead me to feel less feminine | .69 | 1.22 |
| Threaten my ability to be a good mother (grandmother, aunt etc.) | .68 | 1.25 |
| Damage my romantic relationships | .68 | 1.24 |
| Make me feel I am less of a woman | .61 | 1.16 |
| Hurt my relationships with friends and family | .60 | 1.17 |
| Threaten my spirituality or faith | .41 | .99 |
| Prevent me from becoming a mother | .11 | .58 |

Table 8

Exploratory Factor Analysis of CARS

| | Factor | | | |
|---|---|---|---|---|
| | 1 | 2 | 3 | 4 |
| % of Variance Explained | 53% | 9% | 5% | 3% |
| Require further surgery | **.72** | .17 | -.01 | -.02 |
| Upset me emotionally | **.71** | .02 | -.15 | -.07 |
| Keep me from doing things I had planned to do | **.68** | -.09 | -.34 | -.08 |
| Require chemotherapy | **.68** | .03 | .15 | -.20 |
| Threaten my physical health | **.58** | -.13 | -.18 | -.34 |
| Interfere with my ability to plan for the future | **.58** | .01 | -.25 | -.16 |
| Require radiation treatment | **.58** | .14 | -.03 | .11 |
| Cause pain and suffering | **.55** | -.09 | -.31 | -.16 |
| Be more serious than the first diagnosis | **.54** | -.13 | -.11 | -.34 |
| Mean losing my breast(s) | **.51** | .44 | .21 | -.09 |
| Make me feel I don't have control over my life | **.43** | .16 | -.07 | -.37 |
| Lead me to be disappointed in my body or feel my body is attacking me | .28 | .22 | -.27 | -.19 |
| Lead me to feel less feminine | -.01 | **.91** | .05 | -.09 |
| Interfere with my sense of sexuality | -.07 | **.79** | -.03 | -.15 |
| Make me feel I am less of a woman | -.00 | **.78** | -.10 | -.02 |
| Make me feel badly about how my body looks or feels | .20 | **.70** | -.00 | -.10 |

Note: Factor 1 = Health Worries, Factor 2 = Womanhood Worries, Factor 3 = Role Worries, Factor 4 = Death Worries.

**Table 8 continued on the next page**

Table 8 continued

Exploratory Factor Analysis of CARS

| | Factor | | | |
|---|---|---|---|---|
| | 1 | 2 | 3 | 4 |
| Damage my romantic relationships | .07 | **.57** | -.20 | .01 |
| Threaten my identity (how I see myself) | .09 | **.48** | -.36 | .04 |
| Threaten my spirituality or faith | .15 | **.44** | -.15 | .09 |
| Keep me from fulfilling my responsibilities (in my home or at my job) | .06 | .04 | **-.82** | -.10 |
| Keep me from fulfilling important roles (in my home or at my job) | .13 | -.03 | **-.80** | -.15 |
| Hurt my relationship with friends and family | -.07 | .28 | **-.61** | -.03 |
| Interfere with my physical ability to carry out daily activities | .22 | -.09 | **-.57** | -.20 |
| Cause financial problems for me | .02 | .22 | **-.49** | -.00 |
| Harm my self-confidence | .23 | .29 | **-.45** | .10 |
| Threaten my ability to be a good mother (grandmother, aunt etc.) | .04 | .34 | -.37 | -.06 |
| Prevent me from maintaining a positive attitude | .30 | .24 | -.32 | -.18 |
| Threaten my life | -.02 | .15 | -.09 | **-.92** |
| Cause me to die | .19 | .21 | -.05 | **-.57** |
| Alpha Coefficient | .89 | .91 | .90 | .94 |

Note: Factor 1 = Health Worries, Factor 2 = Womanhood Worries, Factor 3 = Role Worries, Factor 4 = Death Worries.

Table 9

Descriptive Statistics for Death, Health, Role, and Womanhood Worries

| CARS Sub-scale | Mean | S.D. | Alpha | Inter-correlations | | |
|---|---|---|---|---|---|---|
| | | | | Death | Health | Roles |
| Death Worries | 2.16 | 1.49 | .94 | -- | | |
| Health Worries | 1.91 | 1.19 | .89 | .82** | -- | |
| Role Worries | 1.11 | 1.10 | .90 | .65** | .74** | -- |
| Womanhood Worries | .72 | .98 | .91 | .58** | .65** | .70** |

**$p$ < .01. Note. Scale: 0 = "Not at all", 1 = "A little", 2 = "Moderately", 3 = "A lot", and 4 = "Extremely"; The inter-factor correlations of the health and womanhood worries factors to the role and death worries factors were negative due to negative factor loadings on the role and death worries factors. Thus, the relationships among these factors are more accurately represented by positive correlations, as presented here.

Table 10

Descriptive Statistics for Health, Role, and Womanhood Consequences

| Variable | Mean | S.D. | Alpha | Inter-correlations | |
|---|---|---|---|---|---|
| | | | | Health | Role |
| Health Consequences | .98 | .94 | .90 | -- | |
| Role Consequences | .41 | .77 | .81 | .78** | |
| Womanhood Consequences | .41 | .78 | .88 | .69** | .76** |

**$p < .01$. Note. Scale: 0 = "Not at all", 1 = "A little", 2 = "Moderately", 3 = "A lot", and 4 = "Extremely".

Table 11

Correlations among Potential Correlates of Fear

| | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 |
|---|---|---|---|---|---|---|---|---|
| 1. Age | .19* | -.03 | -.42** | -.05 | -.12 | -.36** | -.28** | -.37** |
| 2. Time Since Diagnosis | - | -.11 | -.09 | .06 | -.14 | -.16* | -.18* | -.14 |
| 3. Surgery[a] | | - | .25** | -.04 | -.05 | .20** | .25** | .30** |
| 4. Chemotherapy[b] | | | - | .07 | -.06 | .39** | .27** | .29** |
| 5. Risk | | | | - | -.13 | .35** | .17* | .22** |
| 6. Control | | | | | - | -.00 | .17* | .04 |
| 7. Health Consequences | | | | | | - | .72** | .66** |
| 8. Role Consequences | | | | | | | - | .69** |
| 9. Womanhood Consequences | | | | | | | | - |

*$p < .05$, **$p < .01$, [a]coded as 1 = BCS and 2 = Mastectomy, [b]coded as 0 = no chemotherapy and 1 = chemotherapy.

Table 12

Correlations between Potential Correlates of Fear and Fear Variables

| | Overall Fear | Death Worries | Health Worries | Role Worries | Womanhood Worries |
|---|---|---|---|---|---|
| Age | -.34** | -.34** | -.31** | -.21** | -.31** |
| Time Since Diagnosis | -.15 | -.15 | -.13 | .03 | -.11 |
| Surgery[a] | .12 | .12 | .08 | .17* | .03 |
| Chemotherapy[b] | .25** | .25** | .28** | .26** | .22** |
| Risk | .46** | .35** | .30** | .21** | .18* |
| Control | -.03 | -.09 | -.11 | .09 | .08 |
| Health Consequences | .59** | .59** | .61** | .60** | .45** |
| Role Consequences | .30** | .30** | .34** | .56** | .40** |
| Woman. Consequences | .42** | .42** | .38** | .47** | .58** |

*p < .05, **p < .01, [a]coded as 1 = BCS and 2 = Mastectomy, [b]coded as 0 = no chemotherapy and 1 = chemotherapy

Table 13

Five Regression Analyses Predicting Fear Variables

| | Criterion Variables | | | | |
|---|---|---|---|---|---|
| Predictors | Overall Fear | Death Worries | Health Worries | Role Worries | Woman. Worries |
| **Step 1** | | | | | |
| Age β | -.235** | -.272** | -.226* | -.143$^t$ | -.260** |
| Time β | -.062 | -.077 | -.071 | .025 | -.049 |
| Surgery β | .119 | .071 | -.021 | .130 | -.007 |
| Chemo β | .084 | .114 | .173* | .165$^t$ | .104 |
| Model F | 4.66** | 6.03*** | 5.52*** | 3.83** | 4.50** |
| Adj. $R^2$ | .088 | .117 | .106 | .069 | .084 |
| **Step 2** | | | | | |
| Age β | -.183* | -.240** | -.202* | -.111 | -.236** |
| Time β | -.096 | -.113 | -.105 | .027 | -.049 |
| Surgery β | .141$^t$ | .084 | .030 | .146$^t$ | .004 |
| Chemo β | .064 | .092 | .152$^t$ | .168$^t$ | .105 |
| Risk β | .444*** | .315*** | .256** | .207** | .159* |
| Control β | .020 | -.068 | -.088 | .137$^t$ | .092 |
| Model F | 10.52*** | 6.97*** | 6.35*** | 4.18** | 3.88** |
| Adj. $R^2$ | .273 | .216 | .174 | .111 | .102 |

$^t$p <= .10, *p < .05, **p < .01, ***p < .001

**Table 13 continued on next page**

Table 13 Continued

Five Regression Analyses Predicting Fear Variables

| | Criterion Variables | | | | |
|---|---|---|---|---|---|
| Predictors | Overall Fear | Death Worries | Health Worries | Role Worries | Woman. Worries |
| **Step 3** | | | | | |
| Age β | -.025 | -.119 | -.082 | .030 | -.061 |
| Time β | -.058 | -.082 | -.068 | .072 | -.022 |
| Surgery β | .029 | .016 | -.036 | .030 | -.163* |
| Chemo β | -.065 | -.022 | .021 | .027 | .031 |
| Risk β | .252*** | .146* | .076 | .029 | .017 |
| Control β | .014 | -.048 | -.083 | .074 | .064 |
| Health C. β | .541*** | .592*** | .629*** | .404*** | .136 |
| Role C. β | -.171$^{t}$ | -.273** | -.170 | .218* | -.084 |
| Wom. C. β | .246** | .138 | .048 | .059 | .558*** |
| Model F | 18.42*** | 11.86*** | 11.08*** | 11.02*** | 9.76*** |
| Adj. R$^2$ | .508 | .391 | .374 | .372 | .342 |

$^{t}$p <= .10, *p < .05, **p < .01, ***p < .001

Table 14

Final Model Fs and Adjusted $R^2$ for the Fourth Step of Five Hierarchical Regression Analyses Predicting Psychological Distress and Changes in Adjusted $R^2$ with the Addition of the Respective Fear Variable

| Fear Variable | Final Model F / Adj. $R^2$ | Change in Adjusted $R^2$ |
|---|---|---|
| Overall Fear | 9.93, $p < .001$ / .373 | .070*** |
| Death Worries | 8.46, $p < .001$ / .332 | .029** |
| Health Worries | 8.05, $p < .001$ / .320 | .017* |
| Role Worries | 7.89, $p < .001$ / .315 | $.012^{t}$ |
| Womanhood Worries | 8.94, $p < .001$ / .346 | .043** |

$^{t}p <= .10$, $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

Table 15

Beta Weights for All Variables in the Fourth Step of Five Hierarchical Regression Equations Predicting Psychological Distress

| | Criterion Variable: Psychological Distress | | | | |
|---|---|---|---|---|---|
| Predictors | Equation One | Equation Two | Equation Three | Equation Four | Equation Five |
| Age β | .15$^{t}$ | .17* | .15$^{t}$ | .13$^{t}$ | .16* |
| Time Since Diag. β | .05 | .05 | .04 | .02 | .04 |
| Chemotherapy β | -.07 | -.09 | -.10 | -.10 | -.10 |
| Surgery β | -.03 | -.03 | -.02 | -.03 | .02 |
| Perceived Risk β | -.00 | .06 | .08 | .09 | .09 |
| Perceived Control β | .01 | .03 | .03 | .00 | -.00 |
| Health Conseq. β | .06 | .13 | .15 | .20$^{t}$ | .23* |
| Role Conseq. β | .28** | .28* | .24* | .18 | .24* |
| Woman. Conseq. β | .13 | .19$^{t}$ | .21* | .21* | .07 |
| Fear Variable β | | | | | |
| Equation One: Overall Fear | .39*** | | | | |
| Equation Two: Death Worries | | .24** | | | |
| Equation Three: Health Worries | | | .19* | | |
| Equation Four: Role Worries | | | | .16$^{t}$ | |
| Equation Five: Woman. Worries | | | | | .27** |

$^{t}$p<=.10, *p < .05, **p , >01 ***p < .001

Table 16

Final Model Fs and Adjusted $R^2$ for the Fourth Step of Five Hierarchical Regression Analyses Predicting Psychological Well-being and Changes in Adjusted $R^2$ with the Addition of the Respective Fear Variable

| Fear Variable | Final Model F / Adj. $R^2$ | Change in Adjusted $R^2$ |
|---|---|---|
| Overall Fear | 7.29, $p < .001$ / .295 | .046 |
| Death Worries | 6.66, $p < .001$ / .274 | .025 |
| Health Worries | 6.20, $p < .001$ / .257 | .008 |
| Role Worries | 6.47, $p < .001$ / .267 | .018 |
| Womanhood Worries | 6.58, $p < .001$ / .271 | .022 |

$^{t}p <= .10$, $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$

Table 17

Beta Weights for All Variables in the Fourth Step of Five Hierarchical Regression Equations Predicting Psychological Well-being

| | Criterion Variables: Psychological Distress | | | | |
|---|---|---|---|---|---|
| Predictors | Equation One | Equation Two | Equation Three | Equation Four | Equation Five |
| Age β | -.09 | -.11 | -.10 | -.08 | -.10 |
| Time Since Diag. β | -.00 | .00 | .01 | .03 | .01 |
| Chemotherapy β | .15$^{t}$ | .17* | -.18 | .18* | .18* |
| Surgery β | .00 | -.00 | -.01 | .00 | -.04 |
| Perceived Risk β | -.12 | -.17* | -.18 | -.19* | -.19* |
| Perceived Control β | .14$^{t}$ | .12 | .12 | .15$^{t}$ | .14$^{t}$ |
| Health Conseq. β | .16 | .08 | .08 | .06 | .01 |
| Role Conseq. β | -.35** | -.36** | -.32** | -.25* | -.31** |
| Woman. Conseq. β | -.16 | -.21* | -.23* | -.23* | -.12 |
| Fear Variable β | | | | | |
| Equation One: Overall Fear | -.32** | | | | |
| Equation Two: Death Worries | | -.22* | | | |
| Equation Three: Health Worries | | | -.15$^{t}$ | | |
| Equation Four: Role Worries | | | | -.20* | |
| Equation Five: Woman. Worries | | | | | -.21* |

$^{t}$p<=.10, *p < .05, **p , >01 ***p < .001

Table 18

Descriptive Statistics and Correlations of Acceptance, Denial and Positive Reframing with Fear Variables and Psychological Adjustment Variables

| | Acceptance | Denial | Positive Reframing |
|---|---|---|---|
| Mean (S.D.) | 4.50 (1.91) | 3.34 (1.71) | 2.87 (1.43) |
| Overall Fear | .15 | .19* | .14 |
| Death Worries | .16 | .20* | .12 |
| Health Worries | .08 | .26** | .15 |
| Role Worries | .00 | .29** | .15 |
| Womanhood Worries | -.15 | .37** | .11 |
| Psychological Distress | .07 | .26** | .07 |
| Psychological Well-being | -.07 | -.10 | .11 |

Note: Possible Range = 2-8. *$p$ < .05; **$p$ < .01.

Table 19

Correlations of Coping to Background Variables, Initial Appraisal Variables, and Ongoing Consequences

| | Acceptance | Denial | Positive Reframing |
|---|---|---|---|
| Age | .07 | -.17 | -.11 |
| Time Since Diagnosis | .08 | .01 | .09 |
| Chemotherapy | -.02 | .07 | .08 |
| Surgery | .08 | -.13 | -.10 |
| Perceived Risk | .36** | -.08 | .05 |
| Perceived Control | -.12 | .11 | .10 |
| Health Consequences | .09 | .16 | .07 |
| Role Consequences | .00 | .13 | .05 |
| Womanhood Consequences | .02 | .15 | .08 |

*$p < .05$; **$p < .01$; ***$p < .001$.

Table 20

Five Regression Analyses Examining the Role of Coping in the Relationship Between Fears about Recurrence and Psychological Distress

| Predictors | Fear Variables<br>Overall Fear | Death Worries | Health Worries | Role Worries | Woman. Worries |
|---|---|---|---|---|---|
| **STEP 1** | | | | | |
| Fear Variable β | .557*** | .436*** | .398*** | .457*** | .456*** |
| Model F | 57.553*** | 30.093*** | 24.138*** | 33.754*** | 33.550*** |
| Adj. $R^2$ | .305 | .184 | .152 | .202 | .201 |
| **STEP 2** | | | | | |
| Fear Variable β | .524*** | .391*** | .346*** | .415*** | .435*** |
| Acceptance β | 045 | .062 | .100 | .125 | .184* |
| Denial β | .176* | .200* | .197* | .176* | .147$^t$ |
| Positive Reframing β | -.053 | -.034 | -.050 | -.062 | -.055 |
| Model F | 15.841*** | 9.012*** | 7.429*** | 9.836*** | 10.153*** |
| Adj. $R^2$ | .315 | .199 | .166 | .215 | .221 |
| **STEP 3** | | | | | |
| Fear Variable β | .519*** | .369*** | .305** | .395*** | .453*** |
| Acceptance β | .051 | .053 | .088 | .121 | .182* |
| Denial β | .171* | .181* | .179$^t$ | .165$^t$ | .206* |
| Positive Reframing β | -.046 | -.015 | -.004 | -.032 | -.010 |
| Fear Var. X Accept. β | .005 | -.063 | -.050 | -.068 | .009 |
| Fear Var. X Denial β | .050 | .000 | .009 | -.011 | -.181* |
| Fear Var. X P. Refr. β | .059 | -.037 | -.097 | -.066 | -.177* |
| Model F | 8.964*** | 5.206*** | 4.456*** | 5.816*** | 7.715*** |
| Adj. $R^2$ | .302 | .186 | .158 | .207 | .267 |

Note: The fear variable included in each regression analysis is indicated at the top of the column. Results of each analysis can be seen by reading the column from top to bottom. Psychological distress is the criterion variable for all equations. $^t$*p* <=.10; **p* < .05; ***p* < .01; ****p* < .001.

Table 21

Five Regression Analyses Examining the Role of Coping in the Relationship Between Fears About Recurrence and Psychological Well-being

| | Fear Variables | | | | |
|---|---|---|---|---|---|
| Predictors | Overall Fear | Death Worries | Health Worries | Role Worries | Woman. Worries |
| **STEP 1** | | | | | |
| Fear Variable β | -.467*** | -.384*** | -.352*** | -.417*** | -.376*** |
| Model F | 35.705*** | 22.087*** | 18.125*** | 26.894*** | 21.085*** |
| Adj. $R^2$ | .212 | .141 | .117 | .167 | .135 |
| **STEP 2** | | | | | |
| Fear Variable β | -.474*** | -.378*** | -.356*** | -.436*** | -.417*** |
| Acceptance β | -.063 | -.073 | -.107 | -.132 | -.191* |
| Denial β | -.063 | -.079 | -.070 | -.046 | -.029 |
| Positive Reframing β | .200* | .183* | .201* | .214* | .204* |
| Model F | 10.599*** | 6.743*** | 6.008*** | 8.725*** | 7.555*** |
| Adj. $R^2$ | .229 | .151 | .134 | .193 | .169 |
| **STEP 3** | | | | | |
| Fear Variable β | -.463*** | -.322** | -.261** | -.394*** | -.409*** |
| Acceptance β | -.037 | -.047 | -.067 | -.126 | -.156$^t$ |
| Denial β | -.042 | -.037 | -.031 | -.013 | -.056 |
| Positive Reframing β | .198* | .160$^t$ | .139 | .169$^t$ | .146$^t$ |
| Fear Var. X Accept. β | .120 | .175$^t$ | .194* | .178$^t$ | .178* |
| Fear Var. X Denial β | .060 | .033 | .008 | -.009 | .160$^t$ |
| Fear Var. X P. Refr. β | -.017 | .007 | .076 | .048 | .124 |
| Model F | 6.335*** | 4.505*** | 4.435*** | 5.974*** | 6.315*** |
| Adj. $R^2$ | .224 | .160 | .157 | .213 | .224 |

Note: The fear variable included in each regression analysis is indicated at the top of the column. Results of each analysis can be seen by reading the column from top to bottom. Psychological well-being is the criterion variable for all equations. $^t$p <=.10; *p < .05; **p < .01; ***p < .001.

Table 22

Percentage of Sample Describing Positive, Negative, and Distracting Circumstances

| | | Negative (Distracting) | | |
|---|---|---|---|---|
| | | Yes | No | Total |
| Positive | Yes | 27 (08) | 27 | 54 |
| | No | 38 (10) | 18 | 56 |
| Total | | 65 (18) | 45 | 110 |

Note: Numbers in parentheses represent how many negative circumstances were also coded as distracting.

Table 23

Correlations of Life Circumstances to Overall Fear, Psychological Distress, and Psychological Well-being

| | Positive Circumstances | Negative Circumstances | Distracting Circumstances |
|---|---|---|---|
| Positive Circumstances | -- | -.19 | -.03 |
| Negative Circumstances | -- | -- | .37** |
| Psychological Distress | -.24* | .28* | -.11 |
| Psychological Well-being | .31** | -.21* | .08 |
| Overall Fear | -.14 | .01 | -.17 |

*p<.05; **p<.01

Table 24

*Three Regression Analyses Predicting Overall Fear, Psychological Distress, and Psychological Well-being*

| | Criterion Variables | | |
|---|---|---|---|
| Predictors | Psychological Distress | Psychological Well-being | Overall Fear |
| Positive Circumstances β | -.191* | .276** | -.131 |
| Negative Circumstances β | .329** | -.224* | .054 |
| Distracting Circumstances β | -.238* | .175$^{t}$ | -.197$^{t}$ |
| Model F | 6.680*** | 5.890** | 1.869 |
| Adj. R$^2$ | .140 | .123 | .024 |

$^{t}$<= .10; * *p* < .05; ** *p* < .01

Table 25

Correlations of Life Circumstances to Background Variables, Ongoing Consequences, Initial Appraisal Variables, and Coping

| | Positive Circumstances | Negative Circumstances | Distracting Circumstances |
|---|---|---|---|
| Age | -.08 | .07 | .25** |
| Time Since Diagnosis | .08 | .10 | .25** |
| Chemotherapy | .18 | -.10 | -.33** |
| Surgery | -.04 | -.15 | -.21* |
| Perceived Risk | -.10 | .09 | .03 |
| Perceived Control | -.08 | -.01 | -.13 |
| Health Conseq. | -.02 | .18 | -.16 |
| Role Conseq. | -.28** | .26** | -.19* |
| Womanhood Conseq. | -.15 | .13 | -.12 |

*$p<.05$; **$p<.01$

# Figure Captions

Figure 1. Conceptual model to be tested in Chapter 4.

Figure 2. Percentage of sample reporting low, moderate and high levels of overall fear, perceived risk, and perceived control regarding the possibility of recurrence.

Figure 3. Percentage of sample reporting low, moderate, and high levels of death worries, health worries, role worries, and womanhood worries.

Figure 4. Percentage of sample reporting low, moderate and high levels of health consequences, role consequences, and womanhood consequences.

Figure 5. Conceptual models to be tested in Chapter 5.

Figure 6. Plots of the interaction between fear and acceptance in predicting psychological Well-being.

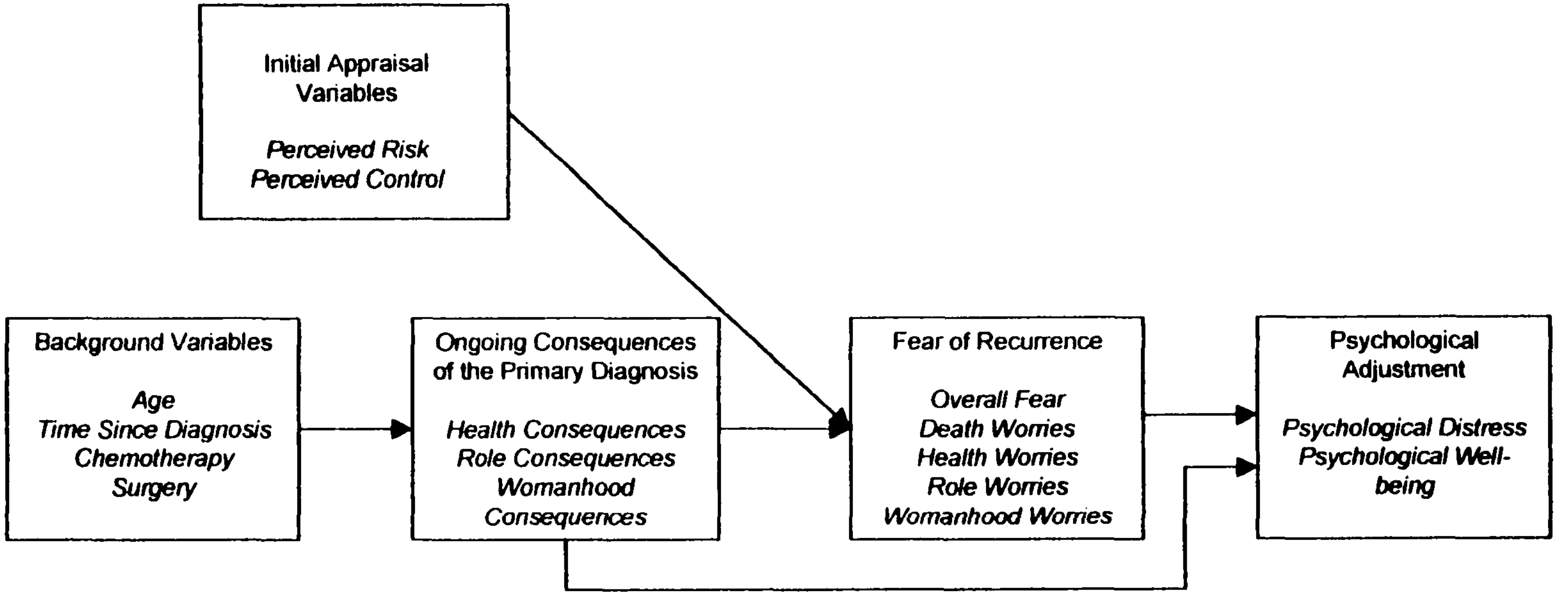

Initial Appraisal Variables
*Perceived Risk*
*Perceived Control*
Background Variables
*Age*
*Time Since Diagnosis*
*Chemotherapy*
*Surgery*
Ongoing Consequences of the Primary Diagnosis
*Health Consequences*
*Role Consequences*
*Womanhood Consequences*
Fear of Recurrence
*Overall Fear*
*Death Worries*
*Health Worries*
*Role Worries*
*Womanhood Worries*
Psychological Adjustment
*Psychological Distress*
*Psychological Well-being*

**Figure 1**

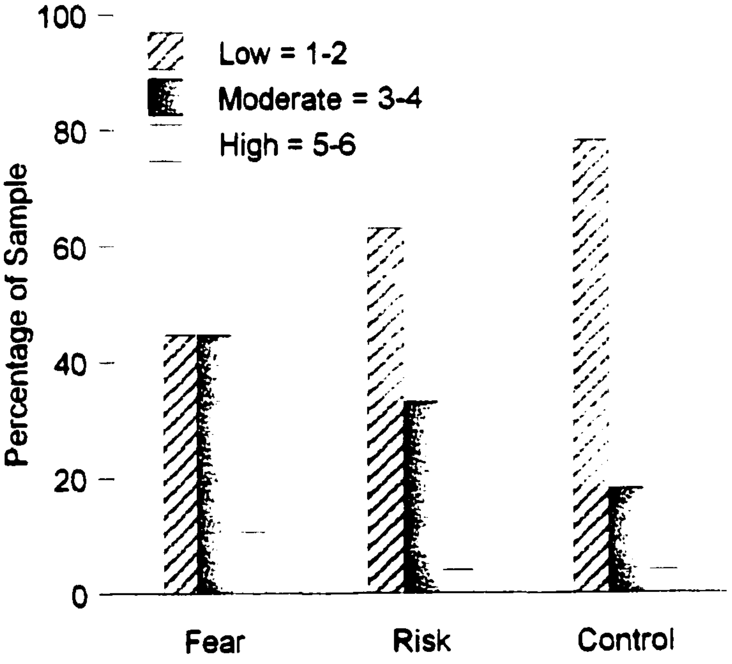

100
80
60
40
20
0
Percentage of Sample
Low = 1-2
Moderate = 3-4
High = 5-6
Fear
Risk
Control

Figure 2

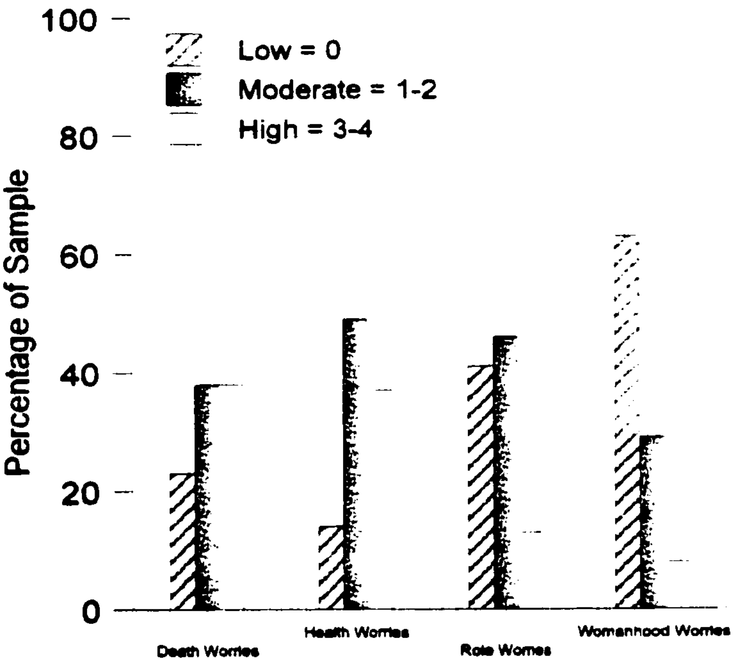

100
80
60
40
20
0
Percentage of Sample
Low = 0
Moderate = 1-2
High = 3-4
Death Worries
Health Worries
Role Worries
Womanhood Worries

Figure 3

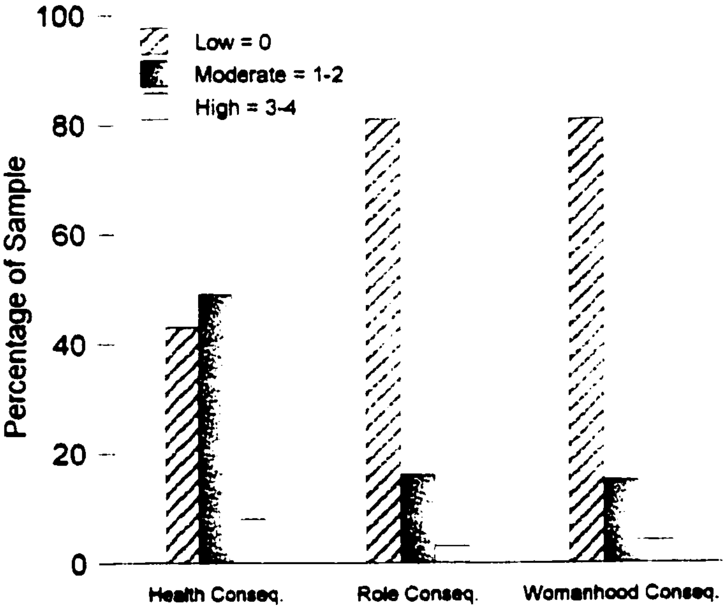
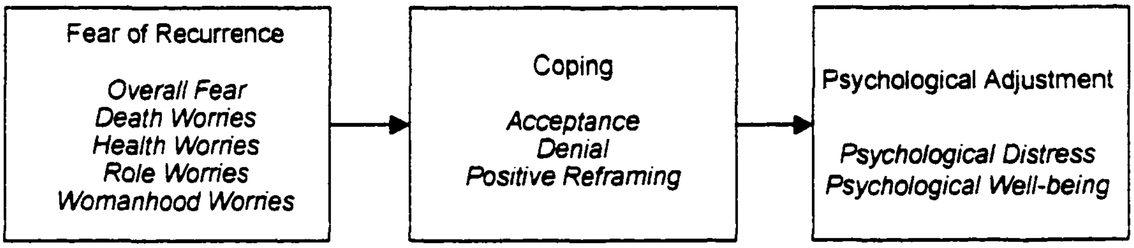
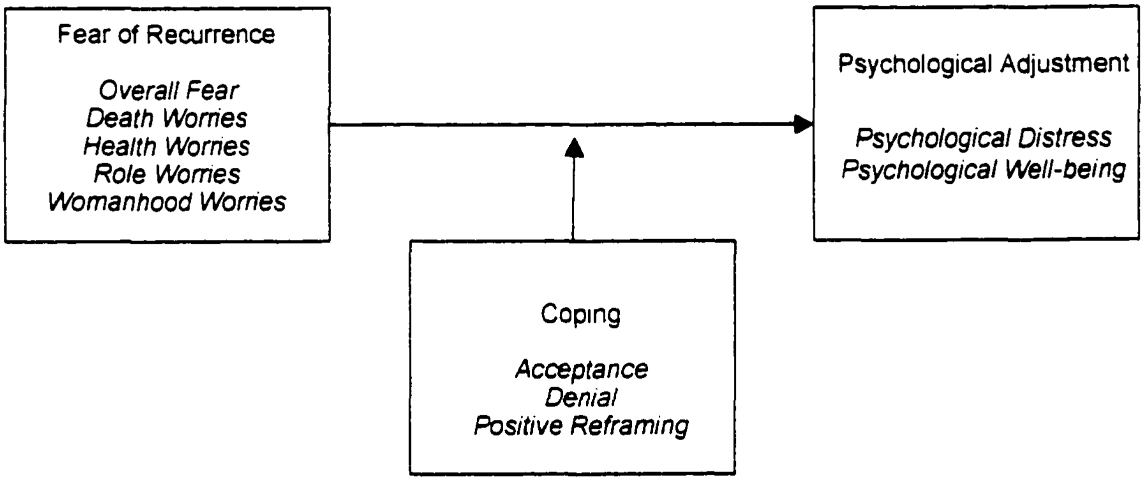

100
80
60
40
20
0
Percentage of Sample
Low = 0
Moderate = 1-2
High = 3-4
Health Conseq.
Role Conseq.
Womanhood Conseq.

Figure 4

Coping as Mediator



Coping as Moderator



Coping as Direct Effect

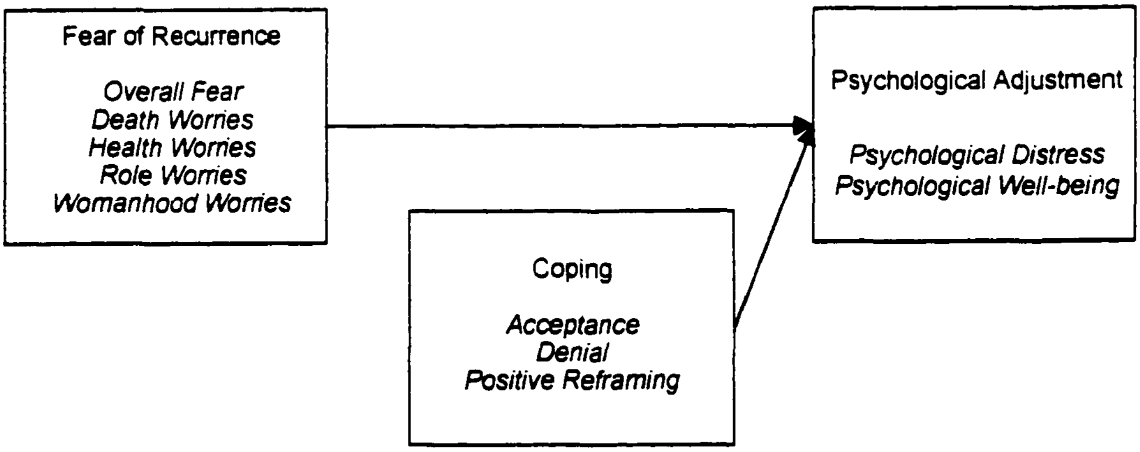
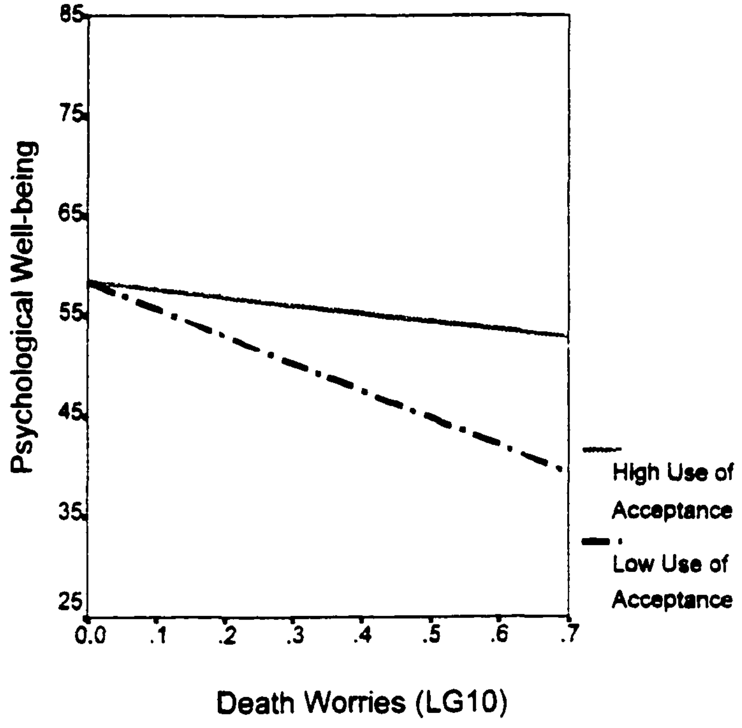


**Figure 5**



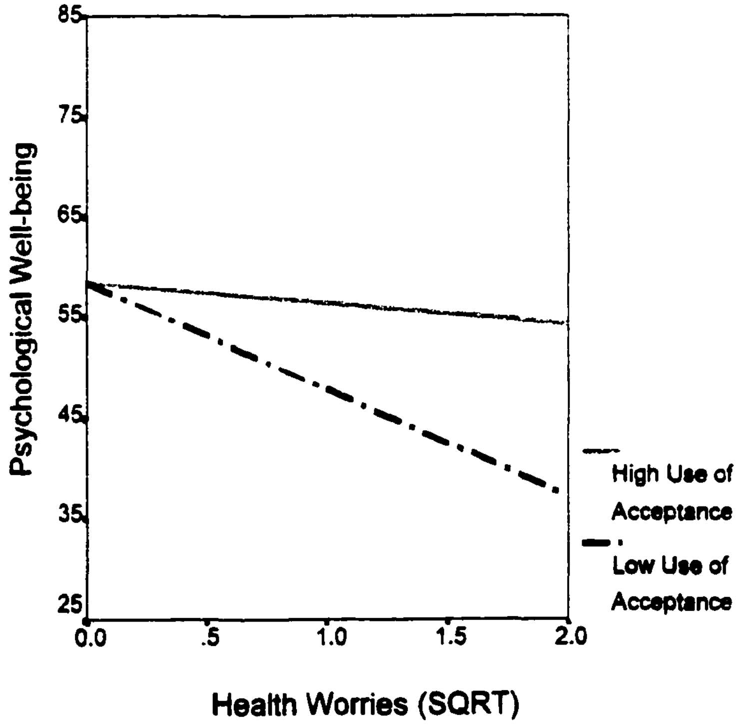


Figure 6 continued on next page

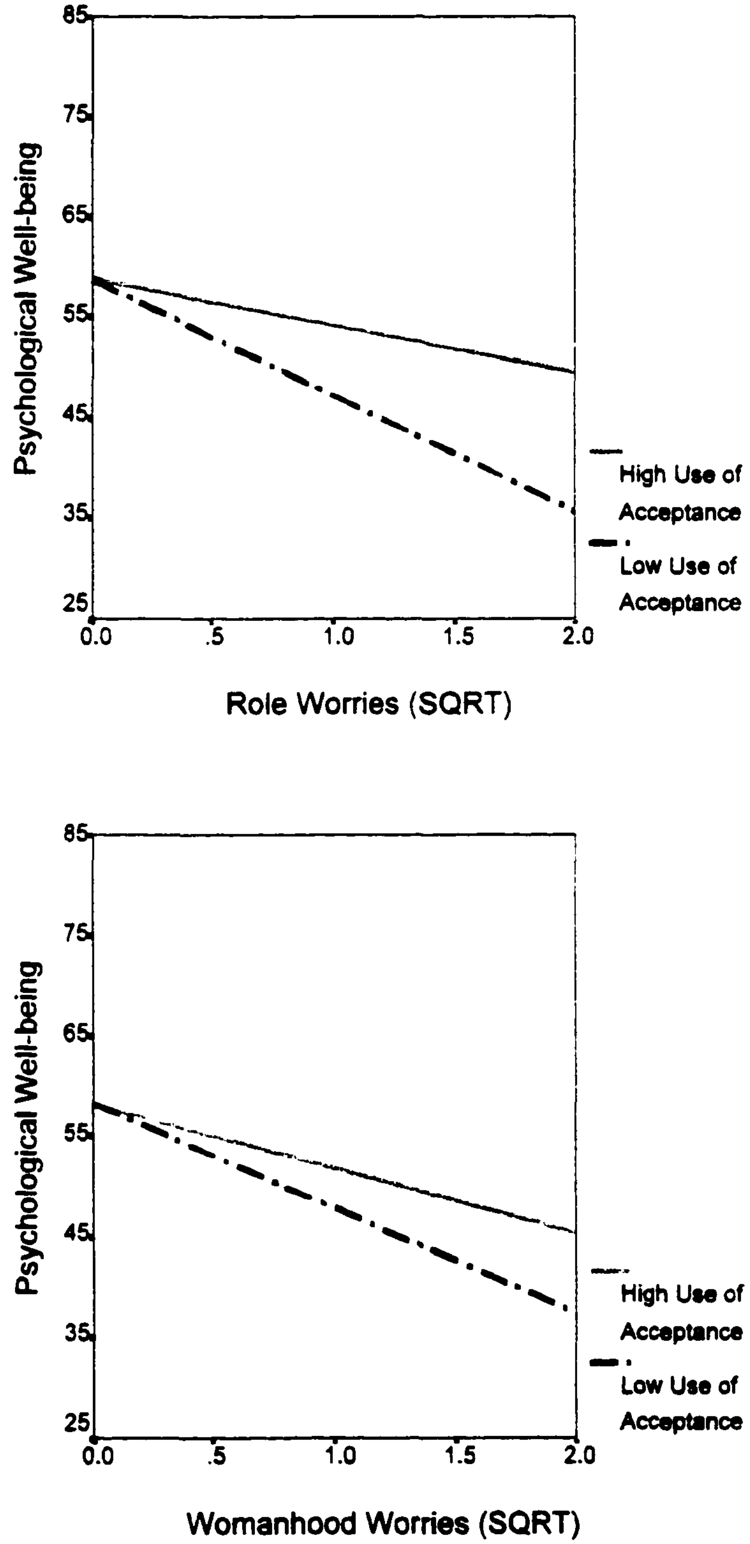

85
75
65
55
45
35
25
Psychological Well-being
0.0
.5
1.0
1.5
2.0
Role Worries (SQRT)
High Use of Acceptance
Low Use of Acceptance
85
75
65
55
45
35
25
Psychological Well-being
0.0
.5
1.0
1.5
2.0
Womanhood Worries (SQRT)
High Use of Acceptance
Low Use of Acceptance

Figure 6

# Appendix A: Qualitative Data Coding Scheme

What are the most commonly reported effects (E) of breast cancer?

Physical (EP)
- Pain
- Lymphadema
- Headaches
- Nausea
- Gynecological Problems (From Tamoxifen)
- Weight Gain
- Memory Loss
- Reduced Range of Motion
- Hair Loss/Change in Appearrence
- Induced Menopause

Psychosocial (PS)
- Anxiety
- Depression
- Fear (Recurrence, Death, Losing Breast, Health Complications, Relative Health)
- Change in Priorities
- Change in Planning
- Questioning why it Happened
- Enriched Life or Understanding of Others

Self-Relationship (SR)
- Difficulty With or Loss of Relationship with Friends of Family
- Lack of Sexual Desire
- Prevented Future Relationships (Motherhood, New Friends/Partners)

How often do these women report thinking/worrying (W) about the possibility of breast cancer recurrence?

Not At All to Very Little (WL)
A little to a Moderate Amount (WM)
A Fair Amount to A Lot (WH)

What possible consequences of breast cancer recurrence do women fear or worry about (F)?

Death (FD)
Chemotherapy (FC)
Emotional Upset (FEU)
Pain (FP)
Worse Prognosis or Metastasis or Untreatable (FWP)
Suffering of Family or Leaving them Behind (FF)
Loss of Breast (FLB)
Ovarian/Uterine Cancer (FG)

What are the situations in which thoughts about breast cancer recurrence are likely to be triggered (T)?

- Reminders/Warnings From Others (TRO)
    - Hearing about Others With Cancer
    - Seeing Something about Cancer on T.V.
    - Hearing Other's Stories or Problems about Cancer
    - Someone Talking About Cancer, Tamoxifen Etc.
    - Study Letter
    - See others Suffering/Being Around people with Cancer
    - Seeing That Others Had Chosen Mastectomy (Did I Make the Right Choice?)
- Physical Reminders (TPR)
    - Pain
    - Taking Tamoxifen
    - Seeing Partically Reconstructed Breast
- Situations that Could Identify a Recurrence (TIC)
    - Doctors Appointments
    - Any New Lump or Potential Symptom (Including Tiredness)
    - Being Told By a Physician That Something Might Be Wrong
- Doing Something Future Oreinted (TFO)
    - Making a Purchase
    - Getting involved in Something New
    - Work-related Things
- Emotions (TE)
    - Being in a Good Mood
    - Being Depressed

What are the strategies used to cope (C) with fears about breast cancer recurrence?

- Support (CS)
  - Friends/Family
  - Support Groups
  - Therapist or Professional
- Cognitive Strategies (CCS)
  - Thinking It Won't Come Back
  - Acceptance
  - Believing in Doctors
  - Hoping
  - Trying Not To Think About It
  - Thinking That There Will Be New Treatments in the Future
  - Being Thankful For Each Day of Health
- Behavioral Distraction (CD)
  - Keeping Busy
  - Usual Routine
  - Work
  - Watching TV, Reading
  - Keeping Mind Occupied
- Health Behaviors (CHB)
  - Exercise
  - Diet
  - Screening/Getting a Clean Bill of Health from Physician
  - Learn about Cancer
- Religion (CR)
  - Prayer
  - Going to Church
  - Reading the Bible
- Emotional Expression (CEE)
  - Crying
  - Laughter

# Appendix B: The Concerns about Recurrence Scale

## *FUTURE WORRIES*

*The next section of the survey asks you to tell us about any worries you may have about the possibility of breast cancer recurrence. By* <u>*recurrence*</u> *we mean the breast cancer coming back in the same breast or another area of the body, or a new breast cancer in either breast.*

*Although most women who have been diagnosed with early stage breast cancer will never have another problem with the cancer, we are aware that many women do worry about this possibility. Other women may not worry about recurrence at all. Either way, your answers to these questions are very important to us. We understand that it may be upsetting to think about or answer questions about the possibility of recurrence. However, we need your help to understand how women think about this possibility.*

*Although some of the questions may sound similar to one another it will be most helpful to us if you answer them all. However, we want to remind you again that you are free to skip any questions that you would rather not answer.*

*Now we are interested in what your concerns are regarding a possible recurrence of breast cancer. When thinking about the possibility of a recurrence what is it about that possibility that you worry about?*

*Although each of the following items may be a possible consequence of recurrence, we are really interested in whether you actually worry about any of these things occurring. For example, you may believe that a recurrence of breast cancer could require further surgery. We would like to know whether you ever actually worry about this possibility.*

*For the following questions, please circle the number indicating how much you worry about each of the following items. If you do not worry about an item or if you think it does not apply to you, please circle "0" for "Not at All".*

| **I worry that a recurrence of breast cancer would:** | Not at All | A Little | Moderately | A Lot | Extremely |
|---|---|---|---|---|---|
| Upset me emotionally | 0 | 1 | 2 | 3 | 4 |
| Keep me from doing the things I had planned to do | 0 | 1 | 2 | 3 | 4 |
| Threaten my physical health | 0 | 1 | 2 | 3 | 4 |
| Make me feel I am less of a woman | 0 | 1 | 2 | 3 | 4 |
| Require chemotherapy | 0 | 1 | 2 | 3 | 4 |
| Hurt my relationships with friends and family | 0 | 1 | 2 | 3 | 4 |
| Make me feel that I don't have control over my life | 0 | 1 | 2 | 3 | 4 |
| Threaten my identity (how I see myself) | 0 | 1 | 2 | 3 | 4 |
| Interfere with my physical ability to carry out daily activities | 0 | 1 | 2 | 3 | 4 |
| Threaten my life | 0 | 1 | 2 | 3 | 4 |
| Lead me to be disappointed in my body or feel my body is attacking me | 0 | 1 | 2 | 3 | 4 |
| Prevent me from becoming a mother | 0 | 1 | 2 | 3 | 4 |
| Harm my self-confidence | 0 | 1 | 2 | 3 | 4 |
| Be more serious than the first diagnosis | 0 | 1 | 2 | 3 | 4 |
| Cause financial problems for me | 0 | 1 | 2 | 3 | 4 |
| Interfere with my sense of sexuality | 0 | 1 | 2 | 3 | 4 |

| **I worry that a recurrence of breast cancer would:** | **Not at All** | **A Little** | **Moderately** | **A Lot** | **Extremely** |
|---|---|---|---|---|---|
| Require radiation treatment | 0 | 1 | 2 | 3 | 4 |
| Threaten my ability to be a good mother (grandmother, aunt etc.) | 0 | 1 | 2 | 3 | 4 |
| Cause me pain and suffering | 0 | 1 | 2 | 3 | 4 |
| Mean losing my breast(s) | 0 | 1 | 2 | 3 | 4 |
| Interfere with my ability to plan for the future | 0 | 1 | 2 | 3 | 4 |
| Threaten my spirituality or faith | 0 | 1 | 2 | 3 | 4 |
| Keep me from fulfilling important roles (in my job or at home) | 0 | 1 | 2 | 3 | 4 |
| Lead me to feel less feminine | 0 | 1 | 2 | 3 | 4 |
| Require further surgery | 0 | 1 | 2 | 3 | 4 |
| Cause me to die | 0 | 1 | 2 | 3 | 4 |
| Damage my romantic relationship(s) | 0 | 1 | 2 | 3 | 4 |
| Prevent me from maintaining a positive attitude | 0 | 1 | 2 | 3 | 4 |
| Keep me from fulfilling my responsibilities (in my job or at home) | 0 | 1 | 2 | 3 | 4 |
| Make me feel badly about how my body looks or feels | 0 | 1 | 2 | 3 | 4 |

**Are there any other possible consequences of a breast cancer recurrence that you worry about? Please tell us about them.**

# Appendix C: Sample Size Available Depending on Measures Included in an Analysis

| Measure(s) Included | n |
|---|---|
| Total Questionnaires Returned | 189 |
| Total Eligible | 169 |
| Risk/Fear/Control | 160 |
| CAR | 160 |
| CBC | 167 |
| MHI | 167 |
| COPE | 137 |
| Life Circumstances | 110 |
| CBC/CAR/Fear/Risk/Control | 153 |
| CBC/CAR/Fear/Risk/Control/MHI | 152 |
| CAR/Fear/MHI/COPE | 130 |
| Life Circ/Fear/MHI | 106 |

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