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UMI
PSYCHOLOGICAL ADJUSTMENT TO UNCERTAIN OUTCOMES:
THE THREAT OF CANCER RECURRENT

BY

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THESIS

Submitted in partial fulfillment of the requirements for the degree of Doctor of Philosophy in Psychology in the Graduate College of the University of Illinois at Urbana-Champaign, 1999

Urbana, Illinois
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THE GRADUATE COLLEGE

FEBRUARY 1999
(date)

WE HEREBY RECOMMEND THAT THE THESIS BY

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ENTITLED PSYCHOLOGICAL ADJUSTMENT TO UNCERTAIN OUTCOMES:

THE THREAT OF CANCER RECURRENCE

BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR

THE DEGREE OF DOCTOR OF PHILOSOPHY

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† Required for doctor's degree but not for master's.
Clinical impressions and anecdotal reports suggest that follow-up exams to detect cancer recurrence can be very stressful, yet recent research posits that most cancer patients recover emotionally from their diagnosis over the one to two years after diagnosis and treatment. The present study employed a limited, longitudinal design to describe the psychological responses of women in remission for a primary diagnosis of breast ($n = 59$) or colorectal ($n = 20$) cancer to follow-up exams, and to identify factors associated with differing levels of adjustment to the exams. Subjects were interviewed at three time points proximate to a follow-up exam: approximately one month before, the night before, and two weeks after the exam was completed and results were known. In addition, physicians provided evaluations regarding prognosis and anxiety level for 67 of the subjects. Analysis of variance, Chi-square analysis, and Pearson product moment correlations revealed that subjects did indeed experience significant anxiety prior to the exams. However, disease site, stage of disease, months since diagnosis, and age of subjects were not related to reactions to the exam. How subjects conceptualized the time line of cancer (i.e., as a chronic/cyclic or acute disease) was the sole variable related to outcome measures of distress and coping. Those with a chronic/cyclic perspective were significantly more anxious, fearful of recurrence, depressed, and evaluated their social support network and medical care as less positive than those with an acute view of cancer. The theoretical issues regarding time line are discussed and clinical implications are suggested.
DEDICATION

For Rich, my partner in completing
a dissertation
and realizing a fulfilled life.
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The women in this study honored me with the privilege of hearing their fears, concerns, and hopes. Their contribution literally completed this research. Their willingness to share daunting thoughts of their own mortality forever altered my own perspective on life, illness, and death.
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CHAPTER 1
OVERVIEW

Due to the unpredictable course of the diseases diagnosed as "cancer," patients may live in an extended state of uncertainty with respect to long-term prognosis. Even when the initial symptoms are successfully treated, most patients understand that they are at higher risk for a future diagnosis of cancer than the general population. Indeed, the chemotherapy or radiation they receive for treatment may put patients at even greater risk for future disease.

Researchers are finally broadening their focus to include "survivors" as well as those struggling with an initial diagnosis and those facing imminent death. There are still many unanswered questions regarding how cancer survivors cope with such a prolonged period of ambiguity.

The present study sought to examine the effects of a variety of relevant variables (e.g., anxiety, coping strategies, optimism) on the psychological adjustment of women who are in remission for breast or colorectal cancer, during an interval preceding a naturalistic stressor with an unpredictable outcome—a follow-up examination for disease recurrence. Assessments were made at three points for each subject, twice before the examination and once after, in order to better understand the processes of psychological disruption and adaptation related to the potentially life-threatening implications of the exam.

The rationale, significance, methods, and results of the present study are discussed in detail following a survey of the relevant literature. The literature review begins with a discussion of the threat and impact of disease recurrence, particularly as compared with the
initial diagnosis. Then the problems associated with an ambiguous prognosis are considered. It is hypothesized, based on a related literature on general surgery patients, that patients who experience a moderate amount of anxiety may be better prepared for negative disease outcomes. Next, literature on the coping process in general and coping with cancer specifically is briefly reviewed. Special issues that cancer patients encounter with respect to social support are then addressed. Finally, controversial data on the relationship between personality variables and cancer are discussed, with an emphasis on how an optimistic disposition may relate to how one copes with the ambiguity inherent in living with cancer. Each of these literatures, while superficially unrelated, contribute a piece to the larger puzzle of how individuals deal with a prevalent, yet enigmatic disease.
Cancer is a chronic disease with an insidious onset and an unpredictable course of indefinite duration (Mendelsohn, 1979). It is influenced by biological, environmental, social, and psychological components (Feuerstein, Labbe, & Kuczmierczyk, 1986; Temoshok & Fox, 1984). Some recent evidence suggests that cancer can be viewed as a transitional event which most patients are able to recover from emotionally, if not physically, within one to two years following diagnosis (Andersen, 1994; Andrykowski et al., 1996; Glanz & Lerman, 1992; Irvine, Brown, Crooks, Roberts, & Browne, 1991; Stanton & Snider, 1993).

Longitudinal data suggest that when localized disease is controlled and recovery follows, the psychological trauma of diagnosis gradually stabilizes with the greatest improvement evidenced 3-4 months post-treatment (Anderson, 1992). Indeed, the cancer itself may be viewed positively as “a catalytic agent for restructuring” patients’ lives (Taylor, 1983) which can result in a desire to experience life more fully (Schaefer & Moos, 1992). Long-term negative effects of the disease and its treatment may be minimized by the feeling that one has a new lease on life (Andersen, Anderson, & de Prosse, 1989; Cella & Lesko, 1988).

While many patients survive a cancer diagnosis and subsequent treatment without serious psychological distress, it has been reported consistently that there is an enduring sense of vulnerability; fears of recurrence appear to be present to some degree in most cancer survivors (Cella & Lesko, 1988; Fredette, 1995; Holland, 1996; Shanfield, 1980). Concerns may range from nagging health worries to death anxiety (Andersen, 1994). Much attention is
now focused on the prevalence of posttraumatic stress disorder (PTSD) in cancer patients (Alter et al., 1996; Cordova et al., 1995). The prototypic components for a diagnosis of PTSD are disfiguring and aversive treatment, unpredictable onset, threat of death, social isolation and helplessness (Andrykowski & Cordova, 1998). It is estimated that 10-20% of cancer patients might meet PTSD criteria within five years of diagnosis (Andrykowski & Cordova, 1998).

Given the potentially severe responses cancer triggers in some individuals, it is imperative to identify risk factors and plan treatment interventions for those who are more vulnerable. Although the pendulum has swung away from the view that a cancer diagnosis immediately sentences the patient to debilitating anxiety and depression, we can also not conclude that the disease is a minor stressor that is easily overcome. For some, especially younger patients and those with a history of psychiatric disorders or other chronic illness, the risk for emotional difficulties is significant (Andersen, 1994; Grassi & Rosti, 1996; Mor, Allen, & Malin, 1994; Schag et al., 1993; Vinokur, Threatt, Vinokur-Kaplan, & Satariano, 1990). Furthermore, the very patients who are most at risk may be under represented in longitudinal studies because they are more likely to either not participate or terminate their involvement prematurely (Ell, Nishimoto, Morvay, Mantell, & Hamovitch, 1989).

Perhaps a reasonable conclusion is that although cancer patients may not be at greater risk for psychopathology than non-oncology patients or healthy individuals, they may be at greater risk for intermittent and minor psychological distress in the form of anxiety or depression based on adjustment reactions (Barbarin, 1987; Kornblith et al., 1992). Long-term adaptation to cancer takes shape in the period after primary treatment has ended and the
The Threat and Impact of Disease Recurrence

It is frequently reported that the initial diagnosis and recurrence are the most stressful episodes in the course of cancer (Andersen & Turnquist, 1986; McEnvoy & McCorkle, 1990; Silberfarb, Maurer, & Crouthamel, 1980). Psychological adjustment at recurrence may be even more difficult than at initial diagnosis since the patient knows that the treatment with the most hope of success has failed (Hacker & Jochimsen, 1986; Holland, 1982). Indeed, while the time of initial diagnosis is very difficult, it can also be the period of greatest optimism because the most effective treatment methods (balanced against the potential for treatment-related mortality and morbidity) are naturally used first (Weisman, 1976). In general, treatment for recurrent cancer is not as successful as treatment after an initial diagnosis (Cella, Mahon, & Donovan, 1990). Also at initial diagnosis, the patient is occupied with integrating a multitude of information (Burgert, 1972-1973), learning medical jargon, and getting acclimated to the medical environment (Moos & Tsu, 1977).

At relapse, the full impact of the disease is realized without the distractions associated with understanding the diagnosis and the mechanics of initiating the treatment. Cella, Mahon, and Donovan (1990) assessed 40 mixed-site cancer patients whose recurrences had been diagnosed within 30 days of participation in the study. Seventy-eight percent of the subjects reported that the recurrence was more upsetting than the initial diagnosis. Similarly,
Northouse, Laten, and Reddy (1995) report that more than half of their subjects, who were one month to three years post-recurrence, described the experience as more emotionally devastating than the initial diagnosis. Even terminally ill cancer patients reported lower levels of distress than patients with newly recurrent disease (Silberfarb et al., 1980). Specifically, these authors found that with respect to treatment, patients with recurrence were much more likely to report a negative reaction to initiating chemotherapy treatment than newly diagnosed patients. This may be due to the fact that recurrent patients had more experience with the negative side effects of chemotherapy. But they also realistically felt more pessimistic about their prognosis, and questioned whether any treatment would help them. Almost half the subjects in Cella et al.'s (1990) sample feared their doctor would not even try to treat the recurrent disease. A recurrence shatters one's sense of security, confirms one's worst fears, and may undermine faith in oneself and one's doctor (Leventhal, Easterling, Coons, Luchterhand, & Love, 1986). In short, there is a collapse of hope (Cella et al., 1990).

If recurrence is viewed as the ultimate disconfirmation of one's illusion of control over their health, the most adaptive response may be to focus on areas of life that one can control (Taylor, 1983). Unfortunately, little is known about how cancer patients cope with the threat of recurrence and recurrence itself. Not surprisingly, most researchers have chosen to focus primarily on the acute phase of cancer; the point when the physical and psychological distress are most poignant and when patients are most likely to be hospitalized and accessible (Mages & Mendelsohn, 1979). In addition, patients with recurrent cancer may be less willing to participate in psychological research projects. Weisman and Worden (1986) found recurrent
patients less likely to admit to problems than newly diagnosed patients. While new patients supposedly participated in the research to garner emotional and informational support, patients with a recurrence reported that their only need was for medical treatment. The authors conclude that for individuals experiencing a recurrence, "early problems have abated and preterminal problems are yet to develop" (p. 14). Yet it is for that very reason that researchers have discovered the necessity of examining the day-to-day experiences between the two points of the cancer continuum.

Prevalence and recurrence data help to put the number of individuals affected in perspective. In 1996 there were approximately 185,700 new cases of breast cancer diagnosed in the United States (including 1,400 among men). The five-year survival rate across all stages is 83.2%, with rates dropping dramatically with distant metastasis (96.1% for localized disease, 74.9% for regional spread, and 19.8% for distant spread) (American Joint Committee on Cancer, 1992; Scientific American, 1996). Survival rates include persons who survive five years after diagnosis, whether in remission, disease-free, or under treatment. Survival after a diagnosis of breast cancer continues to decline beyond 5 years: 67% of women diagnosed with breast cancer survive 10 years, and 56% survive 15 years (American Cancer Society, 1998). A recent epidemiological study, which examined annual hazard rates of recurrence for breast cancer after primary therapy, concluded that the peak hazard of recurrence occurred in the interval of the first one to two years. The hazard decreased consistently in the next two to five years, and beyond five years the hazard decreased very slowly. The mean hazard of recurrence between years 5 to 12 post-surgery was 4.3% per year. As would be expected, higher risk subsets such as patients with more than three
axillary nodes positive had a higher risk of recurrence at all time intervals, while lower risk subsets (e.g., those with negative nodes) had a lower hazard of recurrence in all time periods. Given the finding that younger patients report more emotional distress after a cancer diagnosis, it is notable that women 40 years of age and younger have a worse five-year, cancer-specific survival estimate than their older counterparts. The difference is not solely a reflection of more advanced disease, but may actually reflect differences in tumor biology (Chung, Chang, Bland, & Wanebo, 1996).

There were about 133,500 new cases of colorectal cancer in the U.S. in 1996 (94,500 for colon and 39,000 for rectum) with a 5-year survival rate across stages of 61%. Patients with localized disease had a 91% chance of survival at 5 years, 62.8% for those with regional spread, and only 6.9% for patients with distant metastasis (American Joint Committee on Cancer, 1992; Scientific American, 1996). As with breast cancer, survival continues to decline beyond five years; 51% of persons diagnosed with colorectal cancers survive 10 years (American Cancer Society, 1998).

The National Cancer Institute estimates that approximately 8 million Americans alive today have a history of cancer (American Cancer Society, 1998). Since more patients have many disease-free years which are overshadowed by uncertainty and ambiguity regarding the future, it is critical to document how patients adjust to this most prolonged phase of the disease. It is also conceivable that the type of adjustment, in turn, affects disease progression (e.g., life style patterns such as smoking, alcohol consumption, and exercise); and, perhaps, that chronic stress affects the immune system (Levy, 1985). Chronic stressors (e.g., continued emotional distress, work-related difficulties, social and interpersonal upset,
physical weakness) can plague cancer survivors for years. There is recent evidence that adults who endure chronic stress may exhibit persistent down regulation of elements of their immune systems with resultant adverse health outcomes, such as higher rates of respiratory infections (cf. Andersen, Kiecolt-Glaser, & Glaser, 1994). Further, there are data that psychological interventions (e.g., relaxation, cognitive-behavioral techniques) can modulate immune function in noncancer populations (Kiecolt-Glaser & Glaser, 1992). Given that cancer refers to such a broad group of diseases which differ on a multitude of dimensions (e.g., etiology, site, cell type, and stage), it is not surprising that the directional effects of cancer on the immune system are more complicated than for an illness such as a respiratory infection.

A recent prospective study involving 280 women with Stage 2 breast cancer found no significant predictive effect of the level of psychological distress on length of disease-free and overall survival after controlling for socio-demographic and medical variables (Tross et al., 1996). The authors conclude that in the context of far more potent medical factors, the contribution of psychological factors to disease-free and overall survival is likely to be relatively small. Yet, the biobehavioral model described by Andersen and her colleagues (1992) which charts the psychological (stress and quality of life), behavioral (compliance and health behaviors), and biologic pathways from cancer stressors to disease course is consistent with the immune theory, based on animal models, that affirms the influential role of the immune system in host resistance against metastasis. As Fox (1978) noted in the first issue of the Journal of Behavioral Medicine almost 20 years ago, research exploring the relationship between psychological factors and cancer incidence/progression is an extremely
difficult area of inquiry. Yet there is evidence of progress and the implications for therapeutic interventions are significant and far reaching (Spiegel, 1994).

Effective therapeutic interventions are necessary for those cancer patients who become overwhelmed by the possibility of recurrence or the development of a new cancer. The fear of relapse may diminish with time but can persist indefinitely (Fredette, 1995). Thoughts of recurrence trigger fears of death, loss of function, increased pain, becoming a burden, lack of control, disfigurement, and vulnerability (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995). The experience of coping with an initial diagnosis of cancer will not necessarily aid the patient’s adjustment if there is a recurrence; one cannot assume that an individual knows how to adjust to illness downturns just because he or she has experienced it before (Erdal & Zautra, 1995).

Clearly, the vast majority of cancer survivors are not overcome by anxiety regarding recurrence every minute following the conclusion of treatment. There is evidence that certain events and experiences have the potential to reactivate the fear. Environmental reminders (e.g., a newspaper article on cancer) (Mages & Mendelsohn, 1979), ambiguous symptoms, and visits to the doctor for follow-up evaluations may all precipitate increased anxiety (Auchincloss, 1995; Bloom, 1982; Holland, 1996; Mendelsohn, 1979; Nelson, 1996). Cella and Tross (1986), in a study of 60 male Hodgkin’s disease survivors, found that 85% acknowledged that their awareness of health and concern for symptoms had increased since they were diagnosed. Two-thirds of the patients reported that physical symptoms triggered a fear of recurrence.
Most relevant to the present research, visits to the physician seem to be particularly anxiety-provoking. Waiting for conclusions to be drawn from examinations, scans, and blood tests is often difficult for relatively healthy, non-oncology patients. Individuals who have survived cancer are more vulnerable; the challenge of waiting for test results can intensify feelings of uncertainty (Nelson, 1996). Auchincloss (1995) describes how some gynecologic cancer survivors became anxious as early as two weeks before the appointment, with concerns increasing and peaking the last two days. Those identified at diagnosis to be at high risk for psychological distress in the year after a breast cancer diagnosis reported more anxiety one year later regarding fears about test results and concerns about the cancer progressing (Schag et al., 1993).

There is evidence that anxiety decreases the more time has elapsed since the diagnosis (Holland, 1996). In a prospective study involving 52 cancer patients (mixed site and stage, both sexes) who were assessed at diagnosis and then six years later, Grassi and Rosti (1996) found that the prevalence of psychiatric disorders decreased over the years. Most relevant, the dimension of “disease conviction,” which indicated the patient’s preoccupation with his/her symptoms and affirmation of presence of disease despite medical assurance, was also lower at follow-up. Although the authors did not investigate the relationship between disease conviction and doctor’s visits, it seems conceivable that preoccupation with ambiguous physical symptoms would be more prevalent at certain times.

Interestingly, fear of recurrence does not appear to be related to type of surgery breast cancer patients undergo. It had been argued that breast conserving therapy (e.g., lumpectomy) led to significant fear of disease recurrence, but research has not supported this
contention. Those who undergo modified radical mastectomies do not manifest less fear of recurrence than lumpectomy patients, and lumpectomy patients do not express more fear (Aaronson, 1991; Lasry & Margolese, 1992).

Paradoxically, while medical check-ups during remission may temporarily increase anxiety and fears about the future, the overall decreased medical surveillance can cause heightened fear of recurrence (Hurt, McQuellon, & Barrett, 1994). Cancer patients reported to this author that while they were glad to no longer experience the very unpleasant side effects from chemotherapy and/or radiation, they experienced fear about treatment termination. They viewed the interventions, difficult as they were, as a continual weapon against the disease. Interestingly, a recent study on the identification of posttraumatic stress disorder (PTSD) in cancer survivors found that ongoing treatment with tamoxifen was associated with a decreased risk for PTSD (Alter et al., 1996). The authors suggest that the continued treatment may offer patients some feeling of control over an uncontrollable process as well as a perception of prevention over life threat.

Although medical staff may expect the patient to respond positively to the news that there is no evidence of recurrence, the patient may not be able to relax. As Hurt (1994) and her colleagues describe, it is not a question of mistrusting the physician, but more an issue of mistrusting their own bodies. The authors describe a poignant case study in which “Mrs. M” could not “enjoy” remission because of fears that it would not last. Her initial cancer was not diagnosed swiftly and she did not trust medical tests which indicated absence of the disease. The medical team became frustrated with her and she felt alienated by them. When she did eventually experience a recurrence, the event actually brought a sense of relief. She was
catapulted out of the disconcerting feelings of uncertainty into a new phase where she could actively prepare for death. For her, dying was preferable to the ambiguity of remission.

Ambiguity and Uncertainty Regarding Prognosis

Unfortunately, one may be disease free for 10 years, 5 years beyond the “magic number” 5-year survival rate (as noted earlier, likelihood of recurrence does decline with time; “five years” is a significant marker); and then experience a recurrence, a second primary, or an iatrogenic cancer (Levy, 1985; R. O. Whitten, personal communication, August 22, 1997). Although medical advances encourage patients and their families to plan for a healthy future, the threat of recurrence and death is ever present. Koocher and O’Malley (1981) have aptly labeled this predicament the Damocles Syndrome. The name refers to the ancient myth of the courtier, Damocles, who overpraised the happiness of the tyrant, Dionysius I. In order to teach Damocles a lesson regarding the delicate nature of that happiness, Dionysius seated Damocles under a naked sword suspended by a single horse hair while they dined in luxurious surroundings. Cancer survivors often identify with such a dilemma; the disease could return even when they feel well.

Pattison (1978) describes this uncertainty as the “living-dying interval,” which is resolved by the individual’s death or the certainty that his or her medical status is no longer life-threatening. This period of living in limbo has also been called “neutral time” (cf. Hurt et al., 1994). This interval may last months or, more likely for cancer patients today, years. Indeed, the uncertainty is unlikely to ever be resolved in the patient’s lifetime.
Ambiguity about long-term prognosis is a major concern for cancer survivors. Even in the absence of recurrence, patients must deal with prolonged uncertainty about the progress of the disease (Andersen, 1994; Auchincloss, 1995; Holland, 1996; Mages & Mendelsohn, 1979; Maher, 1993; Mishel, Hostetter, King, & Graham, 1984; Nelson, 1993). Uncertainty is defined as a person’s cognitive and emotional state when an event cannot be adequately structured or categorized due to insufficient cues. The decision maker is unable to accurately predict outcomes (Mishel & Braden, 1987). For healthy individuals, uncertainty can be exciting. In illness, uncertainty may overwhelm the patient and result in confusion, anxiety, and fear (Mishel, 1981, 1990; Nelson, 1993). Management of anxiety associated with uncertainty may be the major task in adjustment to cancer (Morris, Blake, & Buckley; Peters-Golden, 1982; Silver & Wortman, 1980) and perhaps to any illness (Cohen & Lazarus, 1979; Moos & Tsu, 1977).

There are unique aspects of cancer that exacerbate the uncertainty and ambiguity associated with disease. Hurt et al. (1994) utilize Seligman’s (1992) safety signal hypothesis, originally proposed as part of the theory on how helplessness can lead to depression, to suggest that patients living in remission experience unpredictability and subsequent anxiety and fear. The only certainty is uncertainty. The safety signal hypothesis suggests that individuals need to predict safety reliably after a traumatic event in order to recover emotionally. Cancer often has no obvious symptoms; there is in effect no clear safety signal to reassure the patient that the disease will not return. As indicated by the case study of Mrs. M, described earlier, reassuring diagnostic tests may not be enough evidence to quell the fear of recurrence.
Leventhal and his colleagues (Leventhal, Easterling, Coons, Luchterhand, & Love, 1986) conducted a number of cross-sectional and longitudinal studies involving breast cancer patients receiving chemotherapy for either regional metastatic disease or adjuvant treatment. They found that as treatment progresses, many patients (even those without active disease) make appraisals about their health status based on their general feelings of well being; there are often no more concrete indicants to augment these “relatively unstable physical and emotional criteria” (p. 189).

Research indicates that the more ambiguous a situation is, the greater is the contribution of individual factors in shaping the meaning of and response to that situation (Lazarus & Folkman, 1984). There is the greatest latitude for diverse types of appraisal and coping responses under environmental uncertainty (McCrae, 1992; Morris, Blake, & Buckley, 1985). Factors which may affect how well one copes with the ambiguity of undesirable life events include perceived social support, optimism, opportunity for ventilation and free expression of feelings, ability to find meaning in events, and previous experience with other stressors (Carver et al., 1993; Silver & Wortman, 1980).

Ambiguity can intensify threat if cues indicate potential harm or can also reduce threat by allowing alternative interpretations of the significance of an event (Lazarus & Folkman, 1984). According to Lazarus and Folkman’s stress and coping model, the magnitude of the stress is interpreted partly as a function of secondary appraisal; that is, a consideration of suitable means to prevent or overcome the threat and of judgments regarding possible outcomes (with primary appraisal referring to the determination of what is at stake in the situation). In highly ambiguous situations it is difficult to evaluate likely outcomes (Folkman...
Further, being in a prolonged state of conflict causes negative stress. Janis and Mann's (1977) conflict model emphasizes the strain of trying to find a happy medium between leading a normal life and being prepared for a relapse.

One aspect of finding a balance between recognizing the possibility of relapse and living as ordinary a life as possible is achieving a balance between denying and accepting possible outcomes. Although mental health professionals have traditionally venerated reality testing as a hallmark of psychological adjustment, life can be intolerable without some illusion (Taylor, 1983; Taylor & Brown, 1988). There is some evidence that the process of denial may be helpful in coping with uncontrollable events (Lazarus, 1983; Morris, Blake, & Blakely, 1985). Weisman (1972) differentiates denial of fact from denial of implication. While it is not adaptive for a patient to deny factual information to the point that he or she does not seek treatment, it could be helpful to deny the worst implications (i.e., recurrence or death) of an ambiguous diagnosis (Cella & Lesko, 1988). Morris et al. (1985) distinguish denial from what they label “avoidance,” an acceptance of threat but a deliberate attempt not to think about it. Cella and Lesko suggest that suppression may be the best term to describe this conscious denial; a process which aids those who need time to obtain emotional balance, but also does not prevent the person from behaving responsibly about health care.

Suppressing the worst possible outcomes is not maladaptive unless it is associated with depressive or anxiety disorders, poor self-help behavior or noncompliance with medical follow up.

Suppression or denial, while adaptive at times, is not available to all patients. There are some who appear unable to stop thinking about long-term medical threats. Miller, Rodoletz,
Schroeder, Mangan, and Sedlacek (1996) recently assessed 101 women with precancerous cervical dysplasia and 75 gay HIV-infected men to determine whether the subjects were “high or low monitors.” High monitors are characterized as cognitively vigilant to and amplify threat-related cues, while low monitors avoid such cues and blunt their impact. The authors reviewed studies which indicate that high monitors exhibit greater self-reported physical and behavioral distress/dysfunction, slower recovery, and greater treatment side effects. High monitors also report that they are less able to control negative cognitions in frightening medical contexts and tend to overreact to aversive experiences. Most relevant is the finding that they are unable to turn off thoughts about the disease; they cannot distance themselves from the stressor. Since the stressor is never actively confronted and emotionally processed, adaptation and acceptance are less likely to occur (Foa & Kozak, 1986).

It is clear that patients respond to an uncertain health future in a variety of ways. Even the chronicity of the stressor is more complex than first thought; some individuals are permanently traumatized by an acute event while others adjust to a continuing stressor so quickly that one would conclude it was only a temporary setback (McCrae, 1992). Most cancer survivors understand that they live with heightened risk for an assortment of health problems and that their future is less certain than of others their age (Cella & Lesko, 1988). Yet as Weisman (1976) observed, patients can paradoxically accept the reality of their health status and still experience hope. Such a duality serves the purpose of maintaining the integrity of the self system (Taylor, 1983); it is a process of maintaining stability in emotional responses and self-concept in the face of an aversive disease characterized by an existential threat (Leventhal et al., 1986). An optimal level of functioning for the cancer patient who is
living in limbo might be described as maintaining hope for recovery while recognizing that recurrence is a possibility.

Preparing for the Possibility of Recurrence: Is There an "Optimum" Amount of Anxiety?

Being prepared for a relapse seems crucial given the research which indicates how devastating a recurrence can be. Cancer survivors often fear the worst in regard to recurrence, regardless of the medical facts (Ferrell et al., 1995). Years ago, many cancer patients were faced with only one outcome--death. Today, the prognosis for a significant number of patients may be presented in relatively optimistic terms. Consequently, relapse may not be prepared for realistically. Several researchers have found that an important indicator of distress after recurrence is the amount of surprise expressed regarding the recurrence.

Cella et al. (1990) assessed 40 cancer patients with mixed primary disease sites who had experienced a recurrence within 30 days prior to participating in the study. For two-thirds of the sample, it was the first recurrence and virtually all of the patients were considered incurable. They assigned subjects to one of three groups regarding level of surprise: "expected it," "knew it was possible," and "completely surprised." The group as a whole had a high prevalence of clinically significant stress responses. As the researchers expected, patients who reported having been completely surprised by the recurrence and those undergoing their first recurrence reported significantly more intrusive and avoidant

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stress response symptoms (e.g., depression, anxiety and social withdrawal). Similarly, Northouse et al. (1995), in a study examining adjustment of women and their husbands to recurrent breast cancer, found that subjects who reported being most surprised by the recurrence also reported the most emotional distress. In Weisman and Worden's (1986) research on the impact of recurrence, subjects who recognized that recurrence was a possibility were less shocked and less distressed by it than those who were caught completely off guard.

However, experiencing no surprise when there is a recurrence may not be the most adaptive response either. Cella et al. (1990) found that in their sample, patients who “fully expected” a recurrence did not do as well as those who “knew it was possible.” They conclude that the relationship between expectation and intrusive symptomatology may be curvilinear, but warn that their design was retrospective with a relatively small, heterogenous sample. It seems reasonable to suggest that, in moderation, fear may be adaptive in terms of the emotional impact of recurrence. The best scenario may be when the patient acknowledges the possibility of recurrence without dwelling on it (Cella et al., 1990; Weisman & Worden, 1986).

How the patient views the time line of the disease may be related to how surprised he or she will be by a recurrence. Leventhal et al. (1986) asked subjects to characterize their cancer as cyclic (like an allergy), chronic (like diabetes), or acute (like the measles). It is unclear how accurate their characterizations were with respect to their medical prognosis. Lymphoma patients were more likely to view their disease as acute or cyclic (i.e., as more susceptible to cure) than metastatic breast cancer patients. In addition, women with breast
cancer receiving adjuvant chemotherapy treatments who viewed their cancer as cyclic or chronic were more distressed and worried about the disease than those who viewed it as acute. Indeed, the responses for adjuvant patients with a chronic or cyclic model were similar to those for the metastatic group. The authors conclude that these two groups are psychologically alike in that they both worry about a concrete disease, while the adjuvant patients with an acute framework worry about cancer only as an abstract threat.

A classic study which examined how general surgery patients (the type of surgery is not specified) cope with the threat of an impending operation is relevant. Janis (1958) argues that in threatening situations the level of fear can potentially determine the adequacy of adaptation. He proposes that preoperative anxiety of moderate intensity that is situationally relevant stimulates the “mental work of worry” (Marmor, 1958). Thus, patients are able to anticipate post-operative feelings, conditions, and circumstances so as to prepare themselves. Moderate anxiety serves a dual function during the anticipatory period; to signal emotionally the trauma or pain that is imminent and to prompt defensive actions to minimize negative outcomes and maximize subsequent adjustment. Overwhelming anxiety, Janis (1958) contends, would have little additional value for adjustment. Those who minimize the event and express no fear would be insufficiently motivated to prepare cognitively for the postoperative symptoms, and would subsequently experience anxiety, anger, and irritability following surgery.

Other researchers (Sime, 1976; Spielberger, Auerbach, Wadsworth, Dunn, & Taulbee, 1973) found evidence for a linear decline model rather than a curvilinear relationship. That is, all patients regardless of preoperative levels of anxiety exhibit reduced state anxiety across
time. Granted, coping with cancer is very different than coping with a typically limited stressor, such as surgery. Although surgery is often the first step in cancer treatment, the disease itself requires much more than an immediate response to an operation (Mages & Mendelsohn, 1979). Andersen and Tewfik (1985) argue that the linear decline model may not be evidenced among cancer patients and that Janis’ (1958) framework is more applicable. Their data on how cancer patients cope with the stress of radiation treatments fit Janis’ model. The authors generalize their findings to encompass the patient’s experience with cancer in general. They conclude that:

Between the extreme responses to either cancer or medical stressors there presumably lies a moderate, adaptive, and perhaps survival-enhancing response. In essence, the work of worrying may then be a never-ending task when confronted by the changing circumstances of a life threatening disease. (p. 1031)

Coping With Cancer

There is consensus that adjustment to cancer is perceived as stressful to most any individual. That is, the demands of the problem initially exceed one’s resources. Coping with cancer, or any stressor, is a complex process that is difficult to assess (Carpenter, 1992). Effects of stress differ across individuals due to characteristics of the stressor, personality dispositions, biological vulnerability, and environmental conditions (Folkman, 1992). A stress response is more likely when there is low perceived control, lack of predictability, and long duration of the stressor exposure. However, it is difficult to draw firm conclusions even
with a dimension as seemingly clear-cut as the chronicity of the stressor. While some individuals experience long-term trauma from an acute event, others adapt to a continuing problem so quickly that it appears to be only a transient obstacle (McCrae, 1992).

It is necessary to separate the coping strategies one employs from the outcomes such strategies produce. Optimally, coping can act as a buffer from the effects of stress, counteract the effects by directly leading to improved outcomes, and perhaps even remove the stress and thereby reduce its impact (Carpenter, 1992). There are certainly many situations that cannot be mastered; problems are sometimes insoluble and distress may be intense and overwhelming. If we just measured “outcomes,” we would lose the process involved (Folkman, 1992).

Coping is best defined as a process involving a changing set of threats and demands that extend over time (Carpenter, 1992; Lazarus, 1966; Lazarus & Launier, 1978). Lazarus and his colleagues conceptualize coping as cognitive and behavioral efforts to manage (i.e., master and reduce or tolerate) a troubled person-environment relationship. As described in the Goodness-of-Fit model, effective coping is dependent on two fits: the fit between reality and one’s appraisal of the stressor and the fit between one’s appraisal and coping strategies (Folkman, 1992).

Folkman and Lazarus (1985) emphasize the complexity of coping as a process in a study of emotion and coping during three stages of a college examination. In this natural experiment, the stressful encounter was viewed as a dynamic, unfolding process rather than a static, unitary event. The stages included the anticipatory period (when the exam content and
outcome were unknown), the waiting stage (after the exam but before the grade was known), and the outcome stage.

Through students' self-report data, the authors found that problem-focused coping, seeking social support, and emphasizing the positive decreased from the anticipatory stage to the waiting stage. Distancing oneself from the stressful event peaked during the waiting period. The authors contend that there was nothing else for the subjects to do at that point. Coping at the outcome stage was influenced by individual differences in grades. With respect to social support, informational support was used to help prepare for the exam while emotional support was sought during the waiting period. Social support here is conceptualized as a coping process that changes over time. Although the subjects and content are very dissimilar from cancer patients coping with an ambiguous illness course (e.g., the students have some degree of control over exam performance), the conceptualization of and methodology for examining coping processes are very relevant.

The unique characteristics of cancer afford patients a wide range of situations with which to cope. One may have to juggle dealing with physical symptoms, ambiguity regarding prognosis, changes in social relationships, and job-related concerns simultaneously. An adaptive coping strategy for one difficulty may not be helpful for others (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992). Further, as in Lazarus and Folkman's (1985) college exam study, there are temporal changes over the course of the disease with respect to characteristics of stressors and effective coping strategies. For example, Morris, Greer, and White (1977) found that while initially mastectomy patients described themselves as having a "fighting
spirit," by two years post-diagnosis they were more likely to be described as having a "stoic acceptance."

Given the multitude of factors involved, it is not surprising that there are mixed findings regarding how patients cope with the various stages of the disease. Indeed, it is unclear what even constitutes effective coping with cancer (Irvine et al., 1991). Mages and Mendelsohn (1979) concluded that cancer patients cope with the disease in three ways: (a) they utilize techniques to minimize distress (e.g., avoid, forget, detach oneself), (b) they actively attempt to deal with problematic issues, and (c) they turn to others for social support. Lazarus describes a similar process in his differentiation of problem focused and emotion focused coping. However, in any given situation, people tend to use both types of coping most all of the time (Folkman & Lazarus, 1981). The goal of problem-focused coping is to remove or circumvent the source of stress. This effort is more likely to be successful when people believe they have some control over the stressor. Minimization may be appropriate when the patient cannot do anything active (Holland, 1996). In emotion focused coping, the stressor usually must be endured and an attempt is made to reduce the emotional distress associated with the stressor. Carver and Scheier's (1981, 1990) model of behavioral self-regulation suggests a mechanism for linking beliefs to emotional outcomes. Carver and Scheier suggested that when people see desired outcomes (e.g., surviving cancer) as attainable, they engage in continued efforts to reach their goals, and positive feelings result. However, when outcomes appear unobtainable, people reduce their efforts, disengage from goals, and express negative affect. Rothbaum, Weisz, and Snyder (1982) contend that when primary (external) control is unattainable, individuals do not give up all efforts at control.

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They may use inward or secondary control (e.g., passivity and withdrawal) to sustain the perception of control. In short, the premise is that if one cannot change the world, he or she can still alter one’s response to the world.

Seeking information about one’s illness is a common proactive coping strategy employed by patients. While it appears that this tactic is simple and straightforward, the findings regarding its efficacy are complex. Actively gathering data related to the disease can be thought of as antithetical to suppression. With more innocuous stressors such as a college exam, information seeking may indeed be related to positive outcomes (Aspinwall & Taylor, 1992). But in a sample of 55 head-and-neck cancer patients, the highly informed reported more fears, anxiety, changes in their lives, worries about health, and concern with physical symptoms (Kreitler, Chaitchik, Rapoport, & Algor, 1995). However, Felton, Revenson, and Hinrichson (1984) in a mixed sample of hypertensive, diabetic, arthritic, and cancer patients found that information seeking was related to positive affect, while emotion based strategies (e.g., avoidance, blame, and ventilating) were related to negative affect, lower self-esteem, and poorer adjustment to illness.

Muris and van Zuren (1992) hypothesize that under short-term medical threat, monitoring (i.e., seeking information regarding the stressor) is more anxiety arousing than blunting (i.e., avoiding threat relevant information). Similarly, Grassi and Molinari (1988) found that before the stressful situation of tumor biopsy, implicating the threat of diagnosis of cancer, breast cancer patients who inhibited or suppressed their feelings of anger and depression reported low anxiety. Six months after a mastectomy, however, the tendency to
suppress anxiety was associated with depressive symptoms. The authors conclude that suppression is harmful when used over a long period of time.

Contradictory and confused findings are not unexpected given weaknesses inherent in many studies which aim to assess coping patterns among cancer patients. Small sample sizes, lack of control over critical variables (e.g., disease severity), and questionable assessment instruments all combine to cast doubt on the significance of obtained results. Two studies which are methodologically stronger are discussed in more depth. The first is a large-scale project involving a variety of cancer sites and stages, and the second is a prospective study on coping with a breast cancer diagnosis.

Dunkel-Schetter (1987; Dukel-Schetter et al., 1992) modified the widely used revised Ways of Coping Questionnaire (WOC) (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen (1986) for use with cancer patients. The sample of 668 subjects (78% women and 22% men) ranged in age from 21 to 88 years, with a median age of 58 years. The largest percentage of subjects had breast cancer (42%). Time since diagnosis ranged from the newly diagnosed to first diagnosed several years ago. Subjects who reported no current cancer-related stress or who failed to answer three or more items on the coping inventory were eliminated from the study and consequently the results were based on a subsample of 603 individuals.

The authors delineated a small set of specific cancer-related stressors based on past study results: (a) fear and uncertainty about the future due to cancer; (b) limitations in physical ability, appearance, or lifestyle due to cancer; (c) acute pain, symptoms, or discomfort from illness or treatment; and (d) problems with family or friends related to
cancer. Subjects were asked to select the one that had been most stressful for them or to indicate one of their own. They were also asked to indicate how stressful the identified problem had been for them in the past six months.

The authors then evaluated the items on the revised WOC for their applicability to cancer. Certain items were dropped and four items from the original version of the WOC (i.e., most having to do with concern for the future) were included. In addition, four new items which reflected common coping behaviors observed in cancer patients (Dunkel-Schetter, 1982) were inserted. The final inventory (WOC-CA) is comprised of 52 items which are responded to with a 4-point rating scale. Five factors were identified through factor analysis: seek and use social support, focus on the positive, distancing, cognitive escape-avoidance, and behavioral escape-avoidance. Other variables included in the analyses included sociodemographic information, medical status, a basic description of social network, and experience with psychotherapy.

Most significantly for the present study, 41% of the subjects reported that fear and uncertainty about the future were the most stressful aspects of the disease. Clearly, the ambiguous nature of the disease was a profound concern. The specific problem with which subjects were coping did not relate significantly to patterns of coping. However, perceived stressfulness of the identified problem was associated with greater coping through support and greater use of both forms of escape-avoidance. The only effect for type of cancer was that respondents with breast cancer were slightly more inclined to seek support than those with other sites. Subjective appraisals of stress from cancer may be more predictive of
psychosocial adjustment than biomedical factors; medical factors may influence coping most
significantly as they are interpreted through the person’s cognitive appraisal system.

Overall, there was little of evidence of coping styles in these patients. Rather than
adhering rigidly to one strategy, the subjects reported using a large repertoire of behaviors to
cope flexibly with any one threat from the disease (Folkman & Lazarus, 1980; Folkman et al.,
1986). Distancing, both cognitive and behavioral, was the most common primary method of
coping in this sample. The authors hypothesize that distancing is probably used a lot due to
the ambiguity of the outcome of most cancers and the uncontrollability of the disease.
Further, distancing was most frequent at moderate levels of distress and least frequent when
distress was very high or very low. Low stress may not necessitate the use of distancing and
problems producing extreme stress may make it impossible to divert one’s attention. Finally,
this study replicated earlier evidence that escape-avoidance strategies (e.g., hoping a miracle
would happen and avoid contact with others) are associated with more emotional distress and
that positive reinterpretations (e.g., focusing on the positive) are associated with less (Felton

Stanton and Snider (1993) focused on identifying factors that facilitate or hinder
adjustment to a diagnosis of breast cancer and also on specifying at what points over the
course of diagnosis and treatment that distress is most likely. Guided by the stress and
of behavioral self-regulation, Stanton and Snider (1993) followed 147 women age 40 or older
regarding coping processes, personality attributes, cognitive appraisal, and mood variables
before breast biopsy, after diagnosis, and for those who had cancer, after surgery. As in the
Dunkel-Schetter et al. (1992) investigation, it was hypothesized that coping directed at disengagement (e.g., cognitive and behavioral avoidance) would be associated with more negative and less positive emotion over the course of the diagnosis. Further, the investigators expected that coping strategies associated with a “positive orientation” (e.g., seeking social support, positive focus) would contribute to a more positive affect. Finally, they questioned what would happen to women who focused on the positive prior to biopsy and then were confronted with a cancer diagnosis; would negative affect result from the perceived disconfirmation of the positive expectancy (Taylor & Brown, 1988)?

Upon biopsy, 24.5% (n=36) were diagnosed with cancer. Because cancer patients were significantly older than the benign group, the investigators only included women age 40 and older in the analyses, and age was entered first in all analyses. There were no significant effect for Age X Group (cancer, benign). Age was significantly related to tension and anger; older women were less tense and angry than younger women. Age was not related to personality, appraisal, or coping scales.

Before the diagnosis, the benign and cancer groups did not differ on personality measures, appraisals, coping strategies, or moods. After the biopsies but before surgery, women with cancer were more tense, depressed, angry, fatigued, confused, and less vigorous than the women with no cancer. However, three weeks after surgery, the two groups did not differ with respect to tension, depression, anger, and confusion. Profound relief that the surgery was over and reduced ambiguity about the future may have masked lingering anxiety and depression. Because no later follow up was conducted, it is unknown whether the quick emotional recovery was sustained.
Personal attributes, cognitive appraisals, and coping processes were all associated with prebiopsy mood. Those who were younger, less optimistic (a personality dimension discussed later in this study), more threatened, and who engaged in more cognitive avoidance coping were more distressed before diagnosis. Only the coping variables uniquely influenced postbiopsy and postsurgery mood. Just as predicted, coping through seeking social support before biopsy was associated with better adjustment after diagnosis. Women who “focused on the positive” prior to biopsy expressed less vigor after a cancer diagnosis, but this relationship did not persist after surgery. Stanton and Snider (1993) suggest that the disconfirming outcome of a cancer diagnosis might have temporarily disrupted mood. In this case, the patients quickly recovered their positive illusions (Taylor & Brown, 1988) either by finding new benefits in their disease experience or by shifting positive focus to some other aspect of their lives.

Cognitive avoidance coping prior to biopsy was associated with negative affect after biopsy and surgery. The authors argue against the concept that avoidance may be advantageous at times. They conclude avoidant coping may interfere with appropriate action, impede cognitive processing and problem solving, and consume significant effort which takes a psychological and physical toll. As discussed earlier, there is some confusion regarding the differences between denial, suppression, and avoidance. In the Stanton and Snider study, coping strategies as divergent as “hoping a miracle would happen” and those having to do with active distraction are subsumed under the same factor.

It appears premature for researchers to conclude that there are objectively “good” or “bad” coping responses, particularly given the weaknesses inherent in coping research. As
discussed earlier, individuals may utilize a variety of strategies to manage a complex stressor. Further, individuals are not entirely consistent or inconsistent in their coping patterns; rather they fall somewhere in between (Stone & Neale, 1984) making choices based on personal preferences and situational requirements (McCrae, 1992; Muris, Van Zuren, & de Vries, 1994). It is difficult to tease apart personality characteristics, coping strategies, social support factors and assess whether predictor variables in these various realms have direct, mediated, or interactive effects on emotional functioning. Several different models may fit a data set (Aspinwall & Taylor, 1992).

Social Support

Although social support is not a dimension that was rigorously assessed and was not instrumental in the present research, its frequent mention in the psycho-oncology literature and its connection to the variables that were considered merit a brief discussion. For example, in the Dunkel-Schetter et al. (1992) study, patients who lacked a partner and/or children were more likely to report that they coped with cancer by avoiding people, drinking alcohol, eating, smoking, and engaging in other impulsive acts. How one copes can provide interpersonal cues regarding what is needed or wanted in a stressful situation. Ideally, the members of the social environment may then respond accordingly. For example, coping through problem solving may elicit significantly more support than coping through denial or increased alcohol consumption. It is, of course, often very difficult for family members and
friends to fine tune their support in terms of just what the patient might need (Neuling & Winefield, 1988).

Patients may be caught in a dilemma regarding how much distress to reveal; too much can drive significant others away and too little may not garner any support (Silver, Wortman, and Crofton, 1990). Patients at high risk for adjustment problems after a cancer diagnosis, the very individuals who might benefit from more sustained support, often experience tumultuous interpersonal relationships; they may have a harder time receiving the support they need from significant others and the medical team (Schag et al., 1993).

The disease itself can create interpersonal problems (Lichtman & Taylor, 1986; Peters-Golden, 1982; Wortman & Dunkel-Schetter, 1979). Friends and relatives reportedly pull away from the patient physically and emotionally because of their own discomfort about the patient’s condition and fears about cancer and death. They may avoid communicating openly about the disease and its implications for fear of raising unpleasant topics and intensifying their own negative feelings. Even for less traumatic day-to-day stress in healthy populations, the people we rely on for support may create more stress (Carpenter & Scott, 1992).

For years, it was assumed that social support, particularly emotional support, was uniformly positive for cancer patients (Bloom, 1982; 1986; Funch & Mettlin, 1982; Irvine et al., 1991; Peters-Golden, 1982; Revenson, Wollman, & Felton, 1983; Weisman & Worden, 1986; Wortman, 1984; Wortman & Dunkel-Schetter, 1979). The uncertainties and fears associated with the disease seem to warrant an enhanced need for support (Wortman, 1984). Indeed, although lacking consistent replication (e.g., Gellert, Maxwell, & Siegel, 1993), participation in a support group has been linked to extended survival time in cancer patients.
(Spiegel, Bloom, Kraemer, & Gottheil, 1989). Yet for cancer patients, “social relationships may not only fail to buffer them from the stress of the illness, but can constitute an additional source of distress” (Wortman & Conway, 1985, p. 287). Those closest to the patient may have the least tolerance for the victim’s distress (Wortman & Lehman, 1985).

Neuling and Winefield (1988) evaluated the source, type (e.g., emotional/affective, informational, tangible/instrumental), and frequency of support reported by 57 women recovering after surgery for breast cancer. Assessments occurred the month preceding surgery and one and three months following surgery. Those satisfied with support from family members were significantly less anxious and depressed in the hospital than those not satisfied. However, those who received the greatest amount of support prior to the surgery were significantly more anxious, depressed, and had lower self-esteem at the time of surgery. Conclusions regarding causality could of course not be made; the less adjusted patients may have required more assistance from significant others.

In an excellent recent study, Bolger, Foster, Vinokur, and Ng (1996) concluded that although significant others provide support in response to patients’ physical impairment, they withdraw support in response to patients’ emotional distress. It may be easier to be supportive in areas that others view as clearly outside of the patients’ control. Or, as alluded to earlier, support providers may feel uncomfortable or incompetent in the emotional realm. Nevertheless, support did not alleviate patients’ emotional distress or promote physical recovery. The very nature of cancer, an unanticipated health crisis with an uncertain outcome, may be too overwhelming for many lay support providers to handle.
Assistance from the medical team, particularly information and advice, can be an important source of support (Helgeson & Cohen, 1996; Neuling & Winefield, 1988; Taylor, Falke, Shoptaw, & Lichtman, 1986). The physician has been described as the most important provider of support for oncology patients and also as the greatest source of distress (Bloom, 1981). Furthermore, an active, involved relationship with one’s doctor is related to compliance with medical treatment for cancer patients (Levy, 1985; Lewis, Linet, & Abeloff, 1983).

In summary, one’s satisfaction with the support received appears to be the crux of how helpful the support actually is. As the needs of patients change over the course of the disease, so does what is most helpful in terms of support (Lichtman & Taylor, 1986; Neuling & Winefield, 1988). A primary need after diagnosis may be for positive and sensitive emotional support from family and friends. During treatment, some individuals desire information in terms of expectations for symptoms, pain management, and expectations for future functioning. However, as noted earlier, others may find a great deal of information anxiety producing. As treatment ends and patients enter the “cancer survivor” phase, Mishel and Braden (1987) suggest that secure relationships may allow patients to dwell less on future concerns and uncertainties and more on present relationships and activities. Women with cancer who reported having inadequate support reported greater fear of recurrence than those satisfied with their support network (Northouse, 1981), but the directionality of this relationship is always difficult to determine.

When there is a recurrence, problems surrounding adequate social support can be exacerbated (Cella et al., 1990). Women with recurrence of breast cancer reported less
satisfactory social support than those without recurrence, and recurrent patients undergoing chemotherapy experienced the least amount of adequate support (Peters-Golden, 1982). Unfortunately, while recurrent patients may have an increased need for support, relatives and friends often have a hard time providing it. Even the threat of recurrence may be too overwhelming for relatives. Lichtman and Taylor (1986) found that while many women with breast cancer expressed a need to talk about their long-term fears, nearly one-third of the husbands in the study thwarted any attempts to discuss the issue; the husbands coped by insisting that the disease was acute and would not return.

Problematic relationships are not limited to friends and relatives; patients with recurrence report more negative feelings toward their doctors than primary or terminally ill patients (Silberfarb et al., 1980). Of the 40 mixed-site oncology patients with recurrence in the research by Cella et al. (1990) most (90%) reported that less attention was being paid to providing sufficient information about the disease and treatment, and 75% felt that their physician or nurse was incorrect assuming that they were coping well.

Personality Variables

The earliest psycho-oncologists (those doing research long before the term psycho-oncology was introduced) attempted to link personality variables to increased risk for cancer, time to recurrence, and/or length of survival. Anecdotal, clinical, and research reports suggested that helpless, passive, stoic, individuals fared the worst. Some even proposed a "Type C" (i.e., cancer prone) personality style. Long-term survivors have been characterized
as expressing both more hostile affect and joy, and exhibiting a “fighting spirit” (Derogatis, Abeloff, & Melisaratos, 1979; Levy, Seligman, Morrow, Bagley, & Lippman, 1986; Pettingale, 1984). An examination of the role of psychological factors in risk and survival time, discussed briefly earlier in this study, is beyond the scope of this project. However, such an issue is distinct from whether a positive outlook harms or benefits psychosocial functioning and adjustment during the course of cancer (Lazarus, 1982). Over 20 years ago, Weisman (1976) characterized the best adjusted newly diagnosed cancer patients as “optimists by nature.” Taylor and Brown (1988) include optimism as one superordinate mechanism that buffers individuals from stress. The other mechanisms are feelings of personal control, self-esteem, effort, and ability.

Optimism has become a critical construct in behavioral medicine research due largely to the work of Carver and Scheier (1981, 1990). Their research spans a period of years and populations including men with coronary problems, women suffering from postpartum depression, HIV positive men, and breast cancer patients. Results have been remarkably consistent; subjects determined to be optimists, as assessed by Carver and Scheier’s Life Orientation Test (LOT), fare better psychologically and even physically (while controlling for medical status) than those defined as pessimists. They define the concept as generalized expectancies for positive outcomes (Scheier & Carver, 1985), and believe that optimism has beneficial effects on outcomes received (Scheier et al., 1989). Although optimism has correlated with several measures of neuroticism, trait anxiety, self mastery, locus of control, and self-esteem, Scheier and Carver (1985) argue convincingly that there is as yet no compelling reason to attribute the effects of optimism to an alternative construct.
Furthermore, although pessimists and depressed individuals may share some characteristics, there is evidence that the construct of pessimism is not merely another name for depression (Scheier & Carver, 1992).

It appears that differences in coping strategies may account for some of the benefits optimists enjoy. Typically, optimism is associated with active, problem-focused coping that is likely to result in positive outcomes (Scheier, Weintraub, & Carver, 1986). Optimists frequently employ tactics such as humor, positive reframing, and acceptance. While usually expecting things to go their way, they accept things that cannot be changed as well as making efforts to change those that can. In a study on adjustment to college life, Aspinwall and Taylor (1992) found that the beneficial effects of optimism, control, and self-esteem on adjustment were mediated by greater use of active coping and seeking social support, and the nonuse of avoidant coping. Scheier and Carver (1992) argue that denial, while perhaps effective in the short term, is increasingly less adaptive as the duration of the stressor increases. Weisman and Worden (1986) stress that an optimistic outlook is not necessarily inconsistent with maintaining a realistic appraisal of risk for recurrence.

Carver and his colleagues (1993) examined how coping mediates the effects of optimism on distress in a sample of 59 women who received surgical treatment for early stage breast cancer. Their research is particularly relevant to this dissertation study due to the assessment instruments used and the repeated measures design. Carver et al. proposed to examine: (a) individual differences in optimism/pessimism as a predictor of well-being, (b) how coping reactions affect well-being over the course of a stressful situation, (c) whether
coping reactions constitute a mechanism by which optimism/pessimism exerts effects, and (d) the patterns of coping as they occur over the course of a crisis.

The subjects (42 with Stage 1 breast cancer and 17 with Stage 2) were interviewed 1 day presurgery, 10 days postsurgery, and at 3-, 6-, and 12-month follow-ups. In each case, the interviewer was blind to the results of the previous assessments. The psychological measures used included the Life Orientation Test (LOT; Scheier & Carver, 1985), the Profile of Mood States (POMS; McNair, Lorr, & Droppelman, 1971), and the COPE (Carver, Scheier, & Weintraub, 1989), a self-report inventory which assesses a broad range of coping responses. In preliminary analyses, age correlated inversely with distress at the three- and six-month follow-ups and postsurgical distress positively correlated with receiving chemotherapy in the next treatment phase (perhaps an anticipatory anxiety regarding undergoing chemotherapy). Therefore, in the analyses of postoperative distress, age and chemotherapy were controlled for at the appropriate time points.

Overall, patients' reported distress was not extreme at any assessment point. This finding is in line with the recent research described earlier in this proposal. The most distress was reported right before the surgery and then diminished significantly postsurgery. Distress levels at the follow-up points were almost identical to the postsurgery amount. Optimism, as assessed by the LOT in the initial interview, was inversely and strongly related to distress at each time point, even controlling for prior distress.

With respect to coping strategies, reports of utilizing “acceptance” were high while reports of “behavioral disengagement” were lower than any other scale. The authors suggest that this finding indicates that these women maintained an active, engaged orientation to life.
throughout the ordeal. (It is important to note that these women all had early stage disease, with a good prognosis.) Specifically, use of some coping strategies decreased significantly from presurgery to postsurgery and then stabilized (e.g., active coping, planning, and use of religion) while others exhibited more gradual decreases over time (e.g., efforts to suppress attention to competing activities, use of social support, and distraction). Consistent with other studies, optimism was associated with active coping efforts early in the crisis (i.e., before surgery) and with accepting the reality of the situation and using humor at most later time points. High scores on the LOT were inversely related to avoidant coping. Furthermore, early use of overt denial and disengagement was positively related to subsequent distress, and postoperative distress predicted later use of denial and disengagement.

In short, it appears that coping influences distress and distress influences coping. The pattern of results in this study is consistent with the hypothesis that coping differences serve as a mediating mechanism by which differences in optimism influence self-reports of well-being. Through path analyses, three reactions were identified as mediators: acceptance, denial, and behavioral disengagement. Optimistic women were more likely to accept the reality of the situation, and less likely to refuse to deal with it and give up. Adjustment is probably best when coping reactions meet the needs of the stressful situation (Mattlin, Wethington, & Kessler, 1990). Carver et al. (1993) conclude that optimists’ overall positive expectancies for the future allow them to assume that most situations, even a diagnosis of cancer, can be dealt with and that eventually a positive outcome will result.
Unfortunately, it is unclear what role optimism plays when the prognosis is less favorable (C. Carver, personal communication, September 19, 1997). Uncertainty regarding illness course has been associated with a pessimistic outlook, as assessed with the Beck Hopelessness Scale in a sample of women with gynecological cancer (Mishel, Hostetter, King, & Graham, 1984). Furthermore, a pessimistic, uncertain outlook was associated with poor adjustment. The relationship between illness severity, uncertainty, and pessimism/optimism was not statistically significant. Mishel and her associates disagree with those who posit that uncertainty may be a factor in generating hope or optimism.
CHAPTER 3

THE PRESENT STUDY

Rationale, Significance, and Implications

The major goal of the present study was to examine the relationship between several interrelated variables (e.g., anxiety, optimism, and coping strategies) and the psychological adjustment of women who were in remission for breast or colorectal cancer and who were faced with a naturalistic stressor with an unpredictable outcome: a follow-up examination for recurrence. As discussed in the literature review, patients have consistently reported anxiety regarding impending follow-up exams. Unfortunately, there has been no systematic research on the time course of this anxiety nor on how patients cope with these exams; reports of anxiety are primarily anecdotal. Ultimately, the results of the exam may reveal a potential threat to life. Regardless of outcome, doctor’s visits, along with ambiguous symptoms and environmental cues, may remind the patient that she is still vulnerable. The exam makes the threat more salient; suppression or blunting coping strategies, if used at all, may be disrupted. Furthermore, the physical setting and medical staff may elicit previously conditioned reactions developed during treatment (e.g., conditioned anticipatory nausea/emesis).

A follow-up exam is an optimal time to assess patients because it is a clearly defined event that all patients experience at similar time points after treatment for an initial diagnosis has ended. This research approach has not been previously taken, although it is most ecologically relevant since the cancer was not isolated from the rest of the patient’s life.
pattern; rather, a potentially threatening period of the patient’s day-to-day experience was examined.

Specifically, the crux of this research was the effect of the follow-up exam on patients’ psychosocial functioning. As the exam approached, was experienced, and passed, how did patients respond? Three objectives of the proposed study were to: (a) establish guidelines for commonly expected reactions to such an event, (b) identify factors that are associated with better adjustment to the threat, and (c) predict patients’ psychological reactions to the results of the examination. Although this was not an intervention study, the results have implications for identifying those patients who are at high risk for experiencing maladaptive distress at follow-up exams, and for designing effective interventions for such patients.

Specific Research Issues

The primary question that was addressed was whether or not the exam was viewed as a threatening event. It was hypothesized that anxiety and other indices of distress would increase from Time 1 to Time 2 and then decrease again at Time 3, for those patients without a recurrence. Anxiety levels were expected to remain elevated for those with a recurrence. Furthermore, it was expected that the longer the time since diagnosis, the less distress subjects would report. Those who have survived the disease longer may feel less uncertainty and also have had more experience with return doctor’s visits. Due to the consistent finding that younger patients are more at risk for adjustment problems, age was examined.
Three criteria have been suggested for studying coping as a process, as opposed to a trait: (a) assessing coping strategies at multiple time points; (b) examining coping within the context of a specific stressful encounter, and (c) describing what the subject actually does, not what he or she usually does or could do (Folkman & Lazarus, 1985). All three criteria were met in the present study. Assessment points occurred at three time points: about one month before the exam (Time 1), as close to the exam as was possible (Time 2), and after the results of the tests were known (Time 3). The purpose of the first assessment was to get a baseline measure of how patients coped with the ambiguity of the illness course prior to proximity of the threat associated with the upcoming exam. The purpose of the second and third assessments was to explore the differential effects patients experienced as a function of time as the exam approached and was completed.

Coping patterns were tracked across the three assessment points. It was hypothesized that patients would use a variety of coping strategies (i.e., exhibit flexibility), and that the strategies would change as the circumstances and controllability of the event changed. Those who reported the most distress would most likely report the most coping behaviors, although it was also plausible that those who report the most coping behaviors would report less distress as a result of their coping efforts. It was expected that distancing or other cognitive avoidance strategies would be utilized by most subjects at Time 1 and Time 3. At Time 2, immediately before the exam, more active coping (e.g., seeking social support) might have been needed. In addition, the relationship of optimism to distress and coping choices was examined. Based on patients’ subjective evaluations of the stressor, highly optimistic
patients might be more likely to engage in active coping strategies or conversely, simply accept the situation.

The emphasis of this research was how patients cope with the threat of disease recurrence; that is, the threat assessed at a routinely scheduled medical follow-up exam when patients are confronted with the possibility of recurrence. It was expected that after the results of the exam were known, there would be two groups of subjects—those with a recurrence and those with no recurrence at that particular time. Because it was difficult to predict how many patients would have a recurrence, making hypotheses about possible differences between the two groups was problematic. Briefly, it was expected that the type of coping associated with adjustment to recurrence would differ from the type associated with no recurrence. For example, adaptive suppression may be a beneficial strategy for healthy patients, but might have poorer long-term consequences for those with recurrence. Similarly, low levels of anxiety regarding recurrence prior to the exam would likely be more adaptive for patients who do not have a recurrence than for those who do, based on the literature which was discussed earlier regarding the dangers inherent in being totally caught by surprise regarding recurrence.

Even without a recurrence, it was hypothesized that patients with very low or high anxiety at Time 1, would report more distress at Time 2 than those who reported moderate levels of concern at Time 1. It is proposed that the cognitive preparation for a stressful event is adaptive. There is some optimal middle ground between obsessing over every sign of ambiguous physiological arousal and denying any concern at all.
Given the literature suggesting patients' concerns about the medical team with respect to information and level of support provided, subjects were asked about their relationship with their physicians. In addition, physicians were asked to evaluate each subject’s prognosis, anxiety regarding prognosis, and the quality of the doctor/patient relationship. Such information is significant, given the importance patients place on their relationship with their medical oncologist or medical radiologist.

The rationale for including breast and colorectal patients in the study was to assess the generality of the results. As evidenced in the literature review, most research on the psychological aspects of cancer is done with female breast cancer patients. Unfortunately, except for some dated research on colostomy patients, very little is known about colorectal patients per se. The choice of which disease sites to include was a difficult question. The purpose of including two sites in this study was to discover the limits of any effect, and to have more confidence in generalizing any significant results to women with other cancer sites.

Each subject served as her own control. Given the predominantly descriptive and exploratory nature of this research, any other type of control group (e.g., healthy adults and/or medically ill patients with diseases other than cancer) would be meaningless. If only breast cancer patients had been included, however, it would have been impossible to determine whether the findings were unique to breast cancer and its special characteristics (e.g., sexuality issues, physical appearance, etc.). In short, the inclusion of the colorectal subjects can be thought of as a small sample case control.
These different primary cancers are typically very different in terms of treatment course and perhaps in terms of patients’ beliefs about prognosis. The sites were selected for inclusion because of their differences. Most breast cancer patients undergo surgery and then have radiation or adjuvant chemotherapy for an average period of six months. Colorectal cancer patients, however, usually are treated with surgery alone. It is unknown whether or not breast and colorectal cancer patients have different orientations (e.g., cyclic, acute, or chronic) to their diseases. Breast cancer patients, because they typically receive treatment after surgery, may feel that they are more vulnerable to recurrence than colorectal cancer patients who are often told that the surgeon “got all the cancer.” Women with breast cancer might take the very need for treatment as a source of vulnerability, or they may feel more protected against recurrence because of their radiation or chemotherapy treatment.

Due to the fact that a great deal of uncontrolled variation is inherent in naturalistic research, an effort was made to control for factors that appear important to hold constant. Specifically, disease site was limited to two, and sex of subjects was limited to females. In addition to being selected because of their differences, the sites were chosen because they occur more frequently in women than any other site except lung cancer. Lung cancer was not selected for inclusion because of its relatively poor prognosis and the strong influence of one’s behavior on the etiology and course of the disease.

The independent variables of interest were time (i.e., between the three assessment points), trait anxiety level, degree of optimism, level of learned resourcefulness, fear of recurrence, prognosis (physician’s judgments), disease site, and recurrence/nonrecurrence. The overall dependent variables were degree of psychological and somatic distress,
specifically in response to the follow-up examination, and coping strategies. Distress was assessed through measures of state anxiety, amount and severity of psychosomatic symptoms, and physician’s judgments of patients’ anxiety regarding prognosis.

It is important to note that the results of the follow-up examination may not have come as a complete surprise to the patients. They are often aware of how they are feeling and whether or not there is a cause for concern. Their perceptions and attributions can be very accurate. The point is that we cannot rule out that differences in disease course account for differences in behavioral indices of stress and coping processes. There is no real solution to this quandary, but subjects were asked what they believed the probability for disease recurrence was in their particular case, and to specify on what their estimates were based.

In summary, the following hypotheses are advanced and were examined:

1. The exam will be viewed as a threatening event. That is, it is expected that state anxiety levels will rise from Time 1 to Time 2 and then decrease at Time 3.

2. The longer the amount of time since the original diagnosis, the less distress subjects will experience as the exam approaches.

3. Younger subjects will experience more distress than older subjects.

4. Subjects who report very high or low anxiety at Time 1 will report more anxiety at Time 2 than those with a moderate amount of anxiety at Time 1.

5. Differences in reported distress are expected for subjects with different disease sites and different stage of disease at diagnosis. Specifically, those with breast cancer are expected to experience more distress, as are those with later stage disease (i.e., regional metastatic vs. localized).
6. Subjects will exhibit flexibility in use of coping strategies, but will use distancing
and other avoidant approaches less at Time 2 when more active coping maybe necessary.

7. Those in the most distress will use more coping strategies and use them more
intensely than those in less distress.

8. More optimistic subjects will use more active coping strategies than less optimistic
subjects.

Method

Subjects and Study Design

Subjects were recruited from the Cancer Registry at Carle Cancer Center in Urbana,
Illinois. To be eligible for participation in the research, a patient must have (a) been at least
over 35 years of age; (b) have completed treatment for a primary diagnosis of breast or
colorectal cancer at least six months, but no more than five years, prior to participation in the
study; (c) have been scheduled for a routine medical follow-up exam during the period of
data collection (from October 1988 to April 1989); (d) had no major medical problems other
than a history of cancer; (e) have no indication of disease recurrence at the time of
participation in the study; (f) been able to read, write, and understand English; and (e)
provided their informed consent to participate. A letter explaining the study and inviting
participation signed by Dr. Alan K. Hatfield, Carle oncologist, was mailed to 396 women
(see Appendix A). Stamped postcards were enclosed in order for possible participants to
either express their interest in being contacted with more information or to indicate their lack
of interest. If they were not interested, they were asked to briefly explain why.
Out of the 396 postcards mailed, 264 were returned by potential subjects (67%). One hundred eighty-four of these 264 respondents agreed to be contacted (47% of all possible respondents), while 80 stated that they had no interest in participating (of the cards returned, 74% agreed to participate). Thirty-eight of the 80 women who declined stated that the time and distance involved in participating in the study were a hindrance. Eleven women gave no reason while seven stated they could not because of poor health. Four insisted they had "no problems with cancer to discuss" and another four stated that they could not bear to think about or discuss the disease. The rest gave a variety of other answers (e.g., no longer a patient at Carle, had an ill family member). Comparison of those 184 patients who agreed to participate with those 212 women who either failed to respond or actively declined, revealed no significant differences with respect to age, disease site, stage of the disease, or time since diagnosis. The primary investigator phoned all women who agreed to be contacted. The study was explained to them in more depth and a brief phone survey was conducted to ensure that the subject did indeed meet eligibility requirements for the study (see Appendix B). From this screening, 20 women were deemed ineligible due to no scheduled doctor appointments in the near future, more than one previous cancer diagnosis, major illness, or still receiving treatment. Eighty subjects (60 breast and 20 colorectal) were enrolled in the study based on meeting eligibility criteria and having appointments close to the initiation of the study. The enrollment was limited to no more then 80 subjects because the data collection period was terminated due to a long-distance move by the primary investigator.

Because Carle Cancer Center is a regional treatment facility serving a broad region, it was expected that subjects would reside in a variety of communities, some distant from
Champaign-Urbana. Since recruiting subjects was a concern, a choice was given to subjects regarding where the first assessment would take place. Although it was preferable to interview subjects on campus (in a private room at the Psychological Services Center), some subjects requested a home interview or a phone interview. At Time 1, 20 subjects were interviewed on campus, 20 at their homes, and 40 had phone interviews. Phone interviews were conducted with all subjects at Time 2. At Time 3, 62 (77%) subjects received questionnaires in the mail and were interviewed over the phone. The mean number of days between assessments at Time 1 and Time 2 was 26.9 (SD = 4.9) with a range from 19 to 42, between Time 2 and medical exam was 1.5 days (SD = .5) with a range from 1 to 2, and between the exam and Time 3 was 14.5 days (SD = 2.8) with a range from 10 to 27. Interviews were conducted by the primary investigator, a doctoral student in clinical psychology with extensive experience working with oncology patients.

The mean age for all subjects was 59.8 years (SD = 9.4) with a range of 37 to 82. Breast cancer subjects were significantly younger (mean age of 58.1, SD = 9.4) than colorectal subjects (mean age of 65.0, SD = 7.4) (t (77) = -2.98, p = .004). The majority (81%) of subjects were married, and all but six (93%) had graduated from high school. Over 96% described themselves as Protestant or Catholic. The mean length of time from cancer diagnosis to participation in the study was 36.2 months with a range of 8 to 60 months. A slight majority of breast cancer patients (52%) had localized disease, while 48% had regional metastatic involvement. For colorectal patients, 75% had local disease while only 25% had regional involvement. This difference between the two sites was not statistically significant. There were also differences in treatment for the two sites. Among breast cancer subjects, 19
subjects, 19 (32%) had surgery alone; 22 (37%) had surgery and chemotherapy; 13 (21%) had surgery and radiation; and the remaining 6 (10%) had surgery, chemotherapy, and radiation. Seventeen of 20 (85%) colorectal patients just had surgery; 2 (10%) had surgery and radiation; and 1 (5%) had surgery, chemotherapy, and radiation.

This study adopted both a limited longitudinal and a cross-sectional design. Subjects were followed for approximately six weeks around the follow-up exam. The data consist of patients' self-reports (from questionnaires and interviews), physicians' judgments, and patients' demographic and medical status variables. Although it was expected that several patients would experience a recurrence at the time of the exam, actually only one woman did.

Measures

A Temporal Schedule of the Administration of Measures and Forms can be seen in Table 1 for:

1. **Assessment of coping.** The Ways of Coping Inventory which was adapted for use with cancer patients (WOC-CA) by Dunkel-Schetter (1987) and her colleagues (Dunkel-Schetter et al., 1992) was used to assess coping behavior at all three assessment points (see Appendix C). It is comprised of 52 statements describing various ways people actually cope with a specific stressor. Subjects respond to each item, with respect to how often they used a particular coping strategy in a specified time frame. Ratings are made on a 5-point rating scale with the following range of options: **does not apply/never** (0), **rarely** (1), **sometimes** (2), **often** (3), and **very often** (4). Although Dunkel-Schetter (1987) allowed her subjects to specify the cancer-related stressor, in this study the stressor was specified by the investigator.
Table 1

Temporal Schedule of the Administration of Measures and Forms

<table>
<thead>
<tr>
<th></th>
<th>Time 1</th>
<th>Time 2</th>
<th>Exam</th>
<th>Time 3</th>
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<tbody>
<tr>
<td>Informed consent</td>
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<td>Physicians’ evaluations</td>
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<tr>
<td>Release of information</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Demographic information</td>
<td></td>
<td></td>
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<tr>
<td>LOT</td>
<td></td>
<td></td>
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<tr>
<td>POMS-bipolar</td>
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<td>POMS-bipolar</td>
<td>POMS-bipolar</td>
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<td>SCS</td>
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<tr>
<td>STAI</td>
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<td>STAI</td>
<td>STAI</td>
<td></td>
</tr>
<tr>
<td>(trait and state anxiety)</td>
<td></td>
<td>(state anxiety only)</td>
<td>(state anxiety only)</td>
<td></td>
</tr>
<tr>
<td>BSI</td>
<td></td>
<td>BSI</td>
<td>BSI</td>
<td></td>
</tr>
<tr>
<td>WOC-CA</td>
<td></td>
<td>WOC-CA</td>
<td>WOC-CA</td>
<td></td>
</tr>
<tr>
<td>Orientation to health and illness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship Inventory/modified PAIS-SR</td>
<td>Relationship Inventory/exam concerns</td>
<td>Relationship Inventory/exam assessment</td>
<td>MISS</td>
<td></td>
</tr>
</tbody>
</table>

Note. LOT = Life Orientation Test; POMS-bipolar = Profile of Mood States–Bipolar Version; STAI = Spielberger State/Trait Anxiety Inventories; BSI = Brief Symptom Inventory; WOC-CA = Ways of Coping Inventory for Cancer Patients; PAIS-SR = Modified Psychological Adjustment to Illness Scale: Self-Report; and MISS = Medical Interview Satisfaction Scale.
Subjects were asked to describe how they coped with “fear and uncertainty about the future due to cancer.” Before endorsing coping strategies, subjects were asked to specify at Time 1 how stressful this specific stressor had been for them in the last month, at Time 2 the time frame was since they were last interviewed, and at Time 3 it was since the doctor’s appointment. Responses to this question were on a 5-point scale which ranged from (1) extremely stressful to (5) not stressful. Therefore, all subjects were responding to the same stressor in the same time period relative to the exam.

Just as with the revised 66-item Ways of Coping Questionnaire (WOC; Folkman et al., 1986; Lazarus & Folkman, 1984), the WOC-CA was factor analyzed (oblique rotation was selected to permit correlation among factors) by Dunkel-Schetter (1987; Dunkel-Schetter et al., 1992) for the data obtained from the 603 subjects in her sample. A five-factor solution best fit the data and was most consistent with earlier research. Dunkel-Schetter and her colleagues (1992) labeled the factors Seek and Use Social Support, Focus on the Positive, Distancing, Cognitive Escape-Avoidance, and Behavioral Escape-Avoidance. The factor scores, reflecting both the number of strategies used of a particular type, as well as the frequency of their use, were computed based on the factor loadings. Dunkel-Schetter et al. also calculated proportional scores; a computation of each subject’s total coping efforts of each of the five types.

The relatively small number of subjects (i.e., 80) in the present study precluded factor analyzing the WOC-CA based on the data collected here. It was hoped that Dunkel-Schetter’s five-factor solution could be used. However, after preliminary analyses it became clear that each factor contained items that were not conceptually connected to the strategy the
factor was purporting to describe and indeed, had a factor loading below .50. Therefore, it
was decided to use a modified version of Dunkel-Schetter's five-factor solution (Dunkel-
Schetter, 1987; Dunkel-Schetter, et al., 1992) for scoring the WOC-CA in the present study.
Specifically, items which loaded below .50 on a particular factor were eliminated and the
resultant refined five factors contained a total of 27 items (reduced from 49). Refined factors,
factor loadings, and item descriptions are listed in Table 2.

2. Assessment of anxiety, psychological adjustment, and somatic distress. The
Spielberger State/Trait Anxiety Inventory (STAI) was used to assess trait anxiety at Time 1
and state anxiety at Times 1, 2, and 3. In addition, the Profile of Mood States (POMS-
Bipolar version; Lorr & McNair, 1982), and the Brief Symptom Inventory (BSI) (Derogatis &
Spencer, 1982) were administered at all three times. A Fear of Recurrence (FOR)
Questionnaire (Northouse, 1981) was completed at Time 1 in order to specifically assess
patients' concerns regarding current health status. Finally, questions in the interview at Time 2 explored what the patients' expectations were for the doctor's visit, and what aspects of the exam made them anxious.

Developed by Spielberger, Gorush, and Lushene (1970), the STAI (see Appendix D) is the most frequently employed index of anxiety (Buros, 1978). It is a self-report test divided into two subtests, each consisting of 20 brief items. The first subtest measures state anxiety (A-State) and instructs subjects to respond as to how they feel at the moment they are filling out the questionnaire. The other subtest measures trait anxiety (A-Trait) and asks respondents to answer according to how they generally feel. For both subtests, subjects report the frequency of specific symptoms indicating the presence (e.g., “I feel nervous”) or
Table 2

**Refined Coping Factors Derived from the WOC-CA**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Item number</th>
<th>Item description</th>
<th>Factor loading</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seek and use</td>
<td>4</td>
<td>Talked to someone to find out more</td>
<td>.80</td>
</tr>
<tr>
<td></td>
<td>34</td>
<td>Talked to someone about how feeling</td>
<td>.80</td>
</tr>
<tr>
<td></td>
<td>22</td>
<td>Talked to someone who could do something</td>
<td>.72</td>
</tr>
<tr>
<td></td>
<td>20</td>
<td>Let my feelings out somehow</td>
<td>.68</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>Tried to get professional help</td>
<td>.58</td>
</tr>
<tr>
<td></td>
<td>49</td>
<td>Tried to find out as much as I could</td>
<td>.53</td>
</tr>
<tr>
<td>Social support (8 items)</td>
<td>13</td>
<td>Looked for sympathy or understanding</td>
<td>.52</td>
</tr>
<tr>
<td></td>
<td>31</td>
<td>Asked a friend or relative for advice</td>
<td>.52</td>
</tr>
<tr>
<td>Cognitive escape-avoidance (4 items)</td>
<td>7</td>
<td>Hoped a miracle would happen</td>
<td>.60</td>
</tr>
<tr>
<td></td>
<td>44</td>
<td>Prayed</td>
<td>.59</td>
</tr>
<tr>
<td></td>
<td>45</td>
<td>Prepared for the worst</td>
<td>.56</td>
</tr>
<tr>
<td></td>
<td>42</td>
<td>Wished situation would go away/be over</td>
<td>.54</td>
</tr>
<tr>
<td>Distancing (6 items)</td>
<td>40</td>
<td>Tried to keep my feelings from interfering</td>
<td>.69</td>
</tr>
<tr>
<td></td>
<td>30</td>
<td>Didn’t let it get to me; refused to think about</td>
<td>.65</td>
</tr>
<tr>
<td></td>
<td>33</td>
<td>Made light of it; refused to get too serious</td>
<td>.59</td>
</tr>
<tr>
<td></td>
<td>9</td>
<td>Went on as if it were not happening</td>
<td>.58</td>
</tr>
<tr>
<td>Factor</td>
<td>Item number</td>
<td>Item description</td>
<td>Factor loading</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-------------</td>
<td>-------------------------------------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>Distancing (continued)</td>
<td>10</td>
<td>Tried to keep my feelings to myself</td>
<td>.58</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>Looked for the silver lining/bright side</td>
<td>.51</td>
</tr>
<tr>
<td>Focus on the positive (6 items)</td>
<td>26</td>
<td>Found new faith</td>
<td>.77</td>
</tr>
<tr>
<td></td>
<td>27</td>
<td>Rediscovered what is important in life</td>
<td>.71</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>Changed, as grew as a person in a good way</td>
<td>.70</td>
</tr>
<tr>
<td></td>
<td>41</td>
<td>Changed something about myself</td>
<td>.62</td>
</tr>
<tr>
<td></td>
<td>21</td>
<td>Came out of experience better than before</td>
<td>.57</td>
</tr>
<tr>
<td></td>
<td>28</td>
<td>changed something so things will turn out</td>
<td>.57</td>
</tr>
<tr>
<td>Behavioral-escape avoidance (3 items)</td>
<td>29</td>
<td>Avoided being with people</td>
<td>.62</td>
</tr>
<tr>
<td></td>
<td>23</td>
<td>Tried to make myself feel better by eating, drinking, smoking, or drug use</td>
<td>.57</td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>Took a big chance and did something risky</td>
<td>.55</td>
</tr>
</tbody>
</table>

**Note.** Factors are adapted from Dunkel-Schetter (1987) and Dunkel-Schetter et al. (1992).

absence (e.g., "I feel calm") of anxiety on a 4-point scale (not at all = 1, somewhat = 2, moderately so = 3, and very much so = 4). Scoring the STAI is simply a matter of adding the values assigned to each statement together, depending on the phrasing of the statements (i.e., whether endorsement of the item indicates more or less anxiety). Higher scores on each subtest indicate higher levels of anxiety.
The STAI has been found to be a valid and reliable measure of both state and trait anxiety for a variety of adult populations (Spielberger et al., 1970). Test-retest reliability coefficients for the trait anxiety scale ranged from .73 to .86 for administrations of this scale separated by periods of time from one hour to 104 days. Estimates of internal consistency were also high with reported alpha coefficients in the .80s and .90s. Intercorrelations with other popular measures of anxiety such as the IPAT Anxiety Scale (Cattell & Scheir, 1963) and the Taylor Manifest Anxiety Scale (Taylor, 1953) ranged from .75 to .83, suggesting reasonable construct validity. Test-retest reliabilities for the state anxiety scale were predictably low, ranging from .16 to .54, due to the scale’s transitory nature. Spielberger et al. (1970) obtained normative data from high school and college students, neuropsychiatric patients, young prisoners, and general medical and surgical patients.

The Profile of Mood States—Bipolar Version (POMS-BI; Lorr & McNair, 1982) is a list of 72 adjectives or phrases designed to measure six bipolar subjective mood states (see Appendix E). Respondents rate each adjective based on what they experienced during the past week including today, on a 4-point scale: much like this (3), slightly like this (2), slightly unlike this (1), and much unlike this (0). The six bipolar subscales are: composed/anxious, agreeable/hostile, elated/depressed, confident/unsure, energetic/tired, and clearheaded/confused. Since the scales are bipolar, a scale score is the sum of positive item scores minus the sum of negative item scores, plus a constant of 18 (to make all possible scores a positive number).

The Bipolar and Monopolar POMS have been utilized in past studies with chronically ill populations and have acceptable validity and reliability for measuring various mood states.
(Dunkel-Schetter, 1987; Dunkel-Schetter et al., 1992; Goldberg, 1974; Levy, Herberman, Maluish, Schlien, & Lippman, 1985). Test-retest reliability varies from .65 to .74. Predictive and construct validity were determined from studies of brief psychotherapy, outpatient drug trials, studies of response to emotion-inducing conditions, and studies of concurrent validity coefficients and POMS correlates. Norms for cancer patients have been established by Weisman, Worden, & Sobel (1980).

The Brief Symptom Inventory (BSI) (Derogatis & Spencer, 1982), a shortened version of the SCL-90-R, was administered at all three assessment points (see Appendix F). It measures psychiatric symptoms of depression, anxiety, somatization, interpersonal sensitivity, hostility, phobic anxiety, paranoid ideation, and psychoticism. The BSI consists of 53 items, each describing a different symptom. Subjects respond to each item on a 5-point scale of distress (not at all=0, a little bit=1, moderately=2, quite a bit=3, and extremely=4), based on how much each problem bothered them in the past 7 days including today. Twelve sums of item scores, representing the 9 dimensions and 3 global indices of the BSI, are computed using score/profile forms. Raw scores can be transformed into t-scores. The General Severity Index (GSI) is the single best global index of distress associated with the BSI. It combines information on the number of symptoms and the intensity of perceived distress. Normative data is available for psychiatric outpatients and inpatients, and for non-patient normal subjects.

Derogatis and Spencer (1982) reported that alpha coefficients for all nine dimensions on the BSI ranged from a low of .71 on the psychoticism dimension to a high of .85 for depression. Test-retest reliability coefficients, over a two-week interval, ranged from a low
of .68 for somatization to a maximum of .91 for phobic anxiety. The stability for the GSI was .90, indicating that the BSI is a reliable measure over time.

Correlations between the SCL-90-R and the BSI are uniformly high across all nine dimensions, as would be expected. In terms of validity, high convergence between BSI scales and like dimensions of the MMPI provide good evidence of convergent validity. Factor analytic studies of internal structure of the inventory contribute evidence of construct validity (Derogatis & Spencer, 1982).

The Fear of Recurrence (FOR) Questionnaire (Northouse, 1981) is comprised of 22 items which assess cancer patients' fear of disease recurrence (see Appendix G). Patients respond to items on a 5-point scale anchored by strongly agree at one end and strongly disagree at the other. Although it was originally designed for mastectomy patients, the questionnaire was adapted for all cancer patients in this study: In three questions where the words breast cancer or mastectomy are used, the word cancer was substituted. It was not expected that this minor change would influence the reliability or validity of the questionnaire (L. Northouse, personal communication, May 16, 1987).

Scoring is an additive function of responses to each item (half the items have a reverse scoring pattern). The range of possible scores is 22 to 110, with higher scores indicating a greater fear of recurrence. Hilton (1986) reported a Cronbach's alpha of .92 with a sample of 227 initial diagnosis breast cancer patients. Her data yielded moderate correlations between the Fear of Recurrence Questionnaire and Mishel’s Uncertainty in Illness Scale. Unfortunately, while there was little available information on reliability and validity, the questionnaire was the only available one designed to directly assess fear of recurrence, a
major area of interest in this study. According to Northouse (L. Northouse, personal communication, October 1, 1997), there have been no recent problems reported with respect to reliability and validity for the Fear of Recurrence Questionnaire (see Hilton, 1989).

3. Assessment of dispositional optimism and learned resourcefulness. The Life Orientation Test (LOT) designed by Scheier and Carver (1985) was administered at Time 1 to assess degree of dispositional optimism, defined in terms of generalized outcome expectancies (see Appendix H). The LOT consists of 12 items, 4 of which are filler items included to disguise the underlying purpose of the test. Respondents indicate the extent to which they agree with each item using the following response format: 4 = strongly agree, 3 = agree, 2 = neutral, 1 = disagree, and 0 = strongly disagree. The higher the score, the more optimistic the subject.

Cronbach's alpha for the entire 8-item scale was .76 in a sample of 624 undergraduate subjects. The test-retest correlation coefficient, over a 4-week interval, was .79 in a sample of 142, and .72 over a period of 13 weeks in a sample of 182. A variety of correlations have also been obtained between the LOT and other measures, bearing on convergent and discriminant validity such as the Beck Depression Inventory (BDI) and a measure of hopelessness (Beck, Weissman, Lester, & Trexler, 1974). The psychometric properties of the LOT were established based on data from undergraduate students, but the scale has been used with other adult populations, including cancer patients (see Carver et al., 1993; Scheier et al., 1989).

The Self-Control Schedule (SCS; Rosenbaum, 1980) was used to measure individual tendencies to apply self-control methods (e.g., the use of cognitions and self-statements) to
the solution of behavioral problems (see Appendix I). The SCS is a 36-item instrument which covers the following content areas: (a) use of cognitions and self-instructions to control emotional and physiological responses, (b) application of problem solving strategies (e.g., planning, problem definition, evaluating alternatives, and anticipation of consequences), (c) ability to delay immediate gratification, and (d) a general belief in one’s ability to self-regulate internal events (Rosenbaum, 1980; Rosenbaum & Ben-Ari, 1986).

Subjects respond to each item based on their general reactions to a variety of behavioral problems (e.g., dealing with unpleasant thoughts, bad habits). Subjects respond to each item on a six-point scale from very characteristic of me, extremely descriptive (+3) to very uncharacteristic of me, extremely nondescriptive (-3). Subjects’ scores on each item are added to yield a total SCS score. A high score on the SCS is indicative of high self-management capability. Although, based on factor analysis, there is some indication that the SCS is a multidimensional instrument, there have been problems noted with the reliability of the subscales (Redden, Tucker, & Young, 1983; Richards, 1985). Therefore, just the total SCS score will be used in the present research.

The reliability and validity for the Hebrew version of this scale were well established in a series of studies by Rosenbaum and his associates (Rosenbaum, 1980a, 1980b; Rosenbaum & Ben-Ari, 1985; Rosenbaum & Palmon, 1984) and for the English version of the scale (Redden et al., 1983; Richards, 1985). Test-retest reliability over a 4-week period was .86. Internal consistency was satisfactory (alpha coefficients of .78 to .84) (Rosenbaum, 1980). The scores on the SCS varied depending on whether the sample consisted of a college students or older adults, suggesting large individual differences in self-control behaviors as
assessed by the SCS (e.g., students typically having lower self-control). Acceptable validity of the SCS was achieved by correlations with other self-report scales and by subjects’ responses in a cold pressor experiment.

4. **Assessment of patient/medical staff relationship.** After the exam (Time 3), subjects filled out the Medical Interview Satisfaction Scale (MISS; Wolf, Putman, James, & Stiles, 1978). This scale was developed to measure patient satisfaction after an encounter with a physician or other primary care provider (see Appendix J). The instrument assesses satisfaction on three levels: cognitive, affective, and behavioral. When using the full instrument, a global score and three subscale scores are obtained. Cognitive items refer to the doctor’s explanations and information, and the patient’s understanding of the illness and treatment (e.g., “This doctor is very good at explaining the reasons for medical tests”). Affective items refer to the patient’s perception of the treatment relationship (e.g., “I really felt understood by my doctor”). Behavioral items measure the patient’s evaluation of the physician’s professional behavior, physical exam, procedures, etc. (e.g., “The doctor gave me a thorough check up”). Responses to each item are on a 5-point scale ranging from *strongly agree* to *strongly disagree*. Higher scores indicate more satisfaction with the medical encounter. The overall reliability of the scale (Cronbach’s alpha) is .93. Unfortunately, the full scale was not relevant for nonrecurrent patients (i.e., because certain questions refer to a present illness) and therefore subjects responded to only 18 of the 26 questions. Consequently, the subjects’ responses to this abbreviated questionnaire will be treated as preliminary.
Additional questions regarding subjects’ assessments of their relationships with medical personnel and significant others were derived from the Psychological Adjustment to Illness Scale Self-Report (PAIS-SR; Derogatis, 1983; see Appendix K for the selected questions) and administered at Time 1. The PAIS-SR was designed to assess medically ill patients’ overall psychosocial adjustment. The complete questionnaire, which consists of 46 items, was not used because several of the questions are not relevant to cancer patients in remission. A total of 17 questions from the PAIS-SR were used regarding quality of medical care and amount of information received (6 questions), changes in social support due to the illness (5 questions), and quality of sexual relationship with spouse (6 questions). Questions had four or five multiple choice responses. Scores were summed for each of these categories.

At all time points, several questions about patients’ social relationships and support systems were also asked on forms labeled, Relationship Inventory/Exam Concerns—Assessment (see Appendixes L and M). The primary investigator wrote these questions and they were included as an introductory exploration of social support issues in women in remission for breast and colorectal cancer. Subjects were asked to list the initials of all persons (e.g., family members, friends, and others) who provided support or assistance regarding the patients concerns about her experience with cancer in general (asked at Time 1), and concerns about the follow-up exam specifically (asked at Time 2 and Time 3). At all three times, they were asked to specify what type of support the individual had provided (e.g, emotional, informational, tangible) and were asked to rate the quality of the support received on a scale from 1 (excellent) to 4 (poor).
Patients were also asked on the same Relationship Inventory forms at Times 2 and 3 about their specific concerns and experiences regarding the upcoming (Time 2) or completed (Time 3) exam. Specifically at Time 2, patients were asked how concerned they were about their upcoming exam on a scale from 0 (not at all concerned) to 10 (as concerned as could be), what they were most concerned about (open-ended question), if they had discussed their concerns with anyone (response of yes or no), and if they deliberately avoided discussing their concerns with anyone (again, yes or no response). At Time 3, they were asked to describe the follow-up exam in terms of what it was like for them emotionally in sentences and to also choose from a list of five options (from much better than I expected to much worse than I expected).

5. Assessment of orientation to disease and the likelihood of recurrence. Questions were included at Time 1 to assess the patient’s appraisal of the time line of cancer (e.g., cyclic, chronic, or acute; Leventhal et al., 1986). Basically, patients were asked to describe cancer as chronic (like diabetes), acute (like the measles), or cyclic (like allergies). In addition, questions written by the author were included which assessed what situations elicited anxiety about cancer (e.g., visiting the physician, reading about cancer), what factors subjects believed may have caused the cancer initially (e.g., heredity, diet), what strategies they used to prevent the cancer from recurring (e.g., special diet, avoiding stress), and their evaluation of the chance that the cancer would recur (on a 10-point scale with definitely not at one anchor and definitely will at the other (see Appendix N).

6. Assessment of other factors of interest. Basic demographic information (e.g., age, marital status, place of residence) was obtained from patients during the initial interview (see
Appendix O). In addition, medical records yielded information regarding date of initial diagnosis, site and stage of disease, treatment received, physician’s name, and next scheduled appointment time. An authorization to release medical information was obtained from each subject (see Appendix P) in addition to a full informed consent to participate in the research (see Appendix Q).

7. Physicians' judgments of patients’ medical and emotional status. A letter and brief questionnaire were mailed to each patient’s physician to assess medical prognosis, how anxious the patient appeared to be during the exam, how the physician would describe the quality of his/her relationship with the patient, and how the physician thinks the patient would describe the quality of the relationship (four questions total). The physicians were asked to complete the evaluations immediately after the exam (see Appendix R) and mail back the completed forms. Due to follow-up exams with primary care physicians in a number of small towns, 21 different physicians completed questionnaires, although 3 oncologists accounted for 50 of the subjects. Assessments were completed for 67 (84%) subjects.

Responses were marked on four Visual Analog Scales (VAS; Scott & Huskisson, 1976). The VAS consists of a 10 cm. line with the left end labeled excellent or no anxiety and the right end labeled extremely poor or anxiety as bad as it could be. The physicians indicated their evaluations by placing a mark somewhere along the line between the two endpoints. Ratings on the VAS are measured in millimeters from the left endpoint to the respondent’s mark. Hence, scores on the VAS can range from zero to 100. The Visual
Analog Scale may enhance the sensitivity of the measurement possible, especially when compared to numerical and categorical rating scales (Scott & Huskisson, 1976).
First, descriptive results are presented regarding measures of worry, fear, anxiety, and other distress. Intercorrelations among these dependent measures are reported, as are patterns in reported anxiety across time. Variables associated with individual differences on these measures are presented with respect to changes in anxiety across time, and the relationship between subjects' conceptualization of the time line of cancer and measures of distress are reported. Second, results from coping measures are summarized in the same format as described above: The data are presented descriptively, then intercorrelations between factors from the WOC-CA are reported, changes in coping patterns across time are then examined, as are individual differences with respect to coping behavior and the relationship between the time line variable and coping. In the third section, the relationship between measures of coping and measures of distress, worry, fear, and anxiety are addressed. Finally, in the last section, the time line variable is explored in more detail. Data pertaining to specific hypotheses are presented in the appropriate sections corresponding to the research questions.

Every subject who enrolled in the study (n = 80) completed all phases of the research at the three assessment points. Data from the single subject diagnosed with a recurrence were excluded from analyses in order to maintain the homogeneity of the sample. Thus, the total sample included 59 women originally diagnosed with breast cancer and 20 women with colorectal cancer.
Overview and Descriptive Data

Means and standard deviations for the primary study variables for the two disease sites are shown in Table 3. It was predicted that disease site would be related to outcome measures, but the only significant difference between the two groups was that colorectal patients rated the quality of their sexual relationships with their partners higher than breast cancer patients ($t(62) = -2.3, p = .03$). There were also no differences between the two groups on the coping measures that will be discussed in subsequent analyses.

Table 3

Means and Standard Deviations for Primary Study Variables for Breast and Colorectal Groups

<table>
<thead>
<tr>
<th>Variable</th>
<th>Breast</th>
<th>Colorectal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Fear of Recurrence Questionnaire</td>
<td>70.48</td>
<td>15.10</td>
</tr>
<tr>
<td>Life Orientation Test</td>
<td>21.56</td>
<td>3.97</td>
</tr>
<tr>
<td>Estimate of recurrence likelihood</td>
<td>3.80</td>
<td>2.20</td>
</tr>
<tr>
<td>Fear of exam</td>
<td>3.80</td>
<td>3.10</td>
</tr>
<tr>
<td>Self-control schedule</td>
<td>37.97</td>
<td>21.20</td>
</tr>
</tbody>
</table>

(table continues)
Table 3 (continued)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Breast</th>
<th>Colorectal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Cancer worry composite score</td>
<td>21.34</td>
<td>14.34</td>
</tr>
<tr>
<td>Trait anxiety</td>
<td>35.02</td>
<td>9.80</td>
</tr>
<tr>
<td>State anxiety, Time 1</td>
<td>30.34</td>
<td>9.50</td>
</tr>
<tr>
<td>State anxiety, Time 2</td>
<td>33.83</td>
<td>13.00</td>
</tr>
<tr>
<td>State anxiety, Time 3</td>
<td>32.49</td>
<td>13.23</td>
</tr>
<tr>
<td>POMS-composed/anxious, Time 1</td>
<td>24.42</td>
<td>7.76</td>
</tr>
<tr>
<td>POMS-composed/anxious, Time 2</td>
<td>23.85</td>
<td>8.49</td>
</tr>
<tr>
<td>POMS-composed/anxious, Time 3</td>
<td>25.34</td>
<td>8.53</td>
</tr>
<tr>
<td>Doctors’ ratings of prognosis</td>
<td>20.59</td>
<td>11.42</td>
</tr>
<tr>
<td>Doctors’ ratings of anxiety</td>
<td>29.94</td>
<td>23.40</td>
</tr>
<tr>
<td>Quality of sexual relationship</td>
<td>16.85</td>
<td>2.64</td>
</tr>
</tbody>
</table>

*Note. n = 59 for breast and n = 20 for colorectal for all variables except Doctors’ ratings of prognosis/anxiety where n = 51 for breast and n = 15 for colorectal. Lower scores for the POMS indicate more distress.

*p < .05

The next analyses examined any differences in the primary study variables based on stage of disease at initial diagnosis (see Table 4). Forty-six subjects were described as having localized and 33 as regional metastatic disease based on information recorded at initial diagnosis. This differentiation between the two groups was supported by doctors’ prognoses given after the follow-up examinations. Doctors returned evaluations for 35 localized and 31...
### Table 4

**Means and Standard Deviations for Primary Study Variables for Localized and Regional Metastatic Groups**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Localized</th>
<th></th>
<th>Metastatic</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Fear of Recurrence Questionnaire</td>
<td>71.80</td>
<td>14.83</td>
<td>68.15</td>
<td>15.14</td>
</tr>
<tr>
<td>Life Orientation Test</td>
<td>21.35</td>
<td>3.50</td>
<td>21.42</td>
<td>5.02</td>
</tr>
<tr>
<td>Estimate of recurrence likelihood</td>
<td>3.31</td>
<td>2.15</td>
<td>4.06</td>
<td>2.23</td>
</tr>
<tr>
<td>Fear of exam</td>
<td>4.41</td>
<td>3.13</td>
<td>3.82</td>
<td>3.34</td>
</tr>
<tr>
<td>Self-control schedule</td>
<td>35.57</td>
<td>22.81</td>
<td>43.70</td>
<td>18.80</td>
</tr>
<tr>
<td>Cancer worry composite score</td>
<td>19.83</td>
<td>14.61</td>
<td>20.33</td>
<td>13.86</td>
</tr>
<tr>
<td>Trait anxiety</td>
<td>35.30</td>
<td>10.29</td>
<td>32.55</td>
<td>8.30</td>
</tr>
<tr>
<td>State anxiety, Time 1</td>
<td>31.09</td>
<td>9.24</td>
<td>28.46</td>
<td>9.19</td>
</tr>
<tr>
<td>State anxiety, Time 2</td>
<td>35.61</td>
<td>13.59</td>
<td>31.33</td>
<td>10.42</td>
</tr>
<tr>
<td>State anxiety, Time 3</td>
<td>31.83</td>
<td>13.20</td>
<td>32.12</td>
<td>11.37</td>
</tr>
<tr>
<td>POMS-composed/anxious, Time 1</td>
<td>23.09</td>
<td>8.15</td>
<td>25.88</td>
<td>6.48</td>
</tr>
<tr>
<td>POMS-composed/anxious, Time 2</td>
<td>22.41</td>
<td>9.07</td>
<td>25.12</td>
<td>6.87</td>
</tr>
<tr>
<td>POMS-composed/anxious, Time 3</td>
<td>25.23</td>
<td>8.82</td>
<td>25.58</td>
<td>7.25</td>
</tr>
<tr>
<td>Doctors’ ratings of prognosis</td>
<td>16.31</td>
<td>12.01</td>
<td>25.61</td>
<td>9.9*</td>
</tr>
<tr>
<td>Doctors’ ratings of anxiety</td>
<td>33.29</td>
<td>21.87</td>
<td>27.97</td>
<td>22.65</td>
</tr>
<tr>
<td>Quality of sexual relationship</td>
<td>17.60</td>
<td>2.50</td>
<td>16.82</td>
<td>2.90</td>
</tr>
</tbody>
</table>

**Note.** \(n = 46\) for localized disease and \(n = 33\) for regional metastatic disease for all variables except Doctors’ ratings of prognosis/anxiety where \(n = 35\) for localized disease and \(n = 31\) for regional metastatic disease. Lower scores for the POMS indicate more distress.

\*\(p < .001\).
metastatic disease patients. Those with localized disease were rated by their physicians as having a significantly better prognosis than those with regional metastatic disease ($t (64) = -3.44, p < .001$). There were no other significant differences on any of the primary study variables between localized and regional metastatic disease subjects in these analyses and therefore these two groups are combined for subsequent analyses.

Means, standard deviations, and ranges for the primary study variables for the entire sample are presented in Table 5. Since the major focus of the present research was distress and coping associated with fear of disease recurrence, subjects were asked at Time 1 how much they had worried over the past month about the possibility of the cancer coming back. On a scale of 0 (never) to 10 (all the time) the mean response was 3.57 with a range of 0 to 10 (SD = 3.17). They were also asked how much they worried “about the possibility of the cancer coming back” when visiting their physician ($M = 4.68, SD = 3.27$), when they felt physically sick ($M = 3.71, SD = 3.17$), when they read or heard about cancer in the media ($M = 3.66, SD = 3.16$), and when they heard that someone they knew had cancer ($M = 4.42, SD = 3.28$).

These five questions regarding how much subjects worried about recurrence in general and in specific situations were all assessed on the same scale and equally weighted. Intercorrelations among these five items ranged from .65 to .85. The computed coefficient alpha, .93, indicates a high degree of internal consistency. Therefore, it was concluded that the five worry items were basically measuring the same construct and that the data could be reduced to one measure of “cancer worry.” Scores, which were summed for these five
Table 5

**Descriptive Statistics for Primary Study Variables: Complete Sample**

<table>
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<th>Variable</th>
<th>Mean</th>
<th>Observed range</th>
<th>Potential range</th>
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<td>Quality of sexual relationship</td>
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<td>5 - 20</td>
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*Note. N = 79 for all variables except Doctors’ ratings of prognosis/anxiety where n = 66.*

variables, ranged from 0 to 50 with a mean of 20.04 (SD = 14.21). This variable is referred to as the **cancer worry composite score**.

At Time 1, when asked to estimate the likelihood that their cancer would recur, with 0 indicating **definitely will not** and 10 **definitely will**, the mean response was 3.64 with a range...
Sixty-two subjects described what information they utilized to assess their recurrence estimates (the other 17 subjects did not respond to the question). Subjects could only endorse one choice. Fifty-seven percent of the women who responded based their views on doctors’ comments and/or cancer statistics in the medical literature. The remainder assessed their present health status (13%), a “gut feeling or woman’s intuition” (18%), diet/exercise (7%), or family history (5%).

With regard to the upcoming medical follow-up itself, when subjects were asked in the Relationship Inventory Form at Time 2 (i.e., mean of 1.5 days prior to the exam) how concerned they were about the upcoming exam, subjects reported a moderate amount of concern. The mean response was 4.17 (SD = 3.21) on a scale from 0 (not at all concerned) to 10 (as concerned as I could be) with a range of 0 to 10. Fifty-seven subjects (72.2%) reported that their greatest concern about the exam was that the doctor would detect a recurrence of the cancer. Only four subjects (5%) feared pain from the exam itself and, not surprisingly, those four subjects were colorectal patients who anticipated uncomfortable exams. Of the remaining subjects, 16 (20%) stated that they had no concerns and 2 (3%) reported that they were most concerned about being at Carle Clinic. At Time 3, a mean of 14.5 days after the exam, half of the subjects reported that they were nervous and anxious during the exam. Thirty-three (41.8%) stated that the exam was routine and they felt little upset. Two subjects described it as “a relief” and the four colorectal subjects who expected it to be painful did indeed characterize it as painful, yet they reported no anxiety regarding future prognosis. Overall, most subjects (70%) concluded that the exam was what they expected.
With respect to hypotheses regarding the number of disease-free months prior to the exam, Pearson Product moment correlations were computed between time since diagnosis (in months) and scores on the FOR ($r = -.05$), the LOT ($r = .03$), the cancer worry composite score ($r = -.17$), trait ($r = .05$) and state anxiety ($r = .12$ at Time 1, $r = -.03$ at Time 2, and $r = -.02$ at Time 3), and the depression subscale of the BSI ($r = -.10$). No significant correlations were found (all $p$ values were greater than .05). While most of these measures were administered at Time 1 only, the state anxiety measures were given at Time 2 and Time 3 also. Thus having survived the disease for a longer period of time was not associated with less fear of recurrence, anxiety, depression, or more optimism. Similarly, age was not significantly related to any of the aforementioned variables, other than the small difference between breast and colorectal patients which was reported earlier. Younger women did not report more fear of recurrence, anxiety, or depression than older women.

**Correlations Between Primary Study Measures of Distress**

Intercorrelations between measures assessing worry, fear, anxiety, and other measures of distress and optimism are presented in Table 6. Not surprisingly, given that most all of the instruments in this study assessed various manifestations of distress, there were statistically significant intercorrelations among many of the measures (all $p$'s $< .05$). There were significant positive correlations between the Fear of Recurrence (FOR) Questionnaire administered at Time 1 and measures of trait anxiety, state anxiety at all three times, subjects’ recurrence estimates, how much subjects feared the exam, the General Severity Index (GSI)
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<th>State anxiety</th>
<th>Estimate of recurrence</th>
<th>Fear of exam</th>
<th>GSI</th>
<th>&quot;Worry&quot;</th>
<th>LOT</th>
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**Primary Study Measures**

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**1.000**

**.67*** .1.000

**.62*** .69 *** .1.000

**.29* .28* .30** .1.000

**.26* .27* .08 .31** .1.000

**.71*** .66*** .69 *** .23 .21 .1.000

*(table continues)*
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* p < .05, ** p < .01, *** p < .001.
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1.
of the Brief Symptom Inventory (BSI) at all three times, and the cancer worry composite score. The FOR correlated negatively with the Life Orientation Test (LOT), the Self-Control Schedule (SCS), and the Composed-Anxious Scale of the POMS-BI at all three points of assessment. These negative correlations were expected due to the scoring direction for LOT, SCS, and the POMS-BI (i.e., higher scores indicated more optimism, more self-control, and less anxiety).

Similarly, in addition to the FOR, the LOT was significantly correlated with trait anxiety, estimate of recurrence, SCS, the cancer worry composite score, state anxiety at all three times, the GSI at all three times, and the Composed-Anxious Scale of the POMS at all times. The cancer worry composite score was also highly correlated with subjects' estimates of disease recurrence, fear of the exam, state anxiety at all three times, the GSI at Time 1, the Composed-Anxious Scale of the POMS-BI at Time 2, SCS, and trait anxiety.

Doctors' ratings of patients' anxiety during the exams correlated positively with the FOR, how much patients stated they feared the exam, trait anxiety, state anxiety at Time 1 and Time 2, the GSI at all three times, and the Composed-Anxious Scale of the POMS-BI at Time 1 and Time 2.

With respect to correlations not listed in Table 6, depression scores, as assessed with the depression subscale of the BSI, were significantly correlated with the Elated-Depression scale of the POMS-BI at Time 1 ($r = -.68, p < .001$), Time 2 ($r = -.72, p < .001$), Time 3 ($r = -.74, p < .001$), trait anxiety ($r = .79, p < .001$), state anxiety at Time 1 ($r = .74, p < .001$), Time 2 ($r = .79, p < .001$), Time 3 ($r = .74, p < .001$), the LOT ($r = -.45, p < .001$), SCS
(r = -.59, p < .001), FOR (r = .32, p = .004), subjects’ estimates of recurrence likelihood (r = .23, p = .05), and doctors’ ratings of subjects’ anxiety during the exam (r = .30, p = .01).

As would be expected, the other five subscales of the POMS-BI (i.e., agreeable-hostile, elated-depressed, confident-unsure, energetic-tired, and clearheaded-confused) were also significantly correlated with indices of worry and anxiety. The six subscales were highly intercorrelated; when subjects reported distress, they did so consistently across scales. In summary, most all measures of distress, optimistic outlook, and self-control were associated in the anticipated direction.

Patterns in Reported Anxiety Across Time

A one-way repeated measures ANOVA indicated that subjects’ state anxiety scores did indeed change (see Figure 1) across assessments from Time 1 (M = 29.99, SD = 9.25) to Time 2 (M = 33.82, SD = 12.47) to Time 3 (M = 31.95, SD = 12.4) (F (2,156) = 6.23, p = .002). Post hoc tests (paired t-tests) showed that the difference in means between Time 1 and Time 2 is significant (t (78) = -3.7, p < .001). Similarly, a one-way repeated measures ANOVA with scores on the Composed-Anxious scale of the POMS-BI as the dependent measure, indicated change across time (see Figure 2) with a mean of 24.25 at Time 1 (SD = 8.28), 23.54 at Time 2 (SD = 8.15), and 25.37 at Time 3 (SD = 7.58) (F (2, 156) = 3.48, p = .03). For this analysis, post hoc tests indicated that there was a significant difference between the means at Time 2 and Time 3 (t (78) = -2.4, p < .05). Although the pattern of anxiety is somewhat different for the state anxiety measure and the Composed-Anxious scale
Figure 1. Mean state anxiety scores at three times.

Figure 2. Mean POMS-BI composed-anxious scores at three times. Note. Lower scores indicate more anxiety.
of the POMS-BI, the crux of these analyses is that Time 2 is the most stressful point. No other scale on the POMS-BI showed any significant changes over time.

In addition, a one-way repeated measures ANOVA was performed on subjects’ responses to the question on the WOC-CA regarding how much stress they had experienced because of “fear and uncertainty about the future due to cancer” at the three time points. As noted earlier, responses were on a 5-point scale which ranged from (1) extremely stressful to (5) not stressful. Here, there was no significant difference between reported stress at Time 1 ($M = 4.14, SD = .1$) and Time 2 ($M = 4.24, SD = .11$), but subjects reported significantly less stress at Time 3 ($M = 4.6, SD = .08$) ($F(2, 156) = 15.47, p < .001$).

**Individual Differences: Anxiety Change Scores**

A primary focus of this research was how subjects’ anxiety levels changed across time. As noted above, state anxiety levels across subjects did significantly increase from Time 1 to Time 2 and then decrease at Time 3. Of course, the group means may describe all, some, or none of the individual subjects. In an attempt to examine individual differences in anxiety change patterns, change scores on state anxiety measures from Time 1 to Time 2 and Time 2 to Time 3 for each subject were calculated. Rising change scores were defined as scores that were one standard deviation above the mean, while decreasing change scores were one standard deviation below the mean. All other scores were defined as “stable.” The mean change score in state anxiety from Time 1 to Time 2 was 3.84 ($SD = 9.31$) and 1.87 ($SD = 9.8$) for Time 2 to Time 3. Initially, the anticipatory period was examined (i.e, change from Time 1 to Time 2). Women were assigned to one of three groups based on the change in
their state anxiety scores from Time 1 to Time 2: Stable (n = 62), rising (n = 8), and decreasing (n = 9).

In order to ascertain whether change scores were related to distress regarding the follow-up exam, one-way ANOVAS using the group classifications described above (i.e., stable, decreasing, and rising) as the between groups factor were conducted. The dependent measures included scores on the FOR, LOT, BSI, and the cancer worry composite score (all assessed at Time 1). Results revealed no significant differences between subjects with regard to fear of recurrence, optimism, “worry,” depression, or other measures of distress. That is, a large jump in anxiety from Time 1 to Time 2 was not related to the other variables.

To examine patterns across all points of assessment, women were assigned to one of nine groups based on their change scores from Time 1 to Time 2, and from Time 2 to Time 3: Stable-stable (n = 48), stable-rising (n = 10), stable-decrease (n = 4), decrease-stable (n = 8), decrease-rising (n = 1), decrease-decrease (n = 0), rising-stable (n = 5), rising-decrease (n = 3), and rising-rising (n = 0). For example, a woman in the stable-stable group would have had state anxiety scores at both Time 1 and Time 2 that were not more than one standard deviation above or below the mean score for that time. Again, one-way ANOVAS using group assignment based on changes scores as the between groups factor and scores on the FOR, LOT, BSI, and cancer worry composite score as the dependent measures yielded no significant results. Alternative classification of subjects (e.g, comparing the 8 women with rising scores from Time 1 to Time 2 to the 62 stable and the 9 decreasing subjects, combining the stable-stable and stable-decrease individuals and comparing them to the stable-rising group) also yielded no differences, probably due to having too few subjects in cells.
Measures of Distress and Time Line Conceptualization of Cancer

In summary, disease site, stage of disease, months since diagnosis, age, and change in anxiety levels did not differentiate the sample with respect to any of the measures of worry, fear, anxiety, optimism or self-control. The next variable to be examined was subjects’ perceptions of time line of the disease. As described in Methods (Chapter 3), time line was assessed by asking subjects to describe cancer as being similar to diabetes (chronic), allergies (cyclic), the measles (acute), or some other disease. Note that subjects were asked to describe not their cancer, but cancer in general.

Twenty-three subjects (29%) described it as being like diabetes, 15 (19%) like allergies, 22 (28%) like the measles, and 19 (24%) as something else. Subjects who responded “other” all went on to describe an acute type of illness (e.g., “so many cancers can be cured” or “if you get treatment, you are ok”), while those who selected diabetes or allergies were in essence all describing a disease that never completely goes away. The primary investigator and a fourth-year undergraduate psychology major independently agreed that all 19 descriptions subsumed under the “other” category were basically describing an acute illness. Because the cyclic/chronic and acute/other choices were theoretically distinct, the groups were combined in order to increase the numbers in each cell. A total of 41 women described the disease as acute and the remaining 38 as chronic or cyclic.

Across stage of disease, how women viewed the time line of cancer is related to almost every measure of distress. As shown in Tables 7 and 8, women who viewed the disease as chronic/cyclic reported lower optimism, greater fear of recurrence, a higher estimate that the cancer will recur, higher state anxiety at all three time points, a lower score on the
Table 7

Means and Standard Deviations for Primary Study Variables for Chronic/Cyclic and Acute Groups

<table>
<thead>
<tr>
<th>Variable</th>
<th>Chronic/cyclic</th>
<th>Acute</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Fear of Recurrence Questionnaire</td>
<td>77.55</td>
<td>15.32</td>
<td>63.54</td>
</tr>
<tr>
<td>Life Orientation Test</td>
<td>19.97</td>
<td>3.80</td>
<td>22.68</td>
</tr>
<tr>
<td>Estimate of recurrence likelihood</td>
<td>5.03</td>
<td>1.77</td>
<td>2.39</td>
</tr>
<tr>
<td>Fear of exam</td>
<td>5.40</td>
<td>3.33</td>
<td>3.02</td>
</tr>
<tr>
<td>Self-control schedule</td>
<td>30.74</td>
<td>20.31</td>
<td>46.60</td>
</tr>
<tr>
<td>Cancer worry composite score</td>
<td>28.03</td>
<td>14.44</td>
<td>12.63</td>
</tr>
<tr>
<td>Trait anxiety</td>
<td>38.90</td>
<td>10.44</td>
<td>29.76</td>
</tr>
<tr>
<td>State anxiety, Time 1</td>
<td>33.63</td>
<td>10.26</td>
<td>26.61</td>
</tr>
<tr>
<td>State anxiety, Time 2</td>
<td>39.37</td>
<td>14.03</td>
<td>28.68</td>
</tr>
<tr>
<td>State anxiety, Time 3</td>
<td>36.50</td>
<td>14.91</td>
<td>27.73</td>
</tr>
<tr>
<td>BSI-general severity index, Time 1</td>
<td>0.64</td>
<td>.50</td>
<td>0.29</td>
</tr>
<tr>
<td>BSI-general severity index, Time 2</td>
<td>0.59</td>
<td>.50</td>
<td>0.26</td>
</tr>
<tr>
<td>BSI-general severity index, Time 3</td>
<td>0.52</td>
<td>.47</td>
<td>0.29</td>
</tr>
</tbody>
</table>

Note. **p < .01. ***p < .001.
Table 8

Means and Standard Deviations for POMS-BI Subscales for Chronic/Cyclic and Acute Groups

<table>
<thead>
<tr>
<th>Variable</th>
<th>Chronic/cyclic</th>
<th>Acute</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>Composed/anxious, Time 1</td>
<td>21.76</td>
<td>8.33</td>
<td>26.56</td>
</tr>
<tr>
<td>Composed/anxious, Time 2</td>
<td>20.42</td>
<td>8.70</td>
<td>26.44</td>
</tr>
<tr>
<td>Composed/anxious, Time 3</td>
<td>23.42</td>
<td>8.58</td>
<td>27.17</td>
</tr>
<tr>
<td>Agreeable/hostile, Time 1</td>
<td>28.21</td>
<td>5.90</td>
<td>30.93</td>
</tr>
<tr>
<td>Agreeable/hostile, Time 2</td>
<td>27.95</td>
<td>6.07</td>
<td>31.02</td>
</tr>
<tr>
<td>Agreeable/hostile, Time 3</td>
<td>27.53</td>
<td>5.06</td>
<td>31.27</td>
</tr>
<tr>
<td>Elated/depressed, Time 1</td>
<td>23.61</td>
<td>8.44</td>
<td>27.51</td>
</tr>
<tr>
<td>Elated/depressed, Time 2</td>
<td>24.03</td>
<td>7.94</td>
<td>27.10</td>
</tr>
<tr>
<td>Elated/depressed, Time 3</td>
<td>24.00</td>
<td>8.75</td>
<td>27.49</td>
</tr>
<tr>
<td>Confident/unsure, Time 1</td>
<td>19.79</td>
<td>6.77</td>
<td>26.02</td>
</tr>
<tr>
<td>Confident/unsure, Time 2</td>
<td>21.08</td>
<td>5.71</td>
<td>25.00</td>
</tr>
<tr>
<td>Confident/unsure, Time 3</td>
<td>21.11</td>
<td>6.91</td>
<td>26.29</td>
</tr>
<tr>
<td>Energetic/tired, Time 1</td>
<td>20.95</td>
<td>8.50</td>
<td>25.07</td>
</tr>
<tr>
<td>Energetic/tired, Time 2</td>
<td>19.53</td>
<td>9.01</td>
<td>24.88</td>
</tr>
<tr>
<td>Energetic/tired, Time 3</td>
<td>20.95</td>
<td>8.79</td>
<td>25.32</td>
</tr>
<tr>
<td>Clearheaded/confused, Time 1</td>
<td>27.79</td>
<td>7.16</td>
<td>31.22</td>
</tr>
<tr>
<td>Clearheaded/confused, Time 2</td>
<td>26.9</td>
<td>6.76</td>
<td>30.44</td>
</tr>
<tr>
<td>Clearheaded/confused, Time 3</td>
<td>27.55</td>
<td>7.23</td>
<td>30.34</td>
</tr>
</tbody>
</table>

Note. *p < .05. **p < .01. ***p < .001.
Self-Control Scale, and poorer outcomes on the General Severity Index of the BSI and almost every scale of the POMS-BI (all p’s < .05) at all three times.

Because of the striking and consistent results regarding time line and indices of distress, disease time line was examined in further analyses regarding depression. Subjects received raw scores on the depression subscale of the BSI for all three time points. Raw scores were converted to t-scores (Derogatis & Spencer, 1982) and a mean overall t-score across all three points of assessment was computed for each woman. Subjects were identified as depressed if their mean t-score across the three assessments on the depression scale of the BSI was greater than 60 (this criteria was chosen because it is one standard deviation above the mean). Ten subjects were classified as depressed given this criteria. Of the 10 subjects, only two described cancer as an acute disease while 8 characterized it as chronic/cyclic ($\chi^2 = 4.7, p = .03$). Across all subjects, those in the chronic/cyclic group reported significantly more depression as indexed by their t-scores on the BSI depression subscale ($M = 53.2, SD = 8.23$) than those in the acute group ($M = 47.25, SD = 5.88$) ($t(66) = 3.7, p < .001$).

Time line conceptualization was examined with respect to the anxiety change scores that were discussed earlier. From Time 1 to Time 2, there was a trend for those in the chronic/cyclic group to have more of a rise in anxiety (i.e., higher change scores) ($M = 5.74, SD = 10.01$) than those who characterized the disease as acute ($M = 2.01, SD = 8.27$) ($F(1,77) = 3.1, p = .08$). Although stage of disease appeared unrelated to measures of distress in preliminary analyses, stage was examined further due to the significant findings regarding time line. In order to examine whether stage of disease played a role in anxiety change scores, a 2X2 ANOVA was performed with anxiety change score (from Time 1 to Time 2) as
the dependent variable and Time Line (chronic/cyclic vs. acute) and Stage (localized vs. regional metastatic) as the between groups factors. Time 1 State Anxiety scores were entered as a covariate to adjust for initial level of anxiety. The ANOVA produced no significant main effects and no interaction (F (1, 75) = 1.93, p = .17), even though from the means (see Table 9), it appeared that among localized disease subjects, those with a chronic/cyclic orientation (M = 8.1, SD = 12.41) had a higher mean change score than those in the acute group (M = 1.8, SD = 9.6).

Table 9 also lists mean state anxiety scores at all three assessment points for subjects in all subgroups of stage and time line conceptualization. As noted earlier, women in the chronic/cyclic group consistently reported more state anxiety than those in the acute group. Indeed, within each stage, women in the chronic/cyclic group consistently have higher scores. It appears that women with localized disease who have a chronic/cyclic orientation reported the most anxiety. To assess whether the differences in state anxiety across the three time points differ as a function of disease time line orientation and stage of disease, a State Anxiety (at three times) X Time Line (chronic/cyclic vs. acute) X Stage (localized vs. metastatic) repeated measures ANOVA was performed. The cell means employed in this analysis are presented in Table 9. While there were significant main effects for time (F (2, 74) = 6.88, p = .002) and time line orientation (F (1, 75) = 18.47, p < .001), there was no main effect for stage of disease and no significant interactions of any kind. Thus, the significant main effects indicate that there are significant differences in anxiety scores based just on the time of the assessment and how subjects conceptualized the disease (i.e., chronic/cyclic or acute).
Table 9

Mean State Anxiety Scores: Chronic/Cyclic Versus Acute and Localized Versus Regional Metastatic Disease

<table>
<thead>
<tr>
<th>Stage and time line</th>
<th>Localized</th>
<th>Metastatic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Chronic/cyclic (n = 20)</td>
<td>Acute (n = 26)</td>
</tr>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Time 1</td>
<td>35.4</td>
<td>10.7</td>
</tr>
<tr>
<td>Time 2</td>
<td>43.5</td>
<td>15.4</td>
</tr>
<tr>
<td>Time 3</td>
<td>38.2</td>
<td>16.7</td>
</tr>
<tr>
<td>Change from Time 1 to Time 2</td>
<td>8.1</td>
<td>12.4</td>
</tr>
</tbody>
</table>

Due to the cell means which suggested that women with localized disease with a chronic/cyclic orientation reported the most anxiety, it was hypothesized that these women would report the least optimism in the sample. A 2X2 ANOVA was performed with stage (localized vs. metastatic) and time line (chronic/cyclic vs. acute) as the grouping variables and the LOT scores as the dependent variable. The cell means employed in this analysis were as follows: Women with a chronic/cyclic view who had localized disease had a mean LOT score of 20.05 (SD = 3.36) and those with regional metastatic disease had a mean score of 19.89 (SD = 4.34). Women with an acute view in the localized group had a mean of 22.35 (SD = 3.32) while those with regional metastatic disease had a mean of 23.27 (SD = 5.3).
The only significant finding was a main effect for time line ($F(1,75) = 9.5, p = .003$). The women with localized disease with a chronic/cyclic orientation were not significantly less optimistic than the other women.

**Summary.** There were no significant relationships between the primary study variables and disease site, stage of disease, months since diagnosis, age of the subjects, or the magnitude of the change in anxiety from Time 1 to Time 2. Subjects did express a moderate amount of concern with respect to the follow-up exam and the source of anxiety for 70% of them was fear of disease recurrence. The pattern of anxiety, as predicted, was characterized by a rise from Time 1 to Time 2 and then a decrease at Time 3. There was a significant positive correlation between physicians' ratings of subjects' anxiety and subjects' actual reported anxiety. The measures assessing worry, distress, fear, and optimism were highly intercorrelated. Finally, time line conceptualization of disease was the one variable that was significantly related to almost every measure of distress, including depression.

**Coping Strategies**

**Overview and Descriptive Data**

Coping was primarily assessed with the WOC-CA at all three time points, although information regarding subjects' understanding of what caused their illness to occur and strategies employed to prevent disease recurrence were also obtained at Time 1. Questions assessing social support were asked at all three time points.
Regarding subjects' understanding of what caused their cancer, 27 subjects (34.2%) stated that they knew what caused their cancer to occur. Table 10 lists the various etiologies subjects endorsed. Subjects were instructed to endorse as many items that they felt were applicable ($M = 6.4$, $SD = 2.8$, range: 0 to 11). All subjects responded to these items whether they claimed that they knew the cause of the disease or not. Subjects who stated that they knew the disease etiology were more likely to endorse heredity ($\chi^2 = 6.38, p = .01$) and stress/overwork ($\chi^2 = 3.86, p = .05$) as factors in their disease. Table 11 lists strategies the women used in order to help prevent disease recurrence. Thinking positively (89.9%), praying (81%), and keeping busy (69.6%) were methods utilized by most of the women. In response to a single question asking subjects to rate how effective their overall strategies would be, subjects reported a high degree of satisfaction ($M = 7.07$, $SD = 3.18$) that their strategies would be effective (0 = not at all satisfied to 10 = very satisfied).

**Results From the WOC-CA: Reported Stress, Intercorrelations, and Changes in Coping Across Time**

The first question on the WOC-CA, a simple inquiry regarding how stressful the designated problem (i.e., fear and uncertainty about the future due to cancer) had been for subjects prior to each of the three data collection points, yielded a split in the sample. Thirty women reported no stress on the WOC-CA at any of the three time points even though they then went on to endorse specific strategies. One subject reported no stress on the WOC-CA and endorsed no coping items, yet circled a “9” (scale of 1 to 10) on the question regarding
how much she worries about cancer when she goes to the doctor. The remaining subjects (n = 49) reported stress and endorsed coping items at all three time points.

Table 10

<table>
<thead>
<tr>
<th>Items Endorsed Regarding Disease Etiology</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item</td>
</tr>
<tr>
<td>---------------------------------------</td>
</tr>
<tr>
<td>Virus</td>
</tr>
<tr>
<td>Heredity</td>
</tr>
<tr>
<td>Stress or overwork</td>
</tr>
<tr>
<td>Diet or eating habits</td>
</tr>
<tr>
<td>Obesity</td>
</tr>
<tr>
<td>Smoking habits</td>
</tr>
<tr>
<td>Drinking habits</td>
</tr>
<tr>
<td>Medication, birth control pills, or estrogen replacement</td>
</tr>
<tr>
<td>Chemicals in the food, air, or water</td>
</tr>
<tr>
<td>Poor constitution or lack of immunity</td>
</tr>
<tr>
<td>God’s will or fate</td>
</tr>
<tr>
<td>Chance</td>
</tr>
<tr>
<td>Injury</td>
</tr>
</tbody>
</table>

Note. Percentages are for within each subgroup.

<sup>a</sup> Refers to subjects (n = 52) who answered “yes” to question regarding whether they knew cause of cancer.  
<sup>b</sup> Refers to subjects (n = 27) who answered “no” to question regarding whether they knew cause of cancer.
Table 11

Strategies Employed to Prevent Disease Recurrence

<table>
<thead>
<tr>
<th>Item</th>
<th>Number of subjects who endorsed item (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercising or body building</td>
<td>45 (57.0)</td>
</tr>
<tr>
<td>Eating special diet</td>
<td>48 (60.8)</td>
</tr>
<tr>
<td>Keeping busy</td>
<td>55 (69.6)</td>
</tr>
<tr>
<td>Relaxation or getting a lot of rest</td>
<td>44 (55.7)</td>
</tr>
<tr>
<td>Taking vitamins</td>
<td>24 (30.4)</td>
</tr>
<tr>
<td>Quitting smoking</td>
<td>12 (15.2)</td>
</tr>
<tr>
<td>Taking drugs other than those prescribed by doctor</td>
<td>2 (2.5)</td>
</tr>
<tr>
<td>Praying</td>
<td>64 (81.0)</td>
</tr>
<tr>
<td>Thinking positively</td>
<td>71 (89.9)</td>
</tr>
<tr>
<td>Using imagery</td>
<td>20 (25.3)</td>
</tr>
<tr>
<td>Keeping thoughts of cancer out of mind</td>
<td>36 (45.6)</td>
</tr>
<tr>
<td>Avoiding too much emotional stress</td>
<td>48 (60.8)</td>
</tr>
<tr>
<td>Avoiding getting upset/angry</td>
<td>35 (44.3)</td>
</tr>
</tbody>
</table>

Note. Subjects could endorse multiple strategies.

Not surprisingly, when women who reported stress (n = 49) were compared to those who stated that they were experiencing no stress (n = 30) at any of the three time points, those who acknowledged stress had significantly higher scores on several other measures of distress. On the FOR, those who reported stress on the WOC-CA had a mean score of 77.6 (SD = 13) compared to 58.9 (SD = 9.8) for those who reported no stress (t (77) = -6.8, p <
The stressed group also reported more state anxiety at Time 2 ($M = 36.8$, $SD = 12.4$) than those in the “no stress” group ($M = 29.2$, $SD = 11.3$) ($t (77) = -2.8$, $p = .007$), but there were no significant differences between their state anxiety scores at Time 1 or Time 3. The stressed group had a higher cancer worry composite score ($M = 26.3$, $SD = 14.1$) for “stressed” and $M = 10.3$, $SD = 7.5$ for “no stress”) ($t (77) = -5.8$, $p < .001$). Finally, those who reported stress estimated a higher likelihood of disease recurrence ($M = 4.5$, $SD = 2$) than those with no reported stress ($M = 2.4$, $SD = 1.9$) ($t (77) = -4.5$, $p < .001$). Reported stress on the WOC-CA is discussed further in the section on coping and time line conceptualization.

With respect to specific coping strategies, the WOC-CA yielded 15 coping scores for each subject, one for each of the 5 factors at the 3 time points (see Table 2 for a list of factors and specific items). Scores are an indicant of the frequency and intensity of coping responses. Table 12 lists the mean coping scores and standard deviations for the five factors at each of the three points of assessment. As would be expected, the factors are all highly intercorrelated (see Table 13), especially within each time point.

As seen in Table 2, each factor is comprised of differing numbers of items. For Social Support, the factor is comprised of 8 items and since the scale is zero to four, the total possible score is 32. The total possible for Cognitive Escape-Avoidance is 16, for Distancing and for Focus on the Positive it is 24, and for Behavioral Escape-Avoidance it is 12. Subjects used Distancing more than any other coping factor, which is particularly evident when the means were examined as a proportion of each possible scale score. Use of Distancing ranged from 44% to 52% of the maximum amount possible across the three time points. Cognitive
Table 12

Means and Standard Deviations for WOC-CA Factor Scores

<table>
<thead>
<tr>
<th>Factor</th>
<th>Time 1</th>
<th></th>
<th>Time 2</th>
<th></th>
<th>Time 3</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
<td>M</td>
<td>SD</td>
</tr>
<tr>
<td>Social support</td>
<td>7.49</td>
<td>5.72</td>
<td>6.84</td>
<td>5.6</td>
<td>6.38</td>
<td>5.98</td>
</tr>
<tr>
<td>Cognitive escape-avoidance</td>
<td>6.58</td>
<td>4.14</td>
<td>6.41</td>
<td>4.25</td>
<td>5.87</td>
<td>4.5</td>
</tr>
<tr>
<td>Distancing</td>
<td>11.89</td>
<td>6.6</td>
<td>12.54</td>
<td>5.9</td>
<td>10.54</td>
<td>7.01*</td>
</tr>
<tr>
<td>Focus on positive</td>
<td>8.79</td>
<td>6.45</td>
<td>8.25</td>
<td>6.67</td>
<td>7.71</td>
<td>6.4</td>
</tr>
<tr>
<td>Behavioral escape-avoidance</td>
<td>.99</td>
<td>1.57</td>
<td>.82</td>
<td>1.47</td>
<td>.87</td>
<td>1.56</td>
</tr>
</tbody>
</table>

Note. Higher scores indicate greater frequency and intensity of that particular type of coping.

* p < .05.

Escape-Avoidance was also used frequently with a range of 37% to 41%. Next in magnitude was Focus on the Positive with a range of 32% to 37% and Social Support with a range of 20% to 23%. The strategy used least proportionately was Behavioral Escape-Avoidance with a range of 7% to 8%. From the means shown in Table 12, it appears that coping efforts dropped off at Time 3. However, in repeated measures ANOVAS with individual factor scores across time as the dependent measure, the only significant effect is for Distancing (F (2, 77) = 4.5, p = .013).

In addition to assessing frequency and intensity of coping strategies, factors were examined in a dichotomous manner. If a subject endorsed any coping item at any level of intensity within a factor, she was described as having used the strategy described by the
Table 13

Correlation Matrix of WOC-CA Factors

<table>
<thead>
<tr>
<th></th>
<th>S1</th>
<th>S2</th>
<th>S3</th>
<th>C1</th>
<th>C2</th>
<th>C3</th>
<th>D1</th>
<th>D2</th>
<th>D3</th>
<th>F1</th>
<th>F2</th>
<th>F3</th>
<th>B1</th>
<th>B2</th>
<th>B3</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1</td>
<td>1.00</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>S2</td>
<td>.611***</td>
<td>1.00</td>
<td></td>
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<tr>
<td>S3</td>
<td>.573***</td>
<td>.65***</td>
<td>1.00</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>C1</td>
<td>.586***</td>
<td>.316**</td>
<td>.301**</td>
<td>1.00</td>
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<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C2</td>
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<td>.488***</td>
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Note. S = Seek and use social support; C = Cognitive escape-avoidance; D = Distancing; F = Focus on the positive; B = Behavioral escape-avoidance; 1 = Time 1; 2 = 2.

* p < .05. ** p < .01. *** p < .001.
### CA Factors

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*port; C = Cognitive escape-avoidance; D = Distancing; F = Focus on the positive; B = Behavioral escape-avoidance; 1 = Time 1; 2 = Time 2; 3 = Time 3.
factor. Table 14 lists each coping factor and the percentage of subjects who used the factor at each of the three time points. Contrary to the proposed hypothesis, Distancing was the only factor that showed an increase in usage at Time 2 followed by decrease at Time 3. The proportion of women using Focusing on the Positive remained fairly consistent across time. For the remaining factors, the number of subjects utilizing each strategy decreased across time. Distancing and Cognitive Escape-Avoidance were the most common strategies utilized. Clearly, the least used strategies involved items subsumed in the Behavioral Escape-Avoidance factor (e.g., avoiding others, coping through alcohol use, smoking, etc.).

Most of the women (n = 58) exhibited stable coping patterns across time. That is, their scores on the five factors across time did not vary more than one standard deviation above or below the mean. The remaining women were fairly equally divided among those with an increase and those with a decrease in coping frequency and intensity. Subjects who showed an increase in one factor, did not necessarily exhibit increases in other factors. For example, only six subjects consistently increased or decreased their coping efforts across time.

Coping and Time Line Conceptualization of Cancer

There is a relationship between time line conceptualization and whether stress was reported on the WOC-CA at any of the three time points. Of the 38 women who viewed cancer as chronic/cyclic, 29 reported stress in at least one of the assessment points and 9 reported none at any of the three time points. For those in the acute group, the sample is more evenly divided with 22 reporting no stress and 19 reporting stress ($\chi^2 = 7.43, p = .006$).
Table 14

Proportion of Subjects Using Any Strategy Within Five Coping Factors Across Time

<table>
<thead>
<tr>
<th>Factor</th>
<th>Did use specific coping strategy</th>
<th>Did not use specific coping strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Seek and use social support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1</td>
<td>69</td>
<td>87.3</td>
</tr>
<tr>
<td>Time 2</td>
<td>64</td>
<td>81</td>
</tr>
<tr>
<td>Time 3</td>
<td>57</td>
<td>72.2</td>
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<td>Cognitive escape-avoidance</td>
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<tr>
<td>Time 1</td>
<td>73</td>
<td>92.4</td>
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<td>Time 2</td>
<td>71</td>
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<td>Time 1</td>
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<td>Behavioral escape-avoidance</td>
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<td>Time 3</td>
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With respect to coping efforts, there are significant differences when time line conceptualization of disease is considered. Table 15 lists the mean scores for each coping factor for subjects in the chronic/cyclic and acute groups and the results of t-tests performed to assess differences between the two groups. At all three times and for most factors, those who viewed cancer as chronic/cyclic reported more coping effort. Specifically, significant

### Table 15

**Means and Standard Deviations for WOC-CA Factors for Chronic/Cyclic and Acute Groups**

<table>
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<th>Chronic/cyclic</th>
<th>Acute</th>
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<td>SD</td>
<td>M</td>
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<td>Time 1</td>
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<td>4.66</td>
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<td><strong>Cognitive Escape-Avoidance</strong></td>
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<tr>
<td>Time 1</td>
<td>7.42</td>
<td>3.66</td>
<td>5.81</td>
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<tr>
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<td>3.85</td>
<td>5.49</td>
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<td>Time 3</td>
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<td>4.43</td>
<td>4.93</td>
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<tr>
<td><strong>Distancing</strong></td>
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<tr>
<td>Time 1</td>
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<td>5.95</td>
<td>10.54</td>
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<tr>
<td>Time 2</td>
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(table continues)
Table 15 (continued)

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<td>SD</td>
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<td>Time 3</td>
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<td>1.88</td>
<td>0.51</td>
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</table>

*P < .05. **p < .01.

differences were found for Social Support at all three times, Cognitive Escape-Avoidance at Time 2 and Time 3, Distancing at Time 3, and Behavioral Escape-Avoidance at Time 1 and Time 3. It is noteworthy that there are no significant differences between the two groups at any time for Focus on the Positive, and that there are no differences for Distancing and Behavioral Escape-Avoidance at Time 2, the assessment right before the exam.

To determine whether there were differences across time with respect to coping patterns for subjects with different time line orientations, one-way repeated measures ANOVA with time line as the grouping variable and each coping factor as the dependent variable were computed. From the means, it appeared that subjects with an acute orientation reduced their coping efforts more at Time 3 than those with a chronic/cyclic orientation. There was a
significant main effect for time line on Distancing, \( F (2, 76) = 5.53, p = .006 \). There were no significant findings for any of the other factors.

Other than the WOC-CA, coping was assessed by asking subjects at Time 1 what strategies they had used to prevent the disease from recurring. These items are listed in Table 11. Subjects with a chronic/cyclic orientation endorsed 6.8 items (\( SD = 2.8 \)) and those in the acute group endorsed 6.1 (\( SD = 2.8 \)), a difference which is not significant (\( t (77) = 1.18, p = .24 \)).

Furthermore, with respect to perceived social support, subjects who viewed cancer as a chronic/cyclic disease rated their relationships with their spouses, families, and friends as less satisfying than those who viewed the disease as acute. These analyses are based on responses to selected questions from the PAIS-SR (see Appendix K). In short, questions involved rating the quality of the relationships with one's spouse (sexual and nonsexual), family, and friends since the cancer diagnosis. When asked to evaluate the relationship with the spouse, those in the chronic/cyclic group give a mean rating of 11.1 (\( SD = 2.1 \)) compared to 11.9 (\( SD = .42 \)) (\( t (30) = -2.03, p = .05 \)) for those in the acute group. Regarding the sexual relationship, chronic/cyclic subjects have a mean rating of 16.4 (\( SD = 3.0 \)) while the others have a mean of 17.9 (\( SD = 2.2 \)) (\( t (48) = -2.2, p < .05 \)). For the evaluation of relationships with friends and family, the chronic/cyclic group rating is 11.1 (\( SD = 1.5 \)) and for the acute group it is 11.95 (\( SD = .22 \)) (\( t (38) = -3.3, p < .01 \)).

Table 16 lists the number of subjects in the chronic/cyclic and acute groups who stated that they deliberately avoided discussing their health concerns regarding cancer with others. A \( \chi^2 \) analysis was performed to assess whether there was a significant difference.
Table 16

Number of Patients Who Avoided Discussing Health Concerns With Others at Time 2 for Chronic/Cyclic and Acute Groups

<table>
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<th>Time 1</th>
<th>Time 2</th>
<th>Time 3</th>
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<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Chronic/cyclic</td>
<td>11</td>
<td>27</td>
<td>11</td>
</tr>
<tr>
<td>Acute</td>
<td>9</td>
<td>32</td>
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</table>

between chronic/cyclic and acute subjects’ responses at Time 2, the time characterized by the highest levels of anxiety. There was a significant difference between the two groups ($\chi^2 = 4.7, p < .05$). To determine whether there were significant differences in the pattern of responses across time with respect to avoiding discussion with others, a repeated measures ANOVA was performed with time line orientation as the grouping variable and number of subjects who stated that they did avoid discussion as the dependent variable. From the numbers presented in Table 16, it appears that subjects in the chronic/cyclic group showed almost no differences across time with respect to discussing their concerns but that subjects in the acute group did exhibit some variation, especially at Time 2 (fewer subjects avoiding discussing their concerns with others). The results of the ANOVA, however, produced no significant main effect for avoidance (Wilks’ lambda = .977, $F (2,76) = .904, p = .41$) and no interaction (Wilks’ lambda = .974, $F (2,76) = 1.03, p = .36$). It should be noted that the number of
subjects in this analysis was small (i.e., the number of those who stated that they had avoided discussing their concerns ranged from 4 to 11).

Summary. Although coping was assessed primarily with the WOC-CA, responses to individual questions regarding coping strategies indicated that over 80% of the subjects tried to think positively and pray. The five factors generated from the WOC-CA were highly intercorrelated. Contrary to the proposed hypothesis, distancing was used most at Time 2 and then dropped off at Time 3. Distancing and Cognitive Escape-Avoidance were used more than any other coping strategy. Most of the women exhibited stable coping patterns across time. Women with a chronic/cyclic disease orientation exhibited more coping effort at higher intensity levels. Such women also reported less satisfactory relationships with their spouses, friends, and family members, and were more likely to deliberately avoid discussing their concerns about cancer with others.

Relationship Between Measures of Distress and Coping

To determine any relationship between differences in coping change scores and measures of anxiety, depression, optimism, and fear of recurrence, partial correlations (with coping scores at Time 1 as the covariate) were computed between the difference scores for each coping factor from Time 1 to Time 2 and the STAI, depression subscale of the BSI, LOT, and the FOR. Except for Social Support, the correlations ranged from -.21 to .12, none of which were significant at less than .05. Coping change scores for Social Support were negatively correlated with State Anxiety scores at Time 1 ($r = -.37, p = .001$) and Time 2 ($r = .
and the depression subscale of the BSI ($r = -0.32, p < .01$). That is, an increased use in reported behaviors utilizing social support from Time 1 to Time 2 is associated with lower anxiety and depression scores.

To determine any relationship between distress change and coping strategies, partial correlations (with State Anxiety scores at Time 1 as the covariate) were computed between the difference scores in anxiety from Time 1 to Time 2 and coping scores on the five factors across time. The correlations ranged from -.16 to .15, none of which were significant at less than .05.

When the anxiety change scores are related to coping change scores, it is apparent that the majority of women exhibited few dramatic alterations in anxiety or coping efforts across time. All 11 subjects who significantly increased their coping efforts from Time 1 to Time 2, were characterized as “stable” by their anxiety change scores. That is, subjects with markedly rising change scores did not exhibit a corresponding jump in coping effort. Forty-five subjects were described as “stable” in both their anxiety and coping change scores.

Although coping change scores did not correspond to changes in anxiety, coping efforts at all times (frequency and intensity) were correlated with fear of recurrence and the cancer worry composite score (see Table 17). The more fear and worry regarding future health status specifically, as opposed to measures of generalized anxiety, the more coping activity reported. Data from the questions regarding strategies subjects used to prevent a cancer recurrence also suggest that more coping effort was related to greater fear of recurrence: Higher scores on the FOR were associated with more prevention strategies endorsed ($r = 0.32, p < .01$).
Table 17

Intercorrelations of FOR and Cancer worry Composite Scores and WOC-CA Factors

<table>
<thead>
<tr>
<th>Factor</th>
<th>FOR</th>
<th>Cancer worry composite score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seek and use social support</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1</td>
<td>.35**</td>
<td>.42***</td>
</tr>
<tr>
<td>Time 2</td>
<td>.35**</td>
<td>.32**</td>
</tr>
<tr>
<td>Time 3</td>
<td>.40***</td>
<td>.38***</td>
</tr>
<tr>
<td>Cognitive escape-avoidance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1</td>
<td>.42***</td>
<td>.47***</td>
</tr>
<tr>
<td>Time 2</td>
<td>.46***</td>
<td>.40***</td>
</tr>
<tr>
<td>Time 3</td>
<td>.54***</td>
<td>.45***</td>
</tr>
<tr>
<td>Distancing</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1</td>
<td>.25*</td>
<td>.28*</td>
</tr>
<tr>
<td>Time 2</td>
<td>.14</td>
<td>.20</td>
</tr>
<tr>
<td>Time 3</td>
<td>.32**</td>
<td>.32**</td>
</tr>
<tr>
<td>Focus on the positive</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1</td>
<td>.20</td>
<td>.25*</td>
</tr>
<tr>
<td>Time 2</td>
<td>.17</td>
<td>.14</td>
</tr>
<tr>
<td>Time 3</td>
<td>.31**</td>
<td>.23*</td>
</tr>
<tr>
<td>Behavioral Escape-Avoidance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time 1</td>
<td>.32**</td>
<td>.28*</td>
</tr>
<tr>
<td>Time 2</td>
<td>.22</td>
<td>.13</td>
</tr>
<tr>
<td>Time 3</td>
<td>.42***</td>
<td>.34**</td>
</tr>
</tbody>
</table>

*p < .05.  **p < .01.  ***p < .001.
Individual coping factors as reported on the WOC-CA and by individual items listed in Appendix N, were not significantly related to optimism. Use of Cognitive Escape-Avoidance strategies at all three times correlated negatively with optimism, but only approached statistical significance (Time 1: $r = -.16, p = .08$; Time 2: $r = -.16, p = .08$; Time 3: $r = -.17, p = .06$). To insure that the high level of coping among those in the chronic/cyclic group did not obscure or suppress the relationship of optimism to coping, subjects’ conceptualization of time line was partitioned out in a series of partial correlations. Even with the time line variable controlled, the correlations between each of the five coping factors at the three times and scores on the LOT ranged from .14 to -.11, none of which were significant at a probability level less than .05. Thus the time line variable was not suppressing a relationship between optimism and coping.

As with results for other variables reported earlier, disease stage and site also do not appear to be related to coping. In a repeated measures 2X2X3 ANOVA with stage and site as the grouping variables, neither variable yielded a significant result with respect to coping strategies (stage: $F (1, 77) = .039, p = .84$; site: $F (1, 77) = .363, p = .55$).

**Relationship Between Social Support and Distress**

In addition to questions about seeking social support on the WOC-CA, questions modified from the PAIS-SR (see Appendix K) regarding support from one’s spouse, family, and friends were examined by Pearson Product correlations to assess the relationship between social support and distress. The less positive the evaluation of the relationship with friends and family, the higher the FOR score ($r = -.27, p = .02$), the composite worry score ($r = -.28$, $p = .02$).
p = .02), and state anxiety at Time 1 (r = -.27, p = .02), Time 2 (r = -.32, p = .004), and Time 3 (r = -.30, p = .006). At all three times, subjects listed any individuals who had provided assistance or support to them. At Time 2, subjects were asked to list individuals who had aided them specifically with respect to concerns about the upcoming exam (see Appendix L). The number of individuals listed at Time 2 who had provided support was positively correlated with higher scores on the FOR (r = .30, p = .008) and the worry composite score (r = .38, p = .001).

**Summary.** Except for social support, changes in coping effort across time were not related to changes in state anxiety. Coping effort at all times was correlated with the FOR and the cancer worry composite score. Optimism, as assessed by the LOT, was not related to coping effort, even after controlling for the time line variable. Neither stage of disease nor disease site was related to coping effort. There was a significant negative correlation between subjects’ evaluation of relationships with family and friends and distress: Less positive evaluations were associated with higher scores on the FOR, state anxiety at all three times, and the worry composite score. Finally, the more individuals named at Time 2 as providers of support or assistance to the subject, the higher the subjects’ scores on the FOR and the worry composite score.

**Time Line Conceptualization of Cancer: Further Analyses**

Since the time line variable was significantly related to measures of distress and coping, more analyses were conducted to better understand its relationship to other variables of interest.
A $\chi^2$ analysis was performed to assess the relationship between time line conceptualization and stage of disease. It was possible that those who were diagnosed with regional metastatic disease accurately characterized cancer as cyclic/chronic, while those with localized disease viewed it as acute. Within localized disease subjects, 20 viewed cancer as cyclic/chronic and 26 as acute/other. Within regional metastatic disease subjects, 18 viewed cancer as cyclic/chronic and 15 as acute/other. These differences were not significant ($\chi^2 = .943, p = .33$). So conceptualization of disease time line for cancer was not at all related to subjects’ actual stage of disease at diagnosis. A substantial number of patients with excellent prognoses characterized the illness as chronic, while others with poorer prognoses described it as acute.

Subjects who characterized the disease as chronic/cyclic received significantly poorer prognosis ratings from their physicians ($M = 25.61$, $SD = 10.88$) than those who viewed it as acute ($M = 16.15$, $SD = 11.24$) ($t (64) = 3.43$, $p = .001$). Also, physicians rated chronic/cyclic subjects as significantly more anxious ($M = 36.81$, $SD = 22.76$) than acute subjects ($M = 25.12$, $SD = 20.45$) ($t (62.3) = 2.19$, $p = .03$).

In order to assess whether the time line construct was related to other clinical or demographic variables, $t$-tests were performed with time line conceptualization as the grouping variable (chronic/cyclic and acute) and age, education, time elapsed since diagnosis, and how frequently subjects saw their physicians as the dependent variables. None of these $t$-tests were statistically significant at .05 or below. Thus whether subjects viewed the time line of cancer as chronic or acute was not related to how old they were, highest educational level achieved, amount of time they had lived with the cancer diagnosis or how much contact they had with their doctors.
It was reported earlier that most subjects based their estimates of the likelihood of their cancer recurring on doctors' comments or medical statistics. Subjects' responses with regard to these recurrence estimates appear related to their time line conceptualization of cancer. Table 18 lists the different responses women gave when asked the basis for their assessment of recurrence likelihood. The most striking difference is that four times as many women with an acute representation based their opinion on their doctor's view that they would have a quick recovery (binomial test, $p = .012$). In addition, more women with a chronic/cyclic view did not respond to the question, but this difference was not statistically significant (binomial test, $p = .143$).

Table 18

Proportion of Patients Stating a Specific Rationale for Recurrence Estimate:

Chronic/Cyclic Versus Acute

<table>
<thead>
<tr>
<th>Reason stated</th>
<th>Chronic/cyclic</th>
<th>Acute</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td>Medical statistics/medical reading</td>
<td>8</td>
<td>21</td>
</tr>
<tr>
<td>Doctors' view of a quick recovery</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Present health status</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Gut feeling/women's intuition</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Family history</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Diet/exercise</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>No reason stated</td>
<td>12</td>
<td>32</td>
</tr>
</tbody>
</table>
Just as physicians' judgments of patients with different conceptualizations of cancer varied, so did patients' evaluations of medical care based on stage of disease and time-line orientation. A 2X2 ANOVA with time line orientation and stage of disease as the grouping variables and scores on the MISS as the dependent variable (Appendix J) was performed. Localized disease patients who viewed cancer as an acute illness had a mean score of 81.65 (SD = 7.5), while those who viewed the disease as chronic/cyclic had a mean score of 75 (SD = 12.52). Patients with an acute representation in the regional metastatic disease group had a mean score of 81 (SD = 8.1), and those with a chronic/cyclic view had a mean score of 78.7 (SD = 9.1). While there were no significant main effects, there was a significant interaction for time line and stage (F (1,75) = 3.97, p < .05).

Similarly, a 2X2 ANOVA was performed with time line and stage as the grouping variables and questions regarding medical care adapted from the PAIS-SR (Appendix K) as the dependent variable. Patients with localized disease who viewed the disease as acute had a mean score of 22.81 (SD = 1.74), while those in the chronic/cyclic group had a mean score of 20.65 (SD = 3.2). Metastatic disease patients rated care almost identically regardless of time line conceptualization (Acute: M = 23.13, SD = .99; Chronic/Cyclic: M = 23.15, SD = 1.37). Again, there was a significant interaction for time line and stage (F (1,75) = 4.79, p < .05).

Summary. Whether subjects viewed cancer as chronic/cyclic or acute was not related to their actual stage of disease. Physicians rated those with a chronic/cyclic view as having a poorer prognosis and as having more anxiety than those with an acute orientation. Time line orientation was not related to demographic variables, time since diagnosis, or how frequently
patients saw the doctor. Those with an acute view were more likely to base their ratings of
likelihood of recurrence on their doctor's view of a quick recovery. Stage did play a role in
how subjects evaluated their medical care: For localized disease patients only, those who had
an acute viewpoint rated their medical care more positively than those with a chronic/cyclic
orientation.
CHAPTER 5
DISCUSSION

The discussion of results is organized according to the primary issues of concern in the present study: Describing the psychological responses of women in remission for breast or colorectal cancer to follow-up examinations for recurrence, and identifying factors associated with differing levels and patterns of adjustment to the exams. As in the Results (Chapter 4), findings regarding distress and coping are addressed first. An extended discussion on time line conceptualization of cancer is then presented due to the statistical, theoretical, and clinical significance of the data. Finally, limitations of the present research and implications for future research are presented.

It was initially hoped that a third outcome of the research would be to predict patients' psychological reactions to the results of the examination (i.e., recurrence or no recurrence). As noted earlier in Methods (Chapter 3), only 1 woman out of 80 was diagnosed with a recurrence after the follow-up exam. This is not to say that the other subjects never experienced a recurrence; it is likely that many did at a later point in time. Due to the single recurrence, planned comparisons between patients with and those without a recurrence were not possible. Since the crux of the investigation is the threat of recurrence as opposed to a recurrence itself, the infrequency of recurrence does not detract from the results of the research (and, indeed, was a very welcome outcome for the subjects). The overestimation of expected recurrences, however, does exemplify the practical constraints of conducting psychological research with medically ill patients.

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Distress Associated With Follow-up Examination

Consistent with the fundamental hypothesis, subjects did experience anxiety associated with follow-up exams for recurrence. Subjects reported the most state anxiety, assessed with the STAI and the Composed-Anxious scale of the POMS-BI (see Figures 1 and 2), immediately before the exam, although the pattern for the two instruments differed (i.e., anxiety was lowest at Time 1 on the STAI and at Time 3 on the POMS-BI). At the third assessment, half of the subjects said they felt anxious during the exam. For more than 70% of the subjects, the anxiety was centered on fears that the exam would detect a recurrence of the disease. Furthermore, physicians' ratings of subjects' anxiety and subjects' actual reported anxiety were positively correlated. These findings lend empirical evidence to clinical impressions and anecdotal reports that follow-up exams can be a difficult time for survivors of cancer. Subjects articulated their concerns with comments during the course of the interviews: "I only worry about my health when the doctor's visit is coming up"; "These check-ups ruin the whole month for me"; and "The week before the exam is the worst, I always like the reassurance once it's over; I'm protected for a while longer."

It was hypothesized, based on research with both cancer patients undergoing radiation and general surgery patients (Andersen & Tewfik, 1985; Janis, 1958), that subjects who were extreme in their reported anxiety at Time 1, either expressing little anxiety or a great deal, would be less prepared for all possible outcomes at the time of the follow-up exam than those with a moderate amount of distress. It was thought that those reporting no or little anxiety would have done inadequate mental preparation for the exam, while those with extreme
anxiety would be overwhelmed. The underlying assumption was that a moderate or optimal amount of anxiety would be judicious given the implications of possible outcomes; the "mental work of worry" needed to be initiated (Marmor, 1958).

In contrast to these predictions, analyses which examined individual differences in anxiety change scores suggest that the women in this study were consistent in their reported anxiety across time. Those with low anxiety on the STAI at Time 1 reported the least anxiety at Time 2 and Time 3. Their low distress state was appropriate for a positive outcome. Those with high distress may have felt some temporary relief after a positive outcome from the follow-up exam, but they remained very worried. The hypothesized patterns in anxiety may have been more appropriate for subjects facing a recurrence. Furthermore, optimism was not related to changes in anxiety levels across time; subjects with a big rise in anxiety from Time 1 to Time 2 were not less optimistic.

It was expected that the more disease-free years the patient enjoyed, the less fear of recurrence would be reported because recurrence risk decreases over time. As noted in the literature review, epidemiological evidence indicates that the peak hazard of recurrence occurs in the interval of the first one to two years. The hazard decreases consistently in the next two to five years, and beyond five years the hazard decreases very slowly (Chung et al., 1996). Thus passing the "five-year mark" is often a significant event for cancer survivors; they have endured the period of the greatest risk. While the likelihood of recurrence decreases with time, it is true that it always remains a possibility. There is also the chance that a second primary, or an iatrogenic cancer, will develop (Levy, 1985).
Although the literature supports the position that most patients recover emotionally from a cancer diagnosis over the one to two years after diagnosis and treatment, the results in this study suggest that time since diagnosis (i.e., at least up to five years post-diagnosis) is not a factor in patients' anticipatory fear regarding follow-up exams. Anxiety regarding follow-up exams did not decrease as time since diagnosis increased; more disease-free years did not buffer the patient from fears regarding future health status. It is unknown whether patients who have survived years beyond the five-year marker would feel less vulnerable. Furthermore, contrary to other research (Mor et al., 1994; Vinokur et al., 1990), age was not a factor in how much distress was reported by subjects; younger women were not significantly different from older subjects with respect to anxiety about the exam, depression, or other distress.

It is possible that any effect for time since diagnosis was masked by subjects' differing feelings about treatment termination. While some may have been relieved to finish debilitating treatment, others may have felt more vulnerable. As Hurt et al. (1994) noted, patients in treatment or recently completing treatment may feel protected from a recurrence due to their recent exposure to chemotherapy and/or radiation. The decreased medical surveillance and lack of any intervention once treatment has ended may increase fears of recurrence; the enduring sense of vulnerability may then be triggered by the follow-up examination. Thus, it is difficult to interpret the lack of any significant finding for time since diagnosis. Whatever comfort survivors may have felt as the number of disease-free years increased may have been washed out by the fears associated with lack of treatment and intermittent medical evaluation. This possibility is particularly relevant in the present study.
since these data were collected before widespread use of long-term adjuvant hormonal therapy (e.g., tamoxifen) was implemented.

Disease site was also not related to the primary study variables (e.g., trait anxiety and fear of recurrence assessed at Time 1, state anxiety and depression across assessments), again contrary to the proposed hypothesis (see Table 3). The reason breast and colorectal sites were chosen was to insure that the results could be generalized to a larger cross-section of oncology patients than the typically utilized breast cancer population. While breast and colorectal cancer patients have very similar five-year relative survival rates when matched for stage of disease (American Cancer Society, 1998), breast cancer patients more often receive adjuvant treatment (e.g., chemotherapy or radiation). Given the differences in treatment for the two sites in this sample (i.e., more patients with colorectal cancer had surgery with no other treatment), it was expected that there would be differences in psychological response to the follow-up exam. Specifically, it was thought that breast cancer patients would feel more vulnerable because they more often received treatment after surgery. However, as discussed earlier, the treatment may have made them feel more protected against recurrence.

It appears that the specific site was less important than general fears of recurrence, which one would expect would be related to perceived risk of recurrence. In this sample, site was not significantly related to perceived risk which is consistent with the five-year survival statistics cited above. Indeed, other investigators have included multiple disease sites in preliminary studies without consideration of how site differences may be associated with differences in psychological adaptation (Dunkel-Schetter et al., 1987, 1992).
Regardless of disease site, it was expected that stage of disease would be a critical variable in terms of fear of recurrence (see Table 4). If subjects understood their prognosis based on initial diagnosis, it is logical to expect that those with a poorer prognosis (i.e., as derived from stage of disease) would accurately experience more fear of recurrence because recurrence is statistically more likely. For example, breast cancer patients with more advanced disease stage (e.g., more than three axillary nodes positive) have a significantly higher risk of recurrence (Chung et al., 1996). Surprisingly, the only apparent effect for stage of disease was related to doctors' ratings of prognosis and patients' feelings about medical care (discussed below).

The most powerful results related to time line orientation to the disease, a variable that was not overtly stated in any a priori hypotheses. How subjects conceptualized the disease in terms of chronicity was the single most significant finding of the research. Women who viewed the disease as chronic/cyclic reported more distress on almost every assessment instrument used in this research across all points of assessment. Since time line was also related to coping strategies and patterns, the implications of patients’ time line conceptualizations will be discussed after results from the coping measures are addressed.

Coping Strategies

Subjects reported using a variety of coping strategies to deal with their fears of recurrence and they exhibited stable coping patterns across time. There were no radical departures from one’s baseline strategy, assessed at Time 1, as the exam approached. Coping
efforts at all times were positively correlated with scores on the FOR and the cancer worry composite score; the more fear of recurrence and worry regarding cancer reported, the more coping effort reported. Distancing and Cognitive Escape-Avoidance were used more than any other coping strategy. Disease site, stage, and degree of optimism were not related to frequency or intensity of coping. Women with a chronic/cyclic orientation reported more coping at higher intensity levels across several points of assessment. Findings with respect to social support are somewhat inconsistent in that the data suggest positive and negative outcomes related to support. Again, the most significant finding concerns time line orientation; women with a chronic/cyclic orientation reported more coping efforts at higher intensity levels.

Dunkel-Schetter and her colleagues (1987, 1992), in their research on coping with cancer-related stressors in a sample of 668 patients where they originally modified the WOC for use with an oncology population, also found that distancing and cognitive escape-avoidance were the most frequently used strategies. However, they found that distancing, both cognitive and behavioral, was most frequently used at moderate levels of stress and least frequently when distress was very low or high. In the present study, the hypothesis that distancing would be used the least right before the exam when more active strategies would be utilized was not supported. Distancing may actually be the most appropriate strategy during a waiting period when one has little control over outcomes (Folkman & Lazarus, 1985), yet may be hard to implement when one’s distress level is high. The other factor used frequently was Focusing on the Positive. Except for items associated with Behavioral Escape-Avoidance, a high proportion of subjects used most strategies at least to some degree; that is, they reported utilizing a wide range of coping strategies and exhibited flexibility as predicted. As with
reported distress, subjects exhibited fairly stable coping patterns across time; there were no radical changes across the three assessment points.

It was hypothesized that subjects scoring higher on optimism would utilize more active, problem-focused coping patterns than less optimistic subjects. In this sample, subjects’ scores on the Life Orientation Test were not related to coping strategies regarding fear of recurrence. However, the hypothesis was based on the supposition that the exam would be viewed as a crisis; optimism is associated with active coping during a crisis and acceptance later on. Carver and his associates (Carver et al., 1993) have consistently found an inverse relationship between high scores on the Life Orientation Test (LOT) and reported use of avoidant coping. The exam, especially after one has had multiple experiences with it, may not be viewed as an unexpected, acute crisis at all. It is rather a potentially threatening event to endure, one aspect of contending with an often fatal disease. Distancing might be a very appropriate strategy under such circumstances whether one is optimistic or not.

Although large changes in anxiety from Time 1 to Time 2 were not related to significant changes in coping effort, coping effort at all three times was significantly and positively correlated with fear of recurrence and worry about health status. Thus more fear and worry regarding future health specifically (as opposed to generalized anxiety) were related to more coping effort. Those in greater distress reported doing more to cope with their concerns. It is unclear what the effect of the effort was, however. The information obtained is reported coping effort, not actual coping or coping effectiveness in terms of reduced distress. High reported distress associated with high coping effort may indicate that the coping is ineffective. However, it is unknown how high reported distress would have been if no or
little coping effort was reported. It is possible that subjects who were more willing to admit to distress were also more willing to report their coping efforts, no matter how disconcerting.

Interestingly, coping effort did not mimic fluctuations in anxiety levels. Except for Distancing, the most coping efforts were reported at Time 1. Consistent with the crux of this research, it seems possible that cancer survivors must cope with the threat of disease recurrence constantly. Although anxiety levels may fluctuate somewhat as threatening events occur, the basic coping strategies of trying to remain positive and avoidance of ruminating on worst possible outcomes must always be in use. The threat never completely goes away; it is prominence just waxes and wanes. Those in most distress may have fewer periods of relief.

The data support this conclusion (see Table 15). Subjects who viewed cancer as chronic/cyclic, who were clearly in greater distress, reported more coping effort for most factors (e.g., Social Support at all three times, Cognitive Escape-Avoidance at Time 2 and Time 3, Distancing at Time 3, and Behavioral Escape-Avoidance at Time 1 and Time 3) than those who viewed the disease as acute. At Time 2, the most stressful time, there were no differences between subjects in their use of Distancing, yet at Time 3 (after receiving good news from their follow-up exams) women with an acute view significantly reduced their use of Distancing while those with a chronic/cyclic view did not. Women with a chronic/cyclic view were ever vigilant and actively coping with fears about the disease.

Across all subjects, increased seeking and use of social support from Time 1 to Time 2 was associated with less anxiety and depression at Time 1 and Time 2. Furthermore, less perceived support was associated with greater distress, fear, and worry. This finding is consistent with other research (Bloom, 1982, 1986; Funch & Mettlin, 1982; Irvine et al., 1991;
Peters-Golden, 1982; Revenson, Wollman, & Felton, 1983; Weisman & Worden, 1986; Wortman, 1984; Wortman & Dunkel-Schetter, 1979). Yet the higher number of people named at Time 2 by the patient who had provided assistance or support regarding concerns about the upcoming exam, the higher the patients’ fear of recurrence and worry. This result makes sense in that those who are in most distress may be seeking the most support.

It is remarkable that a significant number of subjects with a chronic/cyclic orientation chose to deliberately avoid discussing their concerns with others immediately prior to the follow-up exam. These were the very subjects who reported the most distress. Furthermore, the chronic/cyclic patients rated their relationships with family and friends as less satisfying than those who viewed the disease as acute. Perhaps women with a chronic/cyclic view felt that social contact with others would be less than satisfying because of a perceived inability to discuss difficult topics and therefore were more likely to deliberately avoid contact. Family members may have been less willing to give support to patients with a negative outlook who might need ongoing support.

Given that increased use of social support was associated with less distress and that less perceived support was linked to more distress, social support during the period after diagnosis and treatment appears to be an important factor in adjustment. It is difficult to tease apart what is the cause and what is the effect with respect to social support. In other studies (Bolger et al., 1996; Neuling & Winefield, 1988), social support has hardly been viewed as uniformly positive. Indeed, it may do little to alleviate distress or promote recovery, even when patients find a friend or relative who is willing to discuss long-term fears (see Lichtman & Taylor, 1986).
The needs of individuals at high risk for adjustment problems after a diagnosis of cancer can be intense. Friends and relatives may be unprepared to assess what the patient needs and then be able to provide it. Furthermore, the more that patients view the disease as a central, traumatizing experience in their lives, the more communication problems may develop with others who fear cancer, do not understand the patient's traumatic response, or simply feel uncomfortable discussing any aspect of the disease (Kornblith, 1998). It is not uncommon for significant others to withdraw support in response to patients' emotional distress (Bolger et al., 1996), particularly as time since the diagnosis increases (Kornblith, 1998). Helping a loved one cope with fears of disfiguring disease and possible death is challenging for even the most empathic and skilled of lay individuals.

A primary aspect of support for any oncology patient is her relationship with the oncologist and treatment team. Subjects repeatedly described very powerful emotions, both positive and negative, about their physicians over the course of the interviews. Cancer patients often complain that the emotional support provided from their oncologists is insufficient (Siegel, 1998). There are data which suggest that patients who wanted more emotional support at the time of diagnosis from their physicians subsequently experienced poorer psychological adjustment (Butow, Kazemi, Beeney, Griffin, Dunn, & Tattersall, 1996).

While emotional support can be offered by other individuals, the patient looks to the physician as the main source for information about the illness. In this sample, most women, particularly those with an acute time line orientation, based their personal estimates of the likelihood of their cancer recurring on their doctors' comments and medical statistics. They stated that they had based their relatively positive outlook on information given to them from
their physicians. (In addition, estimates of recurrence were negatively correlated with subjects’ degree of dispositional optimism; more optimistic subjects estimated their chances of recurrence as lower than less optimistic subjects.) There was a trend for women with a chronic/cyclic orientation to not respond to the open-ended question about what they based their judgments on; it may have been difficult to articulate the source of their more negative estimates of future health status, when it probably did not come directly from their physicians.

Interestingly, stage of disease did play a role with respect to subjects’ evaluations of their physicians. There were no differences between acute and chronic/cyclic regional metastatic disease subjects. But for those with localized disease, the chronic/cyclic patients judged their health care more negatively than those with an acute view. It is possible that the discordance between the subject’s stage of disease and her perception of the disease created more problematic relationships with the medical staff.

Time Line Conceptualization of Cancer

How could disease stage not play more of a role in reported distress, particularly since most subjects said they based their estimates of the likelihood of cancer recurrence on doctor’s comments or medical statistics? It is possible that patients do not understand their stage of disease and or survival statistics associated with their specific cancer. In a recent study (Weeks et al., 1998), 917 adults hospitalized with stage III or IV non-small cell lung cancer or colon cancer metastatic to liver overestimated their chances of surviving 6 months, while physicians estimated prognosis quite accurately. The implications can be significant,
particularly with regard to treatment choices. In the Weeks et al. study (1998), patients who thought that they were going to live for at least 6 months were more likely to favor life-extending therapy over comfort care compared with patients who thought that there was at least a 10% chance that they would not live 6 months.

Evidently, subjects' subjective conceptualizations of their disease differs markedly from the objective information regarding the disease. The most noteworthy finding of the present study concerns patients' temporal assessments of the time line of cancer. On almost every measure of distress, those with a chronic/cyclic orientation reported more upset. They reported greater fear of recurrence, a higher likelihood of disease recurrence, more worry in cancer-related situations, greater fear regarding the impending exam, higher state anxiety at all three time points, higher trait anxiety, less optimism, more distress on almost every subscale of the POMS-BI and the BSI, and were more likely to be depressed than women with an acute orientation. Furthermore, they reported expending much greater coping effort over all three time points than those with an acute orientation.

As reported earlier, the women with a chronic/cyclic orientation in this study had higher trait, or dispositional, anxiety scores and were less dispositionally optimistic than those with an acute orientation. One's representation of illness and the corresponding attributes can critically influence coping efforts and their outcomes (Petrie & Weinman, 1997). Anxious individuals, across a wide range of samples, report more symptoms and distress (Watson & Clarke, 1984; Watson & Pennebaker, 1989). Hypervigilance may lead them to interpret sensations and experiences in a threatening manner. That is not to say that anxious individuals perceive symptoms inaccurately; they may just be more sensitive to somatic

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activity. A diagnosis of cancer provides already anxious individuals with a prominent, accessible target for their worry and rumination. Conversely, low-anxiety individuals may discount and underreport symptoms (Cameron, Leventhal, and Love, 1998).

It is quite remarkable that stage of disease was not at all related to subjects’ time line conceptualization of disease. Those with localized disease were no more likely to have an acute representation than those with regional metastatic disease. Patients with regional metastatic disease were no more likely to have a chronic/cyclic orientation than those with localized disease. While this may suggest that time line orientation is one aspect of a constellation of a dispositional response to illness, it is unclear how well the patients were informed of their disease and prognosis. Even if the biomedical information is communicated clearly and accurately by the physician, the patient must integrate and interpret the data into her everyday experience. Without that intersection, the substantive part of the medical dialogue may be misinterpreted or not processed by the patient (Mishler, 1984). Time line orientation was related to other dispositional measures of fear, worry, and anxiety. However, until the accuracy of patients’ perceptions of their disease can be assessed, the issue of whether time line is a dispositional trait is unresolved.

Interestingly, while physicians accurately rated (on the four VAS scales completed after the exam) those with more advanced cancer at initial diagnosis as having a worse prognosis at the follow-up examination, they also rated women who held a chronic/cyclic orientation as being more anxious and having a poorer prognosis (independent of stage of disease). Clearly, the physicians were able to identify distressed patients in that they correctly identified that patients who self-reported anxiety in the inventories were indeed anxious.
during the follow-up exam. In contrast, other studies have shown that oncologists often fail to recognize emotional distress in their patients (Derogatis, Abeloff, & McBeth, 1976; Ford, Fallowfield, & Lewis, 1994).

Physicians’ accuracy in assessing anxiety bodes well for enlisting them in identifying patients at high risk for distress in anticipation of follow-up exams. The puzzling and somewhat disconcerting finding is that those with a chronic/cyclic view received a worse prognosis rating from physicians regardless of actual stage of disease. It is suggested that prognosis ratings were based on objective data with respect to stage of disease and more subjective variables, such as patients’ behavior during contact with medical staff. The effect of the physicians’ judgments of anxiety and prognosis on patients’ subsequent perceptions or behavior is unknown. In this sample when the data was collected, there was no evidence that patients with a chronic/cyclic view actually experienced recurrences quicker and more frequently than those with an acute view, just that they received a less favorable rating. However, one would have had to follow these subjects for years to ascertain any relationship between their impressions of illness chronicity and disease course.

Little research has been conducted regarding time line conceptualization. Studies which specifically asked subjects to characterize the time line of their cancer, as in the present study, will be discussed. In the Leventhal et al. (1986) study, the data was not available to compare accuracy of patients’ time line characterizations to actual disease state. Heidrich, Forsthoff, and Ward (1994) asked oncology subjects (i.e., mixed sites) to describe their as cancer local or metastatic, and then to characterize it as acute, episodic, or chronic. These researchers collapsed the categories, as in the present study, and ended up with two groups:
Acute and chronic. Of those who described their illness as metastatic, 71% felt their cancer was chronic and 21% said it was acute. Of those who described their illness as local, 80% described their cancer as acute and 20% as chronic. In the Heidrich et al. study, subjects’ self-reports of their health status corresponded in a meaningful way with their perceptions regarding the time line for their illness; those who viewed the disease as metastatic were more likely to view the time line as chronic and those who viewed it as local were more likely to view the time line as acute.

There was no data presented on objective disease status in the Heidrich et al. research, only patients’ perceptions of disease stage. The authors argued that self-assessments of physical health were reliable and valid. Yet in the present study, where objective information on disease staging was provided, there was no meaningful correspondence between actual health status and subjects’ perception of the chronicity of cancer. It is possible that most subjects in the present study who characterized cancer as chronic/cyclic would have then described their disease as metastatic.

In the Leventhal et al. (1986) and the Heidrich et al. (1994) research, subjects were asked to characterize their cancer as acute, cyclic, or chronic. In the present study, subjects were not specifically asked to describe their disease. The three kinds of disease were described and then the subjects were asked, “Which one of these would you say that cancer is like?” Yet their responses were quite instructive in terms of their personal response to their own disease in terms of distress and coping. This differentiation may be important in that subjects were not asked to make a commitment about their own disease. Such a declaration could be quite threatening. For example, in a study on the development of anticipatory nausea
in chemotherapy patients, subjects were asked what side effects they expected to experience (Andrykowski, Redd, & Hatfield, 1985). As they read through the list they commented that while others might have suffered such effects, they did not think that they would. The expectation was too threatening. If the subjects had been instructed in the present study to reference their own disease, there may have been significantly more “acute” responses. Just as on the WOC-CA, when subjects were asked how much fear and uncertainty about the future they had experienced due to cancer, almost half reported no stress yet went on to endorse the coping items and indicate on other instruments that they were indeed experiencing fears about recurrence.

Time line is a critical factor in a patient’s perception of illness (Leventhal & Nerenz, 1985; Meyer, Leventhal, & Gutman, 1985) in that it influences one’s approach to the future, immediately with respect to treatment choices as in the Weeks et al. (1998) study, and in the long-term regarding achievable goals, self-perception, and quality of life (Heidrich et al., 1994). In a study on patients’ reactions to completion of adjuvant breast cancer therapy (Ward, Viergutz, Tormey, DeMuth, & Paulen, 1992), perceptions of illness time line predicted depression in subjects, while objective stage of illness did not. Women with a chronic orientation felt more vulnerable once treatment ended. This finding is consistent with the belief that one who feels their illness is chronic would feel more protected by ongoing treatment. Unfortunately, in the present study, subjects were not specifically asked their feelings regarding terminating treatment. It is proposed that those with a chronic/cyclic view would have felt more vulnerable at treatment termination than those with an acute view.
However, it is also possible that if one believes cancer is a chronic disease, she would posit that no treatment would produce a cure (Leventhal et al., 1986).

The cost of perceiving one's illness as chronic/cyclic appears to be significant, particularly when one has a good prognosis. Given the literature on the importance of preparation for relapse, having a chronic/cyclic view when one has an objectively poor prognosis may be adaptive in terms of cognitive preparation for negative outcomes. One initial thesis of the present research was that there is an optimal amount of worry to have regarding future outcomes: Too little worry and you are unprepared and will have a more difficult time adjusting; too much worry and you are paralyzed with fear, unable to live a fulfilled life.

What about when there is no recurrence or recurrence is an unlikely event? Unless there is a negative outcome to a follow-up exam, an acute orientation seems to have the capacity to protect patients from the distress associated with experiencing cancer. Even when there is a recurrence, if the patient is not in denial to the point of refusing treatment, is an acute view maladaptive? It is unclear. What is clear is that those who hold a chronic/cyclic view experience significantly more distress regarding follow-up examinations. It could be argued that realistically cancer is nearly always a slow killer, even in the best of cases, and that a chronic/cyclic orientation is an accurate one given the nature of the disease. Cancer is not, to use the example from the time line question, the measles. The belief that it is gone forever after treatment is usually inaccurate. Yet as noted in the literature review, there is some evidence that suppression of thinking about worst possible outcomes may be adaptive
(Cella & Lesko, 1988); life can be intolerable without some illusion (Taylor, 1983; Taylor & Brown, 1988).

Women with early stage disease with an acute orientation and women with later stage disease with a chronic/cyclic orientation hold congruous views in that their disease stage and disease view accurately reflect each other. The literature strongly suggests that patients who are unprepared and surprised by a recurrence are at greatest risk for adjustment problems to their medical condition (Cella et al., 1990; Northouse et al., 1995). Thus the risk for women with later stage disease who view cancer as acute is that they may be surprised, angry, and devastated if there is a recurrence. As noted above, if there is no recurrence, the optimistic outlook is likely to be beneficial. The group who may be at greatest risk is women with early stage disease who view cancer as chronic/cyclic. They were less positive about the medical care they received than those with an acute representation. Although not statistically significant in this sample, there was a trend that such women reported the highest levels of anxiety and distress. Like in the case of Mrs. M outlined in the literature review, these women may experience dissonance between their internal representation of cancer and their positive prognosis; they cannot trust what they hear about their own prognosis given what they believe to be true about cancer. Hence they experience distress and have more negative feelings about their medical care. The medical staff in turn may be frustrated by the patient’s negative attitude in light of positive medical information.
Clinical Implications

Certainly the relationship with the physician and medical team is crucial in one’s understanding of and adjustment to cancer (Butow et al., 1996; Hunt, Jordan, & Irwin, 1989; Rotter & Fallowfield, 1998; Siegel, 1998). Explanation of illness etiology, course, treatment, prognosis, and interpretation of the pathologist’s report and lab results are in the hands of the physician. Giving a realistic appraisal while quelling excessive fear is dependent on the skill of the physician. Being able to process complicated and frightening information is often difficult for the patient. Assessing what each patient needs physically, emotionally, and informationally within the parameters of communicating accurate and detailed information about the disease is a Herculean task. Encouraging or discouraging a positive outlook (e.g., acute view of the time line of cancer) is a delicate issue; does the professional aid in maintaining an illusion or help the patient confront the reality of the disease?

Just the act of communicating the prognosis is loaded with possible risk. Patient preferences for communication during diagnostic consultation may not be consistent with published guidelines for oncologists (Butow et al., 1996). It is noteworthy that four times as many women with an acute view said they based their estimate of the likelihood of disease recurrence on their doctor’s view of a quick recovery. What the women perceived that the physician said to them at the time of diagnosis and during treatment notably influenced their judgment of their future health status. This judgment of future health status as assessed by time line, based on information from the physician filtered through one’s own construction of the illness, was the most significant predictor of distress and psychological adjustment.
Subjects in the present study who reported negative feelings about their physicians were all quite concerned that the physicians not hear of their complaints. They literally felt that their lives were in the hands of these men and women and they did not want to risk angering or disappointing them. Such inhibition, especially for women with a lack of social support, may exacerbate their feelings of aloneness at a threatening time. One subject explained that she not only refrains from telling anyone she had cancer for fear of being treated differently, she doesn’t tell her doctor any of her concerns because “it seems to upset him.” Thus as noted in the discussion on social support, the very patients who need the most often feel they get the least.

Given the anxiety reported prior to the follow-up examination and the finding that the anxiety does not appear to dissipate over time, it would be beneficial to identify patients at high risk for distress and offer interventions to assist in coping with impending follow-up exams. The crux of the data presented in this study is that women who viewed cancer as a chronic/cyclic disease were at most risk. Whether accurate or not in terms of disease prognosis, a chronic/cyclic orientation suggests that the patient is at greater risk for psychological difficulties at the time of follow-up exams. They are expecting the worst possible outcome based on their perceptions of the chronicity of the disease; cancer is not a disease you ever recover from. Therefore, each exam is associated with a possible diagnosis of recurrence and subsequent death.

Once diagnosed with cancer, high risk individuals may carry a persistent identification as a cancer patient which alienates them from others and enforces limits to time, space, and available time (Little, Jordens, Paul, Montgomery, & Philipson, 1998). Little and his
colleagues identify this constellation of subjective experiences as **liminality** and argue that time since diagnosis and treatment, and the presence or absence of persistent or recurrent disease does not alter the enduring sense of vulnerability for some patients. The vulnerability may be exacerbated by the decreasing contact with the medical system in the years following treatment. It might be beneficial for high risk patients to have increased, systematic monitoring of psychological distress between infrequent office visits (Kornblith, 1998), and offer interventions to assist such patients.

It is likely that patients experiencing significant distress associated with the exam are also manifesting other concerns associated with surviving cancer. For example, while offering a relatively simple relaxation intervention to patients experiencing anticipatory nausea and vomiting associated with chemotherapy, other cancer-related issues often become apparent (Redd & Hendler, 1983). Some patients are more amenable to initially entering psychotherapy for a circumscribed problem (e.g., methods of controlling anxiety associated with a follow-up exam) and then exploring more difficult underlying fears which cancer patients (and indeed all individuals) have a harder time admitting to and finding an audience for. The basis of cancer patients’ fears is the basis of the most fundamental, overwhelming fear for everyone: The fear of death. Acknowledgment of the fear, recognition of associated feelings of isolation, and support in facing the future are the ultimate services any care giver can offer a patient who is coping with a potentially fatal disease.
Limitations of the Present Research

While the findings regarding time line appear robust and pervasive, there are limitations to the research design and assessment instruments which need to be considered. The primary concern is how participating in the study may have influenced the very behaviors and psychological symptoms that were being measured. Some subjects reported that they usually did not begin thinking about the follow-up exam until a week or even the night before the event. By talking about their fears a month prior to the exam, their typical approach to the doctor’s visit was disrupted.

Furthermore, the subjects may have had some awareness, even a month prior to the exam, what their physical status was. As noted earlier, self-assessments of health status are often correct (Diener, 1984; Heidrich et al., 1994). The one woman who ended up being diagnosed with a recurrence hinted at the first interview that she feared something was wrong. The results of the exam may not have been a complete surprise. The ambiguous, uncertain aspects of their condition, while legitimate, may have been overemphasized.

Although it appeared that there were no significant differences with respect to age, disease site, stage of disease, and time since diagnosis between participating and non-participating subjects, it is likely that these groups could have differed on the key psychological distress and coping variables assessed in this research. Subjects who were willing to discuss their experiences with cancer and those who were not were likely dissimilar groups. It is suspected that those who were unwilling to participate had a lower tolerance threshold for discussions about their cancer. These patients may have experienced higher
levels of distress than participating subjects, yet conversely, may also have reported little distress because they would have felt a need to suppress it. Indeed, subjects who are in such denial that they never return for follow-up exams could never be interviewed. In any case, because of the self-selection of subjects, the levels of distress associated with follow-up exams and fear of recurrence reported in the present study may underestimate the actual rate and intensity of distress in the population of cancer survivors.

Time since diagnosis appears to have no effect on fear of recurrence, but it may have been better to have placed the upper limit for eligibility at the four-year, post-diagnosis mark to avoid any confounding effect of passing the "magic five-year mark" (i.e., the benchmark used in oncology studies). As noted earlier, surviving five years disease-free can be a significant milestone for cancer patients, and the next research examining time line orientation and adjustment to surviving cancer could delineate the eligibility requirements more stringently. However, given that time since diagnosis was unrelated to any variable in this study, eliminating data from subjects who approached the five-year mark was not warranted.

It would have added more power to the statistical analyses to have had more subjects, particularly colorectal patients. There were many more patients with breast cancer to recruit. Site appeared to have little effect on any of the main variables, and it was reassuring to be able to generalize the results to patients with a different site than breast cancer. In retrospect, other sites could have been included to increase the potential subject pool and generalize to other sites.

Most of the assessment instruments were not designed specifically for cancer patients and therefore may not have been the most valid and reliable methods of determining the
distress and coping of cancer patients. Specifically, the WOC-CA had to be radically adjusted for use in this study (i.e., items for each factor had to be deleted) and results were thus hard to interpret at times. Dunkel-Schetter et al. (1987, 1992) wrote that changes in the WOC to adapt it to cancer patients do not appear to have altered the validity or internal consistency of the instrument. Interestingly, Stanton and Snider (1993) in their study of breast cancer patients, used the regular revised WOC (item content identical to the WOC-CA except for seven items), and ended up with the same factors as Dunkel-Scheter and her colleagues. However, as with any self-report measure, there are concerns about response biases and validity (Tennen & Herzberger, 1987).

Arthur Stone (see Stone, Kennedy-Moore, Newman, Greenberg, & Neale, 1992), in particular, has repeatedly argued that the WOC was derived from a very select subsample and that a comprehensive item pool was not obtained. Furthermore, he posits that when subjects respond to the extent that they use a particular strategy, it is unclear if they are referring to frequency, duration, or intensity. The retrospective nature of the subjects' responses is also problematic with respect to construct validity; did they actually cope the way they stated? (Although in the present research there is a very small retrospective interval.) Carver, Scheier, and Weintraub (1989) created their own theoretically based (as opposed to the empirically based WOC) coping instrument, the COPE, because of their view that the WOC has limited range and that some of the items lack clarity.

In the present study, the unexpected results with respect to whether subjects reported stress or not on the WOC-CA are a source of concern. As noted in Chapter 3 (Methods), before subjects responded to any coping items on the WOC-CA, they were asked how much
stress they had recently experienced due to the specified stressor. It is important to note that the stressor was specified for the subjects in this study (i.e., fear and uncertainty about the future due to cancer), while in other research using the WOC-CA the subjects specified their own personal stressor. Those who reported stress on the WOC-CA did indeed report more distress on other measures and were more likely to characterize the disease as chronic/cyclic than those who did not report stress. To review, 30 women reported no stress on the WOC-CA at any of the assessment points, but then went on to endorse coping items. One woman reported no stress on the WOC-CA and endorsed no coping items, yet indicated that she worried a tremendous amount about cancer when she went to the doctor. The remaining 49 subjects reported stress on the WOC-CA and endorsed coping items at all three assessment points.

It was surprising that a significant number of subjects endorsed coping items, yet reported no stress on the instrument; it seemed evident that if subjects endorsed coping items, they must have been experiencing stress. Low perceived stress may be the result of good coping (sometimes defensive coping), so one cannot conclude that subjects do not have to cope just because they say the subject is not stressful (A. Delongis, personal communication, May 12, 1989). It is also possible that individuals who endorse coping strategies without a stressor may be coping with a stressor they defined themselves, rather than the one specified for them. Therefore, they believe that they are not experiencing stress due to an uncertain health status, but may be experiencing some other cancer related stressor and go on to endorse items related to that stressor (C. Dunkel-Schetter, personal communication, October 29, 1997). That conclusion seems unlikely, however, given that the interviewer verbally reviewed
the instrument with subjects and emphasized the specific stressor that subjects should think about as they answered the questions. Acknowledging that fear and uncertainty about the future due to cancer is stressful may have been too threatening for some, especially those who were invested in minimizing or distancing themselves from their worst fears.

Clearly, there may be problems with the validity and reliability of the WOC-CA. Nevertheless, the WOC has been used with medical populations and seemed an appropriate instrument to use to assess coping when the data was collected. It is helpful in terms of comparing coping strategies to other research which used the WOC and WOC-CA. However, future research should assess coping using more current instruments specifically designed for oncology patients.

Implications for Future Research

It is unknown what underlying processes are responsible for one's orientation to illness and why objective stage of disease does not parallel time line orientation. As Leventhal and his colleagues note (1986), the processes through which patients experience worry and distress about cancer are elusive. Theoretically, patients with localized and regional metastatic disease should exhibit different patterns with respect to fear of recurrence. But empirically, in this study, there are few differences. Do the patients not understand their diagnosis, stage of disease, and prognosis; is that information not disseminated clearly or are the patients too preoccupied at the time of diagnosis to digest complex, possibly disturbing data? Or does the patient have a clear understanding of the statistics associated with the illness, but chooses to
base her judgments on subjective perceptions of illness severity and time line as a form of coping with the disease?

Assessing exactly what patients understand about their medical condition and the relationship between their understanding and time line orientation of disease is the next logical research project after the present study. Such a study would also be a means of replicating the present findings in terms of what appears to be a most crucial role of time line orientation. The variables assessed in the present study, such as personality factors, degree of optimism, and social support (e.g., family, friends, medical team) appear related to one’s conceptualization of time line of cancer. It is imperative to specifically assess one’s understanding and view of cancer, and then determine the pathway from illness representation to personal judgments of prognosis and daily functioning.

Ideally, the design would be a longitudinal study following a large sample of women over several follow-up exams (i.e., years beyond the “five-year mark”) with appropriate assessment instruments designed exclusively for oncology patients. A valid coping instrument would allow an examination of how time line may moderate the relationship of coping to distress. For example, if a woman believes that the disease is acute, does she utilize different (e.g., preventive, active) strategies from a woman who believes the disease is chronic/cyclic (e.g., acceptance, avoidance). Comparing subjects with the same disease stage and differing time line orientations on psychological and medical outcome measures would be informative. Multiple sites should be included in order to assess the generalizability of the findings. A sample of men with comparable diagnoses should also be included to determine what, if any, sex differences exist with respect to time line orientation.
Just as in the Weeks et al. (1998) study on the effect of patients' estimates regarding survival time on treatment choices, patients' conceptualization of time line may play a pivotal role in psychological adaptation to cancer as well as acceptance of treatment options and satisfaction with medical staff. It is likely that time line conceptualization will be a concept that is applicable to patients' methods of coping with almost any disease. Assessing how subjects view the time lines of various diseases would be edifying and instructive in terms of understanding models of illness representation and aiding patients at risk for maladaptive distress.

An investigation of what interventions are effective for assisting patients with their fears regarding follow-up examinations is needed. As noted in the section on clinical implications, if the fear is indeed a fear of death, relaxation training and time-limited supportive therapy may not be enough. The subjects in the present study appeared to gain relief from discussing their concerns with a professional within the safety of being a research subject, thereby performing an altruistic act. As one subject said, “I don’t think about the cancer unless I can help someone else.” Creating an intervention that hesitant patients with little social support would agree to participate in, may be the most necessary, challenging, clinically relevant future research.
REFERENCES


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APPENDIX A

RECRUITMENT LETTER FROM ONCOLOGIST
Dear

The Carle Cancer Center is sponsoring a study in conjunction with the University of Illinois to better understand how women who were diagnosed with cancer cope with medical examinations by their physicians. We hope that this study will help to provide better care for our patients.

As a patient who has dealt with cancer, you can help us. We are contacting women over the age of 35 who have completed treatment for breast or colon-rectal cancer at least six months prior to participation in our study. What we will ask you to do is to fill out a series of questionnaires, and talk with Cobie Hendler, Project Coordinator, at three time points. The first time will be about one month prior to your scheduled appointment with your physician. All information will be kept strictly confidential and will be used for research purposes only.

If you qualify for this study and participate, you will receive a $25 gift certificate from a leading Champaign department store as a token of our appreciation.

I hope that you will take the time to help us with this project. The information we obtain from patients is very important in planning how to help current and future patients and their families. If you choose not to participate, this decision will in no way affect your continued treatment at the Cancer Center.

I have enclosed a card for you to complete and mail back to us. It is already addressed and stamped, so you just have to drop it in a mailbox after filling it out. We would appreciate receiving this card whether or not you wish to participate. You can let us know on this card that you wish to be considered for participation or call Cobie Hendler at the Cancer Center (217-337-3010) to volunteer. You will be reimbursed for the cost of the phone call if you are calling long distance. Upon receiving your phone message or card, Ms. Hendler will contact you to explain the project in more detail and schedule your interview.

Thank you for considering participation in this valuable study. We look forward to hearing from you soon.

Sincerely,

Alan K. Hatfield, M.D., F.A.C.P.

CARLE CANCER CENTER

Hematology
James R. Egner, MD
Jessie G. Houston, MD

Medical Oncology
James R. Egner, MD
Alan K. Hatfield, MD, F.A.C.P.
Patricia A. Johnson, MD, PhD
Kenneth M. Rowland, Jr., MD

Radiation Oncology
Stephen R. Andrews, MD
Guy Redford, MD

Radiologic Physics
Richard Nelson, PhD

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APPENDIX B

PHONE SCREENING FORM
PHONE SCREENING

Name: ____________________________ Date: ____________

1. Was your diagnosis of breast/colon/rectal cancer in 198__ your first diagnosis of cancer?
   ____yes  ____no
   If "no", ask for site(s) and date(s) of other diagnosis.

2. What type of treatment did you receive?
   ____surgery  ____radiation
   ____chemotherapy  ____hormones (e.g., Tamoxifen)

3. A) When did you finish treatment?_______________________________
   B) Are you on any medication now? What for? ________________

4. Who is your primary physician for your cancer checks?
   ____________________________

5. A) When was the last time you saw him/her?_______________________
   B) When are you scheduled to see him/her again?__________________
   C) Is this scheduled appointment for a regular cancer check up?
      ____yes  ____no (If "no" find out when next check is)

6. Could you describe your physical health right now. Any major problems? (Look for life threatening ailments, disabilities, etc.).
   ___________________________________________________________________

Interview #1 scheduled for __________________ at _____________.
   Date _______________ Time __________________
   Place: ____________________________

Carle cancer clinics: Mahomet, Monticello, Rantoul, Danville (2), Bloomington-Normal, Urbana.
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Appendix C 159-163

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APPENDIX D

SPIELBERGER STATE/TRAIT INVENTORIES (STAI)
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APPENDIX F

BRIEF SYMPTOM INVENTORY (BSI)
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APPENDIX G

FEAR OF RECURRENT QUESTIONNAIRE (FOR)
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APPENDIX H

LIFE ORIENTATION TEST (LOT)
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APPENDIX I

SELF-CONTROL SCHEDULE (SCS)
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APPENDIX J

MEDICAL INTERVIEW SATISFACTION SCALE
(MISS)
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APPENDIX K

MODIFIED PSYCHOLOGICAL ADJUSTMENT TO ILLNESS SCALE: SELF-REPORT (PAIS-SR)
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Appendix L 197-198

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Appendix M 200-201

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Appendix N 203-205

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UMI
DEMOGRAPHIC INFORMATION

1. What is your sex?
   ____ male
   ____ female

2. In what year were you born? 19__

3. What is your marital status?
   ____ never married
   ____ married
   ____ divorced
   ____ widowed
   ____ separated

4. In what city and state do you live?
   City _____________________________
   State _____________________________

5. Are you currently
   ____ working full time
   ____ working part time
   ____ with a job, but not at work due to illness
   ____ unemployed
   ____ retired
   ____ going to school
   ____ keeping house
   ____ other (please specify)___________________________

6. If you are employed, what is your job title? If you are retired, please indicate your former job.
   ____________________________________________
7. How many people live in your household?

   ____ 1-2
   ____ 3-4
   ____ 5-6
   ____ more than 6

8. What is the highest level of education you have completed? (circle the highest grade completed)

   1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17+
   (high school) (college or post-tech school) grad.

9. What is your family's income range? [Optional]

   ____ below $10,000
   ____ $10,000 - 19,000
   ____ $20,000 - 29,999
   ____ above $30,000

10. What is your religious preference? [Optional]

    ____ Protestant (please specify denomination) ____________________________
    ____ Catholic
    ____ Jewish
    ____ Other (please specify)______________________________________________
Authorization to Release Information

In signing this consent you are authorizing Carle Clinic and Hospital to release only the specific information listed. This information is needed as a part of the research project you are participating in on how women cope with cancer. This information will be held strictly confidential and will not be communicated to anyone else except as necessary for the summarization of the research information.

You have a right to inspect and copy the information to be disclosed. Make sure that all blanks are filled in before signing this form. You have a right to refuse to sign this consent although this will mean that you will not be eligible to participate in the research project.

You may revoke this authorization at any time by writing to Ms. Cobie Hendler, Department of Psychology, University of Illinois, 603 E. Daniel, Champaign, Il., 61820.

I authorize Carle Clinic and Hospital of Urbana, Illinois, to release the following information regarding my past, current, and future treatment:

1. Original diagnosis and stage of illness of cancer
2. Types of treatment and dates of treatment for cancer
3. Any behavioral or emotional reactions encountered during treatments
4. Any referrals for supportive psychological or psychiatric services or prescription of medications during or since treatment of cancer
5. Current state of health or stage of illness and prognosis

The above information in regard to ______________________________ will be released to Cobie Hendler, Department of Psychology, University of Illinois, 603 E. Daniel, Champaign, Illinois, 61820.

_________________________  ____________________________
Signature of patient        Witness

_________________________
Date signed

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APPENDIX Q

CONSENT TO PARTICIPATE IN RESEARCH
CONSENT TO PARTICIPATE IN RESEARCH

"Psychological Adjustment and Coping After Treatment For Cancer"

I state that I am over eighteen (18) years of age and agree to participate in a program of research being conducted by Cobie Hendler of the Psychology Department at the University of Illinois at Urbana-Champaign.

The purpose of the research is to better understand how women who were once diagnosed with cancer cope with an upcoming medical examination by their oncologist.

The extent of my participation will be talking with Cobie Hendler or her research assistant and filling out a series of questionnaires at three different time points. The first time will be about one month before my doctor's visit, the second will be 2-3 days before the visit, and the third will be 2-3 weeks after the doctor's examination. My participation will take approximately 90 minutes at the first time point, and less than one hour at each of the other two times.

I understand that my oncologist will be asked to briefly describe his or her assessment of my condition on a form which only the oncologist and Cobie Hendler will see.

I understand that as a result of participating in this research I may experience some emotional upset as I talk about my reactions to the cancer. I understand that the purpose of this research is not in any way to create feelings of upset, but to express openly ways of coping with stressful events.

I understand that I will not necessarily receive personal benefits from my participation in this research. I do know that this study may benefit future cancer patients by increasing our understanding of how patients adjust to the uncertainties associated with a disease such as cancer, and of how helping professionals can be of better assistance to patients.

I understand that my participation is voluntary and that I may withdraw at any time. However, I understand that I will receive the participation gift for actually completing the entire study. I understand that if I have any questions regarding the research, I may call Cobie Hendler at 333-6312.
I understand that all information that I provide will be number coded so that my name will not be associated with the data. All my answers will be kept strictly confidential and will not be shared with physicians or other staff at Carle without my expressed written consent.

I understand that I may receive a copy of this form if I so desire.

I understand that in the event of personal injury or adverse reactions resulting from this research, there is no compensation available for such injury and that any necessary medical care required will be handled in the same way as my usual medical care.

I understand that a record of my participation in the study will be kept in confidential form and confidentiality is carefully guarded. During their required reviews, representatives of the Food and Drug Administration (FDA) have access to medical records which contain my identity; however, no information by which I can be identified will be released or published.

________________________
Signature of patient

________________________
Signature of witness

________________________
Date
APPENDIX R

LETTERS TO PHYSICIANS AND VISUAL ANALOG SCALES (VAS) RATINGS
Dear Dr.

I am conducting a research project with Dr. Alan Hatfield on how women who were once diagnosed with breast or colon-rectal cancer cope with the threat of disease recurrence. To better understand the patient's reaction, it would be most helpful to have your evaluation of the patient's prognosis, anxiety level, and the quality of your relationship with the patient. Attached is a copy of the specific questionnaire that I would appreciate your cooperation in completing for select patients. A copy of the research proposal is available upon request. When the results of the study are available, I would be happy to send you a summary of the findings.

Specifically, I will send you a questionnaire for the subjects who are your patients several days before they are scheduled for a medical examination. Please try to complete the questionnaire immediately after your appointment with the patient.

I very much appreciate your assistance in the collection of this data. There is little information on how cancer patients cope with potentially threatening events, such as a medical recheck examination for recurrence. We hope that this research will enable us to better predict which patients are at risk for developing problems with long-term adjustment after a diagnosis of cancer, and to plan appropriate interventions to assist medical staff and patients in coping with such problems.

Please call me (333-6312 or 352-9171) if you would like further information or if you have any questions.

Sincerely,

Cobie S. Hendler, A.M.
Dear Dr.

_____________________________ has an appointment scheduled with you for ______________________. As per the letter I sent you describing our research project on how women who were once diagnosed with cancer cope with the threat of disease recurrence, could you please complete the attached questionnaire for the aforementioned patient. Please try to fill out the questionnaire as soon after the appointment as possible. After completing it, please enclose it in the attached envelope and return it to the receptionists in the Oncology Department at Carle Clinic.

Thank you very much for your assistance.

Sincerely,

Cobie S. Hendler, A.M.

CARLE CANCER CENTER

Hematology
James R. Egner, MD
Jessie G. Houston, MD

Medical Oncology
James R. Egner, MD
Alan K. Hatfield, MD, F.A.C.P.
Patricia A. Johnson, MD, PhD
Kenneth M. Rowland, Jr., MD

Radiation Oncology
Stephen R. Andresen, MD
Guy Kedziora, MD

Radiologic Physics
Richard Nelson, PhD

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COPING WITH THE THREAT OF RECURRENCE STUDY
Investigator: Cobie Hendler (333-6312)

PHYSICIAN'S ASSESSMENT

Please answer the following questions immediately after your appointment with the patient. Base your judgments on your experiences with cancer patients. Draw a mark on the line at a point that best describes your response.

Patient's Name _____________________________________________________________

Physician ___________________________________________________________________

Date _______________________________________________________________________

1. The medical prognosis for this patient is

   Excellent _____________________________________________________________ Extremely poor

2. How anxious did the patient appear to be during the examination regarding her prognosis?

   No anxiety _____________________________________________________________ Anxiety as bad as it could be

3. How would you describe the quality of your relationship with this patient?

   Excellent _____________________________________________________________ Extremely poor

4. How do you think the patient would describe the quality of your relationship with her?

   Excellent _____________________________________________________________ Extremely poor
VITA

COBIE S. SILVERMAN

Education
1999  Ph.D.  Clinical Psychology, University of Illinois at Urbana-Champaign
       Major areas:  Clinical Psychology
       Minor areas:  Developmental Psychology & Social Psychology
1986  A.M.  Clinical Psychology, University of Illinois at Urbana-Champaign
1980  B.A.  Psychology, University of Virginia

Professional Memberships
American Psychological Association, student affiliate
Society of Behavioral Medicine, student affiliate

Honors and Awards
1982  Milton Erickson Award of Scientific Excellence for Writing in Hypnosis
1981-1982  NIMH Predoctoral Traineeship, University of Illinois
1980  Phi Beta Kappa
1980  Graduated with High Distinction, University of Virginia
1978  Intermediate Honors, University of Virginia
1978  Psi Chi Psychology Honorary Fraternity
1976-1980  University of Virginia Scholarship
1976-1977  duPont Scholarship, University of Virginia

Clinical Experience
1982-1989  Clinical Psychology Extern, University of Illinois Psychological Services Center: Long- and short-term psychotherapy with adults, children, families, and couples using cognitive-behavioral and psychodynamic approaches; specialization in therapy with medically ill clients.

1985-1986  Clinic Assistant, University of Illinois Psychological Services Center: Intake and diagnostic interviewing; crisis intervention; administration of counseling contract with the Division of Children and Family Services (DCFS); supervision of first-year graduate students in intake interviewing and introductory psychotherapy; supervision of undergraduate Mental Health Worker’s internship at the Psychological Services Center.

1984-1985  Clinical Interviewer, research project directed by Dr. Barton Hirsch on how adolescents cope with the transition to high school: Conducted interviews with adolescents on their friendship networks as well as formal assessments
of their psychiatric histories using the Schedule for Affective Disorders and Schizophrenia (SADS).

1982-1984 Hypnotist and Relaxation Therapist, University of Illinois Psychological Services Center: Trained cancer patients who suffered from chemotherapy-related nausea/emesis on how to use relaxation strategies better control their responses to the aversive side effects of the medication.

1980-81 Psychiatric Technician, David C. Wilson Neuropsychiatric Hospital, Charlottesville, Virginia.

Teaching Experience

1987-1988 Instructor, University of Illinois at Urbana-Champaign, Mental Health Worker’s Program: Taught two introductory classes in interviewing and behavior therapy strategies for junior undergraduate students.

1983-1985 Teaching Assistant, University of Illinois at Urbana-Champaign, Mental Health Worker’s Program: Duties included supervising students (individually and in groups) on their internship duties at community agencies, and assisting in the instruction of interviewing techniques, communication skills, and behavioral strategies of intervention.

1979 Teaching Assistant, University of Virginia, Undergraduate Abnormal Psychology Class (I was the only undergraduate selected to be a teaching assistant).

Research Experience


1983-1985 Master’s thesis research on cancer patients’ compliance with relaxation procedures designed to alleviate the aversive side effects of cancer chemotherapy.

1982-1983 Research Assistant to Dr. William H. Redd, University of Illinois at Urbana-Champaign: Involvement in a variety of psycho-oncology related research projects.

1978-1980 Research Assistant to Dr. James W. Pennebaker, University of Virginia: We jointly designed and completed a project designed to investigate how social factors influence absenteeism in nursery school children.
1977-1978 Research Assistant to Dr. Frank W. Finger, University of Virginia: Experiment Manager for series of circadian rhythm studies with rats.

1979-1980 Research Assistant to Dr. Robert S. Brown, University of Virginia: Designed and administered an exercise inventory to examine the effects of lifelong physical activity patterns on the health status of cancer patients.

1979 Research Assistant to Dr. Jay S. Segal, University of Virginia: Assisted in collating and editing the sexual autobiographies of college undergraduates from five American universities for research on the sexual beliefs and behaviors of college students.

Publications


Presentations
Hendler, C. S., & Redd, W. H. (1985, November). Fear of hypnosis: The role of labeling in patients’ acceptance of behavioral interventions. Presented at the 19th Annual Convention of the Association for the Advancement of Behavior Therapy. (Note: C. S. Hendler was my married name used for the publications and presentation listed above.)