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The Importance of Meaning in the Adjustment of Lung Cancer Patients and Their Partners

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THE IMPORTANCE OF MEANING IN THE ADJUSTMENT OF LUNG CANCER
PATIENTS AND THEIR PARTNERS

By

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ABSTRACT

The purpose of this study was to examine if degree (on a continuum from negative to positive) and/or similarity of patients’ and their partners’ meanings of the lung cancer illness significantly influenced psychosocial adjustment in a low-income, urban sample of couples (n = 35). Findings were consistent with those of other studies. A significant actor effect (p = .00) was found for both patients and partners, with individuals viewing the illness more positively reporting better adjustment. However, no significant partner effect was found. In addition, the degree of similarity between patients’ and partners’ meanings was not significantly related to the psychosocial adjustment of either. Findings suggest that lung cancer patients and their partners who hold a highly negative view of the illness may be appropriate targets for intervention. However, it does not seem necessary that patients and partners are congruent in their meanings attached to the illness. Additional research on the relationship between meaning and psychosocial adjustment to the lung cancer illness is warranted. Implications for the development and delivery of psychosocial interventions in an oncology setting are discussed.
CHAPTER 1

The Importance of Meaning in the Adjustment of Lung Cancer Patients and Their Partners

“There are no psychosocial problems without biological features, and no biomedical problems without psychosocial features.” (McDaniel, Hepworth, & Doherty, pp. 1-2, 1992)

Cancer

Second only to heart diseases, cancer is a leading cause of death in the United States, accounting for one in every four deaths (American Cancer Society, 2006). According to the National Cancer Institute (Ries et al., 2005), cancer death rates are higher in men than in women in every racial and ethnic group, although racial and ethnic differences in cancer cases and death rates exist. African American men and women have the highest rates of cancer mortality, whereas Asian and Pacific Islander men and women have the lowest cancer death rates (i.e., about half that of African American men and women, respectively).

The most recent numbers indicate that there were approximately 10,496,000 individuals (4,692,397 men and 5,803,603 women) alive in the United States who had a history of cancer (Ries et al., 2005). This includes any person alive with active and cured cancers. However, these numbers do not reflect the multiple family members also influenced by the cancer illness. Cancer has increasingly become a family illness, and families, rather than just patients, are at risk after a cancer diagnosis (Mellon, Northouse, & Weiss, 2006). Families experience cancer along with patients, and strong support exists in the research for including family members when planning cancer treatment (Dow, Ferrell, Haberman, & Eaton, 1999).

Lung Cancer

According to the American Cancer Society (2006), lung cancer is the most commonly diagnosed and most fatal cancer in both men and women. Lung cancer causes more deaths than the next three most common cancers, colon, breast, and prostate, combined. Worldwide, over three million people are living with lung cancer, the majority residing in developed countries (American Lung Association, 2006). Approximately 60% of people with lung cancer die within one year of being diagnosed with the illness, and between 70% and 80% die within two years of diagnosis (American Lung Association). Lung cancer deaths among American females are among the highest in the world; however, death rates for males in the United States are still higher than those for females (Ries et al., 2006).

Last year, an estimated 351,344 Americans were living with lung cancer (Ries et al., 2006), with 174,470 new cases of lung cancer expected to have been diagnosed (American Cancer Society, 2006). The experience of living with a potentially fatal illness such as lung cancer can have an influence on the physical, psychological, social, and spiritual dimensions of patients’ and their loved ones’ daily living (Zebrack, 2000).
Researchers have suggested a variety of factors, including clinical, demographic, and health status characteristics, that influence the quality of life of individuals facing lung cancer (Sarna et al., 2005).

Zabona, BrintzenhofeSzoc, Curbow, Hooker, and Piantadosi (2001) reported that, compared to patients with other types of cancer, individuals with lung cancer endorsed the greatest amount of psychological distress. In addition, several researchers have reported that women with lung cancer have higher levels of anxiety and greater concerns after diagnosis than men (Hill, Amir, Muers, Connolly, & Round, 2003; Hopwood & Thatcher, 1990). However, Svobodnik, Yang, and Novotny (2004) reported that women with all stages of the lung cancer illness had significantly better quality of life scores when compared to men.

**STATEMENT OF PROBLEM**

Although evidence exists that a more positive meaning attached to the cancer illness is associated with better outcomes in both patients and partners (e.g., Germino, Fife, & Funk, 1995; Mellon & Northouse, 2001), the body of research supporting this relationship is plagued by both methodological and statistical shortcomings. For example, many researchers who have studied this relationship have failed to control for possible confounding variables, such as site and stage of cancer and type of family unit. Moreover, most of these studies treated the data of patients and their family members as independent rather than pairing them, which is clearly not appropriate for individuals in close relationships. To address many of these limitations, the purpose of this study was to examine if degree (on a continuum from negative to positive) and/or similarity of meaning attached to the illness significantly influenced patients’ and their partners’ psychosocial adjustment to lung cancer. First, I improved upon previous studies by controlling for site of cancer and type of family unit by including only couples facing lung cancer. Second, I examined the importance of congruence of patient and partner meanings in the psychosocial adjustment of each to the lung cancer experience, which has been widely neglected in the research.

Although researchers have often studied the influence of meaning on individual outcomes of cancer patients or their loved ones, there has been little research examining partner data and how individual and relationship variables are linked. Instead, research has commonly focused on individuals’ meaning of the cancer illness without an exploration of how both partners are making meaning of the illness or how each partner’s meaning influences that of the others’. Although family researchers (e.g., Thompson & Walker, 1982) have called for increased focus on the couple as the unit of analysis, few have done so.

**PURPOSE OF STUDY**

The purpose of this study was to examine if the degree and/or similarity of patients’ and their partners’ meanings attached to the lung cancer illness significantly influenced their psychosocial adjustment. This study differed from and addressed many of the limitations of the previous research in several ways. First, the site and stage of cancer was controlled by examining meaning in the context of stage III (A or B) and IV (i.e., advanced) non small cell lung cancer. Although stage of cancer was not originally
used as an exclusionary criterion, all patients in the sample had stage III (A or B) or IV lung cancer. That is, surgery was not an option for these patients due to the fact that the lung cancer was advanced or, in those with stage IV, had metastasized. Second, the type of family unit was controlled by including only couples who were married or had lived together for one year or more. More importantly, patient and partner data were paired, an uncommon feature in previous research. Third, the psychometric properties of the measures of both meaning and psychosocial adjustment to the illness used were supported for use with cancer patients in previous research. Fourth, by sampling from patients and their partners at a community hospital in a large city, participants represented a greater variety of racial, ethnic, and socioeconomic backgrounds than in previous studies. Finally, this study, unlike any other quantitative study found, assessed the congruence of patients’ and partners’ meaning of the illness and examined how this influenced psychosocial adjustment to the lung cancer illness.

RESEARCH QUESTIONS

1. To what extent do patients with more positive meanings attached to their lung cancer have better psychosocial adjustment to the illness?

2. To what extent do partners with more positive meanings attached to their lung cancer have better psychosocial adjustment to the illness?

3. To what extent do patients with more positive meanings attached to their lung cancer have partners with better psychosocial adjustment to the illness?

4. To what extent do patients with partners with more positive meanings attached to their lung cancer have better psychosocial adjustment to the illness?

5. Does the extent to which a couple has similar meanings attached to the illness influence the psychosocial adjustment of patients?

6. Does the extent to which a couple has similar meanings attached to the illness influence the psychosocial adjustment of partners?

CONCEPTUAL DEFINITIONS

For the purposes of this study, meaning of illness was defined as individuals’ unique perceptions of the world as they know it and the ways in which they perceived the illness redefining their world, place in that world, and personal identity (Fife, 1994). Psychosocial adjustment to illness was defined as patients’ and their partners’ perception of their ability to overcome the effects of the illness on their relationships and performance at work and home (Derogatis & Derogatis, 1990).
THEORETICAL FOUNDATION

Symbolic Interactionism

More than any other family theory, symbolic interactionism calls for attention to how events and things are interpreted by social actors (White & Klein, 2002). The term symbolic interactionism represents a diverse set of family theories, all based on the maxim that what individuals define as real has real consequences (Thomas & Thomas, 1928). This provides a linkage between how individuals perceive their environment and how they act in it (Blumer, 1969). Although it posits that individuals are motivated to create meanings to help them make sense of their world, symbolic interactionism is more than simply a motivational theory. In addition, it also encompasses actors’ motives as constructed from the meanings available to the actor and relevant to the situation in which the actor is located (White & Klein). Therefore, the general focus of symbolic interactionism can be summed up as the acquisition and generation of meaning.

Blumer (1969) outlined three core principles of symbolic interactionism:

- People act toward things, including each other, on the basis of the meanings they have for them.
- These meanings are derived through social interactions with others.
- These meanings are managed and transformed through an interpretive process that people use to make sense of and handle the objects that constitute their social world.

To understand the term meaning in a social context, symbolic interactionists focus on the idea of how complex symbol systems are shared. Blumer argued that meaning is neither inherent in an object or event nor a combination of psychological elements of the individual. Instead, meaning is a product of an interactional process between individuals. That is, meaning emerges through the course of social interaction (White & Klein, 2002).

Symbolic interactionism provides a framework for understanding the role of meaning in couples’ responses to the disruption of life that results from lung cancer. Researchers may be able to predict patient and/or partner adjustment by exploring how patients and partners make sense of what it means to have lung cancer or to be in a relationship with someone who has lung cancer. By studying how the lung cancer illness is socially constructed, both within the couple and in society, researchers can examine how social forces shape patients’ and partners’ understanding of and actions toward health, illness, and healing (Brown, 1995).

White and Klein (2002) stated that effective relationships, both in and outside of families, are “dependent on nurturing a culture of shared meanings” (p. 63). Applied to the context of the lung cancer experience, this suggests that couples must have relatively similar meanings of the illness in order to adjust to the demands associated with the experience. However, not all patients and partners are able to achieve this.
Assumptions

1. *Individuals find meaning in the circumstances associated with a traumatic event, for at least it is inherent in the event itself and implicit within the individual’s response* (Blumer, 1969).

2. *Individuals act toward an event based on the meaning that the event holds for them.* The meaning individuals attach to events arises out of both past and present social processes (Stryker, 1959).

3. *Actors define the meaning of context and situation.* Extending upon the previous assumption, humans live in a symbolic world; therefore, what individuals define as real has real consequences (Thomas & Thomas, 1928). How individuals define situations explains what problems they define and what actions and solutions they undertake (White & Klein, 2002).

4. *Individuals have minds* that acquire, integrate, and process information, as well as reflect on their own processes so that the individual can develop a self as both actor (I) and object (me) (White & Klein, 2002).

5. *The human being is both actor as well as reactor* (Stryker, 1959).
CHAPTER 2
REVIEW OF LITERATURE

When an individual is diagnosed with a serious illness, such as lung cancer, a negative outlook seems warranted. On the contrary, some individuals dealing with serious illness seem to find and to focus on the positive aspects of their experience, concentrating on the benefits the illness brings rather than on the losses suffered. Meaning becomes particularly significant in the context of serious illness because such an experience “imposes irrevocable change that totally disrupts the continuity of everyday life” (Fife, p. 309, 1994).

Few life events have a greater impact on families than the life-threatening illness of a member. Because cancer treatment is increasingly provided in outpatient settings and in patients’ homes, friends and relatives often assume the responsibility for assisting patients in managing the illness- and treatment-related side effects (Miaskowski, Kragness, Dibble, & Wallhagen, 1997). Family caregivers, especially spouses, are providing the majority of home health care for individuals with cancer (Kurtz, Kurtz, Given, & Given, 1995). However, most of what is known about adjustment in the face of serious illness is based on studies of individuals (i.e., just patients, just family members, or patients and family members who are not in relationships together).

The meaning individuals ascribe to a serious illness influences their appraisal of the experience, and influences their responses and adjustment (Cassel, 1982). In part because of the stigma (Chapple, Ziebland, & McPherson, 2004) and severity of the lung cancer illness, negative meanings attached to the illness may be more likely in patients with lung cancer than those with other types of cancer and may be negatively related to their adjustment, as well as that of their loved ones.

Meaning

Alfred Adler (1958) said, “Human beings live in the realm of meanings,” adding that “we experience reality always through the meaning we give it; not in itself, but as something interpreted” (p. 1). If this is true, then it seems appropriate to study patients’ and their loved ones’ adjustment to serious illness in terms of the meanings they attach to the experience. This idea that individuals’ ability to adjust to a stressful experience is influenced by the meaning it has for them is not new. Research on this issue has drawn on perspectives from clinical psychology (Beck, 1995; Ellis, 1996; Frankl, 1970), social psychology (Kelley, 1971), and sociology (Antonovsky, 1979). Moreover, the search for meaning as a process and meaning as an outcome are aspects of several theories and models of psychological adjustment to stress, including the ABC-X (Hill, 1949) and Double ABC-X model (McCubbin & Patterson, 1983), Theory of Cognitive Adaptation (Taylor, 1983), Life Schemes Framework (Thompson and Janigian, 1988), extension of the Transactional Model of Stress and Coping (Park & Folkman, 1997), and minimalist model presented by Lee and Dwyer (1995). In addition, the results of observational (Chodoff, Friedman, & Hamburg, 1964; Visotsky, Hamburg, Goss, & Lebovits, 1961) as well as empirical (Bevino & Sharkin, 2004) studies have supported the notion that finding positive meaning in an undesirable experience is especially important for
subsequent adjustment. Thompson (1985) suggested that focusing on the positive aspects of a stressful experience may lead to enhanced coping because it helps people deal with the psychological issues associated with the experience, “to determine why it happened, who (if anyone) is to be held responsible, and what meaning the event has for one’s life and one’s view of the world” (p. 280).

One major obstacle that researchers have come up against in their attempts to understand the role of ascribed meaning to undesirable situations and subsequent adjustment has been the lack of clarity with regard to the definition of meaning. Several researchers have attempted to clarify the concept of meaning and/or meaning-making (e.g., Fife, 1994; Lee, Cohen, Edgar, Laizner, & Gagnon, 2004; Park & Folkman, 1997; Skaggs & Barron, 2006). Clinical scholars have also described the concept of meaning as central to understanding and working with individuals and families (Rolland, 1994; Walsh, 1998). Still, researchers have yet to reach consensus on a definition of the term or the way to most effectively measure meaning.

Two frameworks, meaning-as-significance and meaning-as-comprehensibility (Janoff-Bulman & Frantz, 1997) encompass the various definitions of meaning used in the research. The first, meaning-as-significance, involves focusing on individuals’ perceptions of the significance of the event in relation to life goals and purpose and often involves individuals’ considering the benefits of negative life events (Taylor, 1983). Examples of this include individuals’ reporting that they gained a better perspective on life and closer family relations (Affleck, Tennen, & Gershman, 1985). The second, meaning-as-comprehensibility, explores individuals’ ability to fit the event into their existing worldviews (Janoff-Bulman, 1992). In western culture, this often involves interpreting events so that they appear just and non-random (Janoff-Bulman). Examples of this include individuals’ attributing the event to God’s will or, in the case of lung cancer, the actions of the ill individual. The focus of this study was meaning-as-significance. Within the research examining meaning-as-significance, meaning has been conceptualized as a predictor of adjustment and an outcome in itself. In this study, meaning was considered as a predictor of psychosocial adjustment to the lung cancer illness.

Cancer and Meaning

Several researchers have documented the importance of finding meaning in the face of cancer (e.g., Barkwell, 1991; Lewis, 1989; O’Connor, Wicker, & Germino, 1990). Taylor (1983) has shown that cancer patients and their families in early stages of the disease report a number of benefits from the experience, including increased personal strength, closer family ties, identification of life priorities, and greater insight into life and human nature. Indeed, the search for positive meaning appears widespread in cancer patients, with 40% of patients in the mid-stages of the disease report wanting help in finding meaning in life (Moadel et al., 1999).

Major stressful experiences, such as lung cancer, are clearly influenced by the meaning that individuals and family members give to them (Mellon, 2002). Family members must somehow integrate the changes brought on by the illness, and also comprehend the meaning for themselves as individuals and for the family as a whole (Germino, Fife, & Funk, 1995). In addition, patients and their loved ones might have a
need to find meaning in anticipation of the increasing pain and possible death associated with advanced lung cancer.

Although the meaning attached to the illness has been explored with cancer patients (e.g., Taylor, 1995) and survivors (e.g., Vickberg, Bovbjerg, DuHamel, Currie, & Redd, 2000), few researchers have examined the meaning of the illness to both patients and their loved ones. This is true even though the process of assigning meaning to the cancer experience often occurs in the context of relationships.

A positive relationship between the meaning individuals attach to their cancer experience and several outcomes has been reported in the research. More negative meanings attached to the cancer experience have been linked to more negative outcomes, including greater psychosocial role adjustment problems (Northouse, Mood, Templin, Mellon, & George, 2000) and depression and anxiety (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003) in studies examining the implications of cancer on the family. Further, a more negative meaning of the illness was also related to elevated fear of cancer recurrence for survivors and caregivers (Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007).

Although the research supports the existing relationship between patients with cancer and their family members (e.g., Northouse et al., 2002; Northouse, Templin, & Mood, 2001), research on relational outcomes following a cancer diagnosis is almost nonexistent (Mellon & Northouse, 2001). Speaking to this gap in the research, Mellon (2002) stated that “the need exists to further address meaning of the illness from an individual and a family context and how the search for meaning is related to effective coping strategies for families” (p. 1124).

**Outcomes. Quality of life** has emerged as a critical outcome in cancer research as more patients survive the acute phases of cancer (e.g., Mellon, 2002; Mellon & Northhouse, 2001; Zacharias, Gilg, & Foxall, 1994). Degner, Hack, O’Neil, and Kristjanson (2003) reported that the meaning attached to the illness influences the way that patients with cancer perceive their quality of life. Whereas emphasis has been placed on cancer patients’ quality of life, few studies have addressed the quality of life of their loved ones (Mellon). Although most research on quality of life following a cancer diagnosis has focused on the patient (e.g., Payne, 1992) or survivor (e.g., Garofalo, Hamann, Ashworth, & Baum, 2006), evidence exists that cancer and its treatment have implications for the entire family (Patterson & Garwick, 1994).

Several studies have documented the interrelationships and mutual influence that exist between the quality of life of cancer patients and family members (Mellon & Northhouse, 2001). Other researchers have recently demonstrated that the cancer patient’s and spouse’s quality of life in the face of breast cancer (Northouse, Templin, & Mood, 2001) and colon cancer (Northouse, Mood, Templin, Mellon, & George, 2000) are not only related, but also significantly influence the other’s quality of life. For these reasons, family members are being recognized as appropriate subjects for quality of life research aimed at examining how families cope with the problems they face associated with the cancer experience (Zacharias, Gilg, & Foxall, 1994).

A second outcome, *coping*, is considered both a process and an outcome in the research (e.g., Germino, Fife, & Funk, 1995; Strang & Strang, 2001). According to Lazarus and Folkman (1984), coping is elicited when individuals appraise a situation as taxing or as exceeding their resources. Few studies have examined the coping of family
members of patients with cancer; even fewer have examined patients and family members in the same study.

Coping is today more clearly related to meaningfulness by the introduction of meaning-based coping processes (Folkman, 1997). It has frequently been noted that cancer is a family illness (Germino, Fife, & Funk, 1995). Among those facing cancer, some individuals cope relatively well and have a good quality of life, whereas others fail to thrive, despite the fact that the external circumstances are the same.

In his stress and coping research, Lazarus (1993) noted that an intrusion, such as cancer, will be perceived as a threat when individuals determine that the environment is dangerous and that they lack the resources for mastering it. However, it will be perceived as a challenge if individuals determine that, despite the difficulty of the situation, the environmental demands are not impossible to manage. Pearlin and Schooler (1978) found that one of the functions of coping behavior that facilitates the reduction of distress is the modification of meaning in a way that reduces its threat. Individuals with cancer who appraise their illness as a threat are likely to use more problem-focused coping strategies. Individuals who appraise their illness as a harm/loss, however, are likely to use more avoidance coping strategies. Finally, those who appraise their illness as a challenge are likely to use approach coping strategies. Factors that moderate the relationship between appraisal and coping strategies include age of patients, time since diagnosis, and type of cancer (Franks & Roesch, 2006).

Fewer studies have examined positive meaning as a predictor of adjustment as was done in this study. Schnoll, Knowles, and Harlow (2002) reported that higher levels of social support and meaning of life, and lower levels of avoidant coping behaviors were related to better adjustment in a sample of cancer survivors. Similarly, with a sample of 422 cancer patients, primarily in the early stage of their illness, Fife (1995) reported that meaning was positively associated with psychological adjustment. However, Fife also reported that higher levels of social support were associated with higher levels of meaning. This suggests that patients’ perceptions of their illness, including their constructions of meaning, are influenced by the social support that they receive from loved ones. This points to an important limitation of the research exploring the relationship between meaning attached to the illness and subsequent adjustment – rarely are family members of the patient included.

**Congruence of Meaning**

Most of the research on congruence of meaning focuses on the similarity between individuals’ situational and global meanings. Thompson and Janigian (1988) argued that the extent to which people are able to integrate appraised meaning of an event with their global meaning is related to their adjustment to this event. Park and Folkman (1997) stated that this is consistent with the extensive literature linking a general sense of coherence with better adjustment. This helps individuals to accept what has happened and to move on. However, individuals may become distressed when their global and situational meanings are inconsistent (Park & Folkman). Lyubomirsky and Nolen-Hoeksema (1993) found that people who have not reconciled incongruence between their global meaning and their appraised meaning of the event often become caught in a cycle of rumination, which is associated with poorer adjustment and depression.
Park and Folkman (1997) contended that it is not simply whether meaning is sought or found that may influence adjustment; the content of that meaning will also influence individuals’ adjustment. Thompson and Janigian (1988) suggested that changes in global meanings may have positive or negative effects on adjustment, depending on their content.

However, few researchers have examined congruence between individuals in relationships, such as couples, who are coping with the same stressful situation (Stanton, 1991). This is true even though these experiences are often shared by members of the family. According to McCubbin, Thompson, Thompson, and McCubbin (1993), couple congruence refers to a sense of agreement between two partners regarding their definition of a stressful event and their appraisal of the severity of the stressor. Higher levels of congruence with regard to beliefs and expected level of stress have frequently been linked to higher levels of adaptation to stressful events including the first year of marriage (Odell & Quinn, 1998) and infertility (Peterson, Newton, & Rosen, 2003), respectively.

Patterson (1989) studied congruence as a factor in the adaptation of couples after undergoing treatment for coronary artery disease, and reported that congruence was critical in couples’ successful adaptation to the experience. Patterson (1993) also studied the role of family meaning and adaptation to chronic illness and disability, finding that family congruence generally predicts lower levels of stress during times of crisis. In addition, Omne-Ponten et al. (1995) reported that not only was there a high rate of agreement between spouse’s assessments of the breast cancer experience, but husband’s assessments of the marital relationship, communication, and support were also significantly related to the patient’s psychosocial outcome 13 months later. However, the patient’s assessment at four months was a better predictor of her psychosocial outcome after 13 months.

Whereas Germino, Fife, and Funk (1995) explored divergence and convergence of cancer patients’ and their partners’ qualitative meanings attached to the illness, no quantitative studies were located that examined the congruence of patients’ and partners’ meanings attached to the lung cancer illness and it relation to the psychosocial adjustment to the illness of each.

The goal of this study was to determine whether the relationship reported in the research between individuals’ meanings attached to the illness and adjustment in the face of cancer holds true in a sample of lung cancer patients and their partners. In addition, this study explored whether patients’ meanings attached to the illness influenced the adjustment of their partners, and vice versa. Further, the influence of similarity between patient and partner meaning, something previously unexplored in the research, on the psychosocial adjustment of each was examined.
CHAPTER 3

METHOD

Sample

The sample included 35 heterosexual couples receiving treatment at an outpatient lung cancer clinic in a large, community hospital in the southern United States. Although the clinic served a diverse patient population, most patients were required to show proof that they had little or no family income (< $30,000) in order to receive discounted or free services.

Patients included those individuals who were 18 years of age and older, had lung cancer confirmed by a physician, were aware of their diagnosis, understood written/spoken English, and consented to their own and their partner’s participation in the study. Partners included those individuals who were 18 years of age and older, were aware of their partner’s diagnosis, understood written/spoken English, and consented to participate in the study. In order to participate in the study, patients and their partners had to have been legally married or living together for one year or more.

It varied greatly among patients whether they came to the clinic alone or with another individual; it also varied from week to week with the same patient. Patients, many of whom were no longer able to work, often reported that it was difficult for their spouses and other family members to get off of work to bring them to their appointments. For this reason, patients often came alone to their appointments or had a neighbor or a friend accompany them. Unfortunately, due to the design of the study, only those couples where both the patient and his or her partner were able to physically come to the lung cancer clinic were eligible to participate. Moreover, many patients and partners who were members of minority ethnic groups could not speak or read English without assistance. Due to the design of the study, such couples were not eligible to participate. Because dyad members were distinguishable, the descriptive statistics were computed separately for patients and partners. The mean age of patients (20 males, 15 females) was 48.0 years (SD = 6.8), with the average number of years of education being 12 (SD = .82). The mean age of partners (15 males, 20 females) was 46.2 years (SD = 6.2), with the average number of years of education being 11.4 (SD = .78). No significant differences were found in demographic characteristics of patients and partners. Of the couples, nine (25.7%) were facing stage IIIA lung cancer, 15 (42.9%), stage IIIB, and 11 (31.4%), stage IV. In all couples, both the patient and the partner self-identified as being members of the same racial group. Twenty-five couples (71.4%) self-identified as Caucasian, six (17.1%), as Hispanic, and four (11.4%), as African-American. The length of the couples’ relationships ranged from three to 49 years, with the average relationship length being 18.1 years (SD = 12.6). Further, the number of years couples reported having lived together ranged from one to 49 years, with the average number of years being 17.3 (SD = 13.2). Nineteen of the 35 couples reported being legally married.

Unit of analysis For some time, family researchers have been encouraged to study more than one member of a couple or a family (Thompson & Walker, 1982). Unfortunately, this has led to little more than researchers’ simply obtaining reports from both/all individuals in a relationship and analyzing the data as if they were independent.
This practice does not allow researchers to gain insight the relationship between individuals in a couple or a family (Thompson & Walker). Researchers (e.g., Peterson, Newton, & Rosen, 2003) have argued that individual reports lack the complexity necessary to comprehend relationships. However, Thompson and Walker (1982) cautioned that:

obtaining observations from both partners does not guarantee that the research is dyadic and that, by insisting on both partners as informants, researchers slight the individual as an important source of information about relationships. Rather than being preoccupied with the number of informants, dyadic researchers ought to focus on understanding the relationship between two people from various perspectives and on the generalizability of those perspectives. (p. 890)

Becker and Useem (1942) stated that “two persons may be classified as a dyad when intimate, face-to-face relations have persisted over a length of time sufficient for the establishment of a discernable pattern of interacting personalities” (p. 13). According to Thompson and Walker, inherent in this definition is personal interdependence, also referred to as reciprocity and/or mutuality. It is this interdependence characteristic of interpersonal relationships that is the focus of dyadic research, making the relationship the unit of analysis. For the purposes of this study, analysis of the dyad seems appropriate. Certainly partners in a committed relationship simultaneously influence and are influenced by the other. Moreover, the lung cancer illness is an experience that both the patient and partner must face.

Couple Recruitment. After obtaining approval from the required Human Subjects committees (Appendix A), flyers were posted in the oncology clinic describing the study and inviting interested individuals to participate. The staff at the lung cancer clinic referred those individuals who expressed interest in or who they believed to be appropriate for the study to the primary investigator. Prospective participants were moved to a more private area where they were given details of the study and allowed to ask questions. They were explicitly told that their care would in no way be impacted by their decision to participate. Those who were still interested were guided through the informed consent and Health Insurance Portability and Accountability Act (HIPAA) forms; their signatures on the forms indicated their informed consent. At this time, patients and partners were also asked to complete several questionnaires about how they were dealing with the lung cancer illness, in addition to the two instruments used in this analysis. Couples were asked to fill out the questionnaires independently. Completion of the full series of questionnaires took between 45 minutes and two hours.

Instruments

Demographic Questionnaire. A researcher-designed demographic questionnaire (Appendix B) was used to obtain patients’ and partners’ reports related to illness- and relationship-related factors, such as the age of participant, length of relationship, and stage of lung cancer.

Constructed Meaning Scale. A revised version of the Constructed Meaning Scale (CMS; Fife, 1995) (patient and partner version) (Appendix C) was used to measure meaning attached to the lung cancer illness. The original CMS was designed to measure the meaning that is formulated by individuals as they attempt to adapt to life-threatening
illness. It is based on interviews conducted with individuals undergoing treatment for cancer and assumes the following definition of meaning:

Meaning refers to the individual’s understanding of the implications an illness has for his/her identity and for the future. Specifically, it pertains to individuals’ perceptions of their ability to accomplish future goals, to maintain the viability of interpersonal relationships, and to sustain a sense of personal vitality, competence and power. (Fife, p. 1022)

The original CMS is a self-report measure that includes statements which refer to the impact of the illness on an individual’s sense of identity, interpersonal relationships, and future. The scale includes eight statements, each with four possible responses on a scale of one to four (i.e., strongly disagree, disagree, agree, strongly agree). Responses are coded so that the highest score possible indicates the most positive meaning (i.e., view of cancer as a challenge), whereas the lowest score possible indicates the most negative meaning (i.e., view of cancer as a loss) of the illness.

Fife (1995) reported the psychometric properties of the original CMS, including internal consistency (Cronbach’s alpha 0.81) and provided content- and construct-related evidence of validity with cancer populations. However, a revised version of the CMS, with eleven statements, was used in this study based on the suggestion of the instrument’s creator, Betsy Fife (B. Fife, personal communication, January 31, 2007), who provided an electronic copy of the revised instrument (both the patient and the partner version), as well as instructions for how to score it.

As was true with the original instrument, higher scores on the revised CMS indicated more positive meanings; items 2 and 7 were reflected. In her personal communication, Fife (January 31, 2007) reported that there was face-related evidence of validity for the revised instrument. In this study, the eleven item revised CMS exhibited good internal consistency as evidenced by the .94 alpha coefficient for patients and .93 for partners.

**Psychosocial Adjustment to Illness Scale – Self Report.** The Psychosocial Adjustment to Illness Scale (PAIS; Derogatis & Derogatis, 1990) (Appendix D) is a semi-structured interview designed to assess the quality of a patient’s psychosocial adjustment to a current medical illness or its residual effects. The PAIS was originally created for and validated with individuals with cancer and their families. Derogatis and Derogatis later created a self-report version (PAIS-SR) of the instrument, which, like the original, measures psychosocial adjustment across seven domains: Health Care Orientation, Vocational Environment, Domestic Environment, Sexual Relationship, Extended Family Relations, Social Environment, and Psychological Distress. Health Care Orientation reflects respondents’ attitudes about health care in general, as well as perceptions about the quality of their health care. Vocational Environment is concerned with the impact the illness has on respondents’ ability to complete tasks at work or home. Domestic Environment assesses difficulties in the home or family related to the illness. Sexual Relationship reflects any changes in the quality of sexual functioning associated with the illness. Extended Family Relations is concerned with disruptions in the extended family relationships associated with the illness. Social Environment assesses respondents’ current social and leisure activities and whether there has been any impairment of those activities due to the illness. Psychological Distress measures dysphoric thoughts and feelings that are associated with the illness.
The PAIS-SR was designed to be completed directly by respondents, with an equivalent item for each of the 46 PAIS items, rewritten or modified in a self-report format. A four-point scale of distress (0-3) is also used with the PAIS-SR, but scale direction is reversed on the even numbered items to reduce position response biases.

Using a sample of 69 cardiac patients, Derogatis and Derogatis (1990) provided some evidence of the internal consistency of the seven domains of the PAIS-SR, with alpha coefficients ranging from .47 (Health Care Orientation) to .85 (Psychological Distress). The domains generally showed adequate internal consistency. Derogatis and Derogatis also presented evidence supporting the factor structure of the PAIS-SR and verifying convergent validity of the instrument. Further, the authors reported that the PAIS-SR demonstrated predictive validity when used with a sample of dialysis patients. In this study of lung cancer patients and their partners, the domains generally showed adequate to high internal consistency (see Table 1).

Table 1. Coefficient Alphas for PAIS-SR Domains for Patients and Partners

<table>
<thead>
<tr>
<th>Domain</th>
<th>Patients</th>
<th>Partners</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Care Orientation</td>
<td>.73</td>
<td>.66</td>
</tr>
<tr>
<td>Vocational Environment</td>
<td>.72</td>
<td>.82</td>
</tr>
<tr>
<td>Domestic Environment</td>
<td>.61</td>
<td>.68</td>
</tr>
<tr>
<td>Sexual Relationship</td>
<td>.92</td>
<td>.90</td>
</tr>
<tr>
<td>Extended Family Relationships</td>
<td>.64</td>
<td>.61</td>
</tr>
<tr>
<td>Social Environment</td>
<td>.81</td>
<td>.93</td>
</tr>
<tr>
<td>Psychological Distress</td>
<td>.73</td>
<td>.97</td>
</tr>
</tbody>
</table>

According to Derogatis and Derogatis (1990), the PAIS-SR was designed to be interpreted at three levels: global, domain, and discrete item. The authors reported that data from each of the three levels of interpretation should converge to deliver an integrated picture of the respondent’s adjustment to an illness. Preliminary analyses have suggested that respondents with a PAIS-SR Total Score equivalent to or greater than a T-score of 62 are positive for clinical levels of psychosocial maladjustment. In this sample, with the exception of one patient and one partner (not in a relationship with one another), every participant had a T-score of 62 or higher on the PAIS-SR.

Analysis

Data Entry. Two separate data files were created in SPSS as described in Campbell and Kashy (2002). The first data set, Level 1, was composed of one record for each individual, with each record including a variable identifying dyad (i.e., couple) membership, the individual’s outcome score (i.e., psychosocial adjustment to the illness),
individual’s role (i.e., patient or partner), and the individual’s and his or her partner’s (i.e., actor and partner, respectively) values for the mixed predictor variable, meaning attached to the illness. In addition, two interaction variables, computed by multiplying role times actor meaning and role times partner meaning, were included. The resulting Level 1 data file included 70 records. The second data set, Level 2, was comprised of one record for each couple, with each record including a variable identifying the same variable identifying couple membership from Level 1, as well as couples’ values for the between-dyad variable, similarity of meaning. The resulting Level 2 data file included 35 records. Missing data, which were only encountered on the PAIS-SR, were recorded as blanks. The integer value of the average of item scores presented for the domain was assigned to missing items as was recommended in Derogatis and Derogatis (1990).

**Power.** In dyadic analysis, power must be considered with regard to 1) the power of the test of nonindependence and 2) the reduction or increase in power of the test of the independent variable that occurs when the unit of analysis is changed from individual to dyad. According to Kenny, Kashy, and Cook (2006), the level of consequential nonindependence, the level at which nonindependence results in a *p* value of .10 when it is presumed to be .05, is about .45. They argued that there should be enough power, at least 80%, to test for consequential nonindependence. It is conventionally recommended (e.g., Myers, 1979) that the test for nonindependence be quite liberal, with an alpha of .20. Using this value, the number of dyads needed to test for consequential nonindependence with a power of .80 is 28. Given that 35 couples were included in the analyses in this study, there was sufficient power to conduct this test.

Cohen (1988) recommended setting statistical power at .80, or an 80% chance of ruling out the null hypothesis. The Pearson correlation for the outcome variable, psychosocial adjustment to the illness, was first computed to be .48. Given alpha of .05, the power of a test in a study with a population correlation of .5 and sample size of 40 would be .92. In this study, the sample size was 35 dyads; therefore, there was enough power to test the effect of the independent variables.

**Statistical issues.** According to Kashy and Levesque (2000), dyadic data analysis presents some important challenges for researchers. They argued that the most commonly used statistical techniques assume that the data collected from individuals are independent; however, this assumption is often not appropriate when studying individuals in close relationships. Kashy and Levesque noted that couple and family researchers often ignored this issue by collecting data from only one person involved in a relationship or by using hypothetical scenarios. However, given that interdependence is a defining characteristic of close relationships, avoiding interdependent data restricts researchers’ understanding of close relationships. Researchers are becoming increasingly aware of this problem, and more recently researchers have been striving to collect data from both members of dyadic relationships (e.g., Peterson, Newton, & Rosen, 2003).

This interdependence of data obtained from individuals engaged in close relationships has important implications for research questions and data analysis (Kashy & Levesque, 2000). If nonindependent data are approached with a statistical technique that assumes independence (e.g., linear models), then the alpha level associated with the resulting inferential statistics will not accurately reflect the true probability of making a Type 1 error. The result may be statistical tests that are overly liberal or overly conservative (Kenny, 1996; Kenny, Kashy, & Bolger, 1998).
In particular, one of the most important advantages of gathering data from both or all individuals involved in a relationship is that researchers can examine not only how individuals’ characteristics influence their own behavior, but also how individuals’ characteristics influence their partner’s behavior. Treating the data from couples as nonindependent also allows for the analysis of data addressing issues related to couple similarity (Kenny & Acitelli, 1994). According to Kashy and Levesque (2000):

Clearly, interdependence between related individuals should not simply be considered a statistical annoyance. Rather, it should be embraced as an opportunity to ask old questions in new ways, to ask new questions, and to test theoretical propositions that are explicitly about interdependence. (p. 4)

Unfortunately, researchers who ignore interdependence risk errors in their findings unnecessarily because statistical techniques are available for analyzing interdependent data (Kashy & Levesque).

One important question in dyadic research and data analysis is whether the two dyad members can be distinguished from one another by some variable. The distinguishability issue is important in a discussion of quantitative methods for relationship data because the data analytic techniques which are appropriate for distinguishable dyads might be inappropriate for indistinguishable dyads. In this study, the members of the dyads were treated as distinguishable because they differed on a meaningful factor, role (i.e., patient/partner) (Kenny, Kashy, & Cook, 2006).

Because the dyad members were distinguishable, the level of nonindependence between patients and partners meaning scores was assessed using the Pearson product-moment correlation coefficient, which can be interpreted as the proportion of variance due to the couple (Kenny, Kashy, & Cook, 2006). The unit of analysis in computing the correlation was the dyad, not the individual. Based on Cohen’s (1988) definition of .5 as a large correlation, .3 as medium, and .1 as small was used, a large correlation of .57 was found between patients’ and partners’ psychosocial adjustment to the illness scores.

**Actor-Partner Interdependence Model.** The Actor-Partner Interdependence Model (APIM; Cook & Kenny, 2005; Kenny & Cook, 1999) is a model of dyadic relationships that integrates a conceptual view of interdependence in two-person relationships with the appropriate statistical techniques for measuring and testing it. The model has been recommended for use in the study of families (Rayens & Svavardottir, 2003), close relationships (Campbell & Kashy, 2002), and treatment outcomes in couple therapy (Cook, 1998).

The APIM focuses on an important implication of nonindependence in dyadic research. That is, in the case of couples, one person's score on an independent variable can influence not only that person’s score on the outcome variable, but also that person’s partner’s score on the outcome variable. In such cases, an *actor effect* occurs when an individual’s score on a predictor variable influences that person’s score on an outcome variable, whereas a *partner effect* occurs when an individual’s score on a predictor variable influences a partner’s score on an outcome variable (Kenny & Cook, 1999). In this study, because dyad members were distinguishable, there were potentially two actor effects, one for patient (a₁) and one for partner (b₁). In addition, there were potentially two partner effects, one from patient to partner (p₁₂) and one from partner to patient (p₂₁). Figure 1 depicts the APIM, where a represents actor effects and p, partner effects.
The analysis implied by the APIM is very flexible. Actor and partner effects can be estimated whenever the independent variable is mixed, regardless of whether the mixed variable is categorical or continuous. In this case, meaning of illness would be a mixed variable because there is variation both between and within dyads. The APIM analysis can also incorporate independent variables that are not mixed (i.e., those that are within- or between-dyads), but separation of actor and partner effects can occur only with mixed predictor variables.

![Diagram of Actor-Partner Independence Model](image)

**Figure 1. Actor-Partner Independence Model**

The analysis also allows for interactions between predictor variables, and any interactions with mixed variables can be broken into actor and partner effects. The effect of similarity between dyad members was calculated by obtaining the absolute difference between patients’ and partners’ meaning scores. For the actor-partner interaction estimation needed to assess similarity of meaning, the main effects of actor and partner were controlled for.

**Estimating the APIM with Hierarchical Linear Modeling**

Hierarchical linear modeling was used to estimate the APIM using HLM, Version 6 (Raudenbush, Bryk, & Cheong, 2007), currently the most commonly used computer program for estimating multilevel models (Kenny, Kashy, & Cook, 2006). HLM uses group-level variables (i.e., similarity of patient and partner meaning attached to the illness) to explain variation in the individual-level parameters. It also allows for testing for main effects and interactions both between and within levels.

A detailed description on how to conduct APIM analyses using HLM was outlined by Kashy and Campbell (2002) and served as the guide for the analysis in this study. A Sufficient Statistics Matrix (SSM) containing the means, variances, and covariances for all of the variables in the analysis was created from the raw data. The SSM was checked for any problems in the data; none was found.
To estimate the main effects model, psychosocial adjustment to the illness was identified as the outcome variable. Then, actor (i.e., patient) meaning (AMEANING) and partner meaning (PMEANING) were selected as predictor variables. This resulted in the following Level 1 model:

\[ \text{PAIS} = \beta_0 + \beta_1 (\text{AMEANING}) + \beta_2 (\text{PMEANING}) + r \]

This model suggests that individuals’ psychosocial adjustment to the lung cancer illness is a function of the individuals’ own meaning attached to the illness and their partner’s meaning. In addition, the distinguishing variable, role, and its interactions with the mixed predictor variable, meaning, were added to the Level 1 model. The main effect of role simply estimated and tested whether there were mean-level differences in psychosocial adjustment for patients and partners. The interactions between role and meaning were entered to assess whether any of the actor and partner relationships differed between patients and partners. This final Level 1 model was:

\[ \text{PAIS} = \beta_0 + \beta_1 (\text{AMEANING}) + \beta_2 (\text{PMEANING}) + \beta_3 (\text{ROLE}) + \beta_4 (\text{ROLE} \ast \text{AMEANING}) + \beta_5 (\text{ROLE} \ast \text{PMEANING}) + r \]

Finally, to test the effect of similarity between patients’ and partners’ meaning attached to the illness on psychosocial adjustment, the similarity variable (APSIM) was included in the Level 2 model, making it a predictor of the Level 1 intercept, \( \beta_0 \). This resulted in the following Level 2 model:

\[ \begin{align*}
\beta_0 &= \gamma_{00} + \gamma_{01} (\text{APSIM}) + u_0, \\
\beta_1 &= \gamma_{10}, \quad \beta_2 &= \gamma_{20}
\end{align*} \]

This interaction estimates the degree to which the impact that the partner’s meaning attached to the lung cancer illness has on a person’s psychosocial adjustment to the illness is moderated by the degree of similarity of meaning between patient and partner.

The two-level model was estimated by means of restricted maximum likelihood (REML). Using this approach, the variance-covariance components were estimated via maximum likelihood, averaging over all possible values of the fixed effects. The fixed effects were estimated via Generalized Least Squares (GLS) given these variance-covariance estimates.
CHAPTER 4

RESULTS

Analyses were conducted with the goal of better understanding the relationship between patients’ and partners’ meanings attached to the lung cancer illness and the psychosocial adjustment of each. Means and standard deviations were computed for the predictor and outcome variables for patients and partners (see Table 2). Results are discussed in terms of the corresponding research question.

Table 2. Means and Standard Deviations for Patients’ and Partners’ Meaning and Psychosocial Adjustment

<table>
<thead>
<tr>
<th>Variable</th>
<th>Patients Mean</th>
<th>Patients SD</th>
<th>Partners Mean</th>
<th>Partners SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constructed Meaning Scale</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CMS Total</td>
<td>22.7</td>
<td>5.4</td>
<td>27.2</td>
<td>6.9</td>
</tr>
<tr>
<td>Psychosocial Adjustment to the Illness Scale – Self Report</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PAIS-SR Health Care Orientation</td>
<td>9.8</td>
<td>2.7</td>
<td>10.7</td>
<td>2.9</td>
</tr>
<tr>
<td>PAIS-SR Vocational Environment</td>
<td>8.2</td>
<td>3.8</td>
<td>7.9</td>
<td>2.8</td>
</tr>
<tr>
<td>PAIS-SR Domestic Environment</td>
<td>8.9</td>
<td>2.5</td>
<td>10.1</td>
<td>2.8</td>
</tr>
<tr>
<td>PAIS-SR Sexual Relationships</td>
<td>7.3</td>
<td>4.3</td>
<td>7.7</td>
<td>4.3</td>
</tr>
<tr>
<td>PAIS-SR Extended Family Relationships</td>
<td>2.5</td>
<td>1.5</td>
<td>3.8</td>
<td>2.6</td>
</tr>
<tr>
<td>PAIS-SR Social Environment</td>
<td>8.2</td>
<td>3.8</td>
<td>9.4</td>
<td>3.8</td>
</tr>
<tr>
<td>PAIS-SR Psychological Distress</td>
<td>9.4</td>
<td>4.1</td>
<td>12.1</td>
<td>4.3</td>
</tr>
<tr>
<td>PAIS-SR Total</td>
<td>54.4</td>
<td>15.5</td>
<td>61.6</td>
<td>13.3</td>
</tr>
</tbody>
</table>

Research Question 1: *To what extent do patients with more positive meanings attached to the lung cancer illness have better psychosocial adjustment to the illness?*

Research Question 2. *To what extent do partners with more positive meanings attached to the lung cancer illness have better psychosocial adjustment to the illness?*

Results of the HLM analyses showed a significant actor effect of meaning attached to the illness on psychosocial adjustment, $b = 1.31$, $t (63) = 5.05$, $p = .00$
Therefore, a significant positive relationship exists between the meaning attached to the illness and psychosocial adjustment to the illness for both lung cancer patients and their partners. Specifically, the more positive the meaning attached to the lung cancer illness (for both lung cancer patients and their partners), the better the psychosocial adjustment to the illness.

Tests were conducted to determine whether the actor effect differed significantly between patients and partners. No significant meaning by role (patient versus partner) interaction effect was found, $b = 2.44$, $t (63) = 1.71$, $p = .09$ for role by actor meaning interaction and $b = -2.01$, $t (63) = -1.42$, $p = .16$ for role by partner meaning interaction. However, a main effect for role supported the existence of mean-level differences in psychosocial adjustment to the lung cancer illness for patients and partners, with patients reporting significantly more negative meanings attached to the illness than partners, $b = -11.38$, $t (63) = -2.47$, $p = .02$.

Research Question 3. To what extent do patients with more positive meanings attached to their lung cancer have partners with better psychosocial adjustment to the illness?

Research Question 4. To what extent do patients with partners with more positive meanings attached to their lung cancer have better psychosocial adjustment to the illness?

The results of HLM analyses showed no significant partner effect for meaning attached to the illness and psychosocial adjustment, $b = .02$, $t (63) = .08$, $p = .94$. Therefore, neither lung cancer patients’ nor their partners’ psychosocial adjustment is significantly influenced by the meaning that their partner attaches to the illness.

Research Question 5. Does the extent to which a couple has similar meanings attached to the illness influence the psychosocial adjustment of patients?

Research Question 6. Does the extent to which a couple has similar meanings attached to the illness influence the psychosocial adjustment of partners?

The results of the HLM analyses failed to support a significant relationship between degree of similarity between patients’ and partners’ meanings attached to the lung cancer illness and the psychosocial adjustment to the illness of patients or partners, $b = 2.46$, $t (33) = 1.62$, $p = .12$.

Post Hoc Analyses

Post hoc analyses were conducted to determine what role, if any, sex played in the relationship between meaning and psychosocial adjustment to the illness. As an individual variable, sex was entered as a predictor in the Level 1 model. No significant differences for psychosocial adjustment to the illness were found between men and women, $b = 1.57$, $t(64) = -1.38$, $p = .17$. As a couple variable, patient sex was added as a predictor in the Level 2 model. Once again, no significant differences for psychosocial
adjustment to the illness were found between couples where the patient was male and those where the patient was female, $b = 2.03$, $t(33) = .49$, $p = .63$. 
CHAPTER 5

DISCUSSION

The aim of this study was to better understand how lung cancer patients’ and their partners’ meanings of the illness influence their own and each other’s psychosocial adjustment. Little is known about how couples experience the cancer illness, and even less is known about how couples experience lung cancer. This is because researchers examining couples’ adjustment to cancer often exclude those facing lung cancer due to the severity and rapid progression of the illness (e.g., Chen, Chu, & Chen, 2004; Edwards & Clark, 2004). However, it is because of these illness characteristics that it seems especially important to understand the factors promoting adjustment in lung cancer patients and their partners.

In this study, although patients’ and partners’ meanings were correlated, partners viewed the lung cancer illness more positively than did patients. The presence of a difference between patients’ and partners’ meanings was not surprising given that the individuals’ meanings are shaped by their life experiences, as well as cultural, spiritual, psychosocial, biological, and economic factors (Downe-Wamboldt, Butler, & Coulter, 2006). However, the direction of the difference was less expected and might be interpreted in at least two ways. It might be that, given the poor prognosis of the lung cancer patients in this sample, the patients had begun to face the reality of their illness, whereas spouses may not have (Zacharias, Gilg, & Foxall, 1994). However, it might also be that the partners believed that they had to remain positive for the sake of their ill partners (Gray, Fitch, Phillips, Labrecque, & Klotz, 1999).

Whereas some researchers have reported that family members were more distressed than cancer patients (e.g., Sarna et al., 2006) or survivors (e.g., Northouse, Mood, Templin, Mellon, & George, 2000), others found that patients were more distressed (Northouse et al., 2002). However, in this study, patients and partners did not differ significantly in their psychosocial adjustment to the lung cancer illness, consistent with the results of Baider, Walach, Perry, and Kaplan De-Nour (1998). These findings indicate that advanced lung cancer takes a toll on both patients and partners, as well as the couples’ relationships.

With the exception of one patient and one partner (not in a relationship with each other), every participant in this study scored in the clinically distressed range on the measure of psychosocial adjustment to the illness that was normed with a Mixed Cancer population. This is consistent with the findings of Zabora, BrintenhofeSzoc, Curbow, Hooker, and Piantadosi (2001), who reported that lung cancer patients report more distress than patients with other types of cancer. However, these findings are inconsistent with those of Downe-Wamboldt, Butler, and Coulter (2006), who found that lung cancer patients and their family members reported having little difficulty managing their cancer experience. One possible explanation for this discrepancy in findings is that Downe-Wamboldt, Butler, and Coulter included only patients and their family members who are facing stages I, II, and IIIA lung cancer, which have better prognoses than those in this study. Further, their sample consisted mostly of retired men with relatively high incomes and good physical functioning, whereas the couples in this study reported family incomes
of $30,000 or less and often had diminished physical functioning due to their advanced illness.

It was expected that lung cancer patients and their partners who held a more positive view of the illness would report greater psychosocial adjustment to the illness. In cross-sectional analyses, an actor effect was found for both lung cancer patients and their partners, indicating that the meaning individuals (both patients and partners) attach to the illness significantly affects their own psychosocial adjustment to the lung cancer illness. Similar to the findings of Mellon, Kershaw, Northouse, and Freeman-Gibb (2007), the findings of this study suggest that individuals’ own meanings of the illness, rather than their partners’ meanings, had more influence on individuals’ outcomes.

The finding that more positive meaning attached to the illness is associated with better psychosocial adjustment to advanced lung cancer is consistent with the findings from studies that have explored this issue in the earlier stages of cancer (e.g., Carver, Scheier, & Weintraub, 1983; Curbow et al., 1993). Based on similar findings, researchers have emphasized the need to create new meanings among individuals facing cancer (Germino, Fife, & Funk, 1995; Lee, Cohen, Edgar, Laizner, & Gagnon, 2006). It seems that this study’s findings lend support to this contention.

Even though the lung cancer experience occurred in the context of a relationship for the individuals in this study, no partner effect was found. This suggests that the relationship between the meaning of the illness and psychosocial adjustment in lung cancer patients and their partners is an intrapersonal phenomenon. This may have implications for those partners who report feeling the need to remain positive about the illness for the sake of the patient, their ill partner. That is, informing partners that their meaning of the illness holds no bearing on their partners’, the patients’, psychosocial adjustment might diminish some of the burden they reportedly experience. However, based on this study’s finding that partners with more positive meanings of the illness have better psychosocial adjustment suggests that, although partners’ remaining positive may not promote better adjustment in the patient, it does promote better psychosocial adjustment in the partners themselves. This then begs the question of whether partners’ believing that they must remain positive about the illness for the patients’ sake actually benefits the partners in terms of their adjustment to the illness.

Peterson, Newton, and Rosen (2003) recently called for further examination of congruence in less adjusted populations. This study of couples facing lung cancer was an attempt at such an endeavor. However, no interaction effect for similarity of patients’ and partners’ meanings was found for psychosocial adjustment to the illness in this study. These findings were inconsistent with previous research indicating that high levels of agreement between couples and families often reduce the stress they experience and increase their ability to manage stressful events (Patterson, 1989, 1993; Peterson, Newton, & Rosen, 2003). However, according to Germino, Fife, and Funk (1995), it is not necessarily important that partners hold similar meanings with respect to the cancer illness. What is important is an openness to sharing the meaning held by each individual. In this study, patients and partners were not asked whether they communicated previously about the meaning each attached to the illness; therefore, the degree to which the patients and their partners were open to the meaning held by the other is unknown.

Symbolic interactionism, which holds that people act toward things and each other based on the meanings they have for them, allows researchers to ask questions
about how lung cancer patients and their partners attach meaning to the illness and what impact these meanings have for the couple relationship. It seems that if individuals (patients and partners) hold a negative view of the illness, then they would act toward their partner in a more negative way, which would, in turn, have a negative impact on the psychosocial adjustment of their partner. However, no such effect was found in this study. Further, it seems likely that the meaning individuals (patients and partners) attach to the lung cancer illness is, in part, negotiated between partners, and that those who achieved shared meanings of the illness would also be better adjusted. To the contrary, in this study, patients’ and partners’ degree of similarity with regard to meaning of the illness was not related to the psychosocial adjustment of either individual. It seems that theory may need to be extended to better understand couples dealing with serious illness, such as lung cancer, to answer questions about couples where partners hold drastically different views of the illness or where partners hold similar meanings that are extremely negative.

Limitations

Although this study was designed to address several of the shortcomings of previous research in this area, there were several limitations that should be taken into account when considering the findings. First, the sample was one of convenience. That is, only those patients and partners who were receiving treatment at one lung cancer clinic were invited to participate. Patients who came to an appointment without their partner, but who reported being married or having lived with their partner for one year or longer, were encouraged to bring their partner to the next visit in order to participate. It is possible, however, that those patients with partners who attended treatment with them had more positive meanings attached to the illness and/or were better adjusted. Second, the sample was relatively homogeneous with regard to certain factors, such as stage of lung cancer and income, which influence both meaning of the illness and psychosocial adjustment. All couples were low-income, with a total family income of less than $30,000, and facing advanced lung cancer. Both of these factors may have a negative influence on patients’ and partners’ psychosocial adjustment and limit the variability in meaning attached to the lung cancer illness. Third, participants were only recruited from a lung cancer clinic in a large metropolitan area. This may have reduced the generalizability of the results to lung cancer patients and their partners being treated in other medical settings, such as inpatients units and/or rural or smaller regions. Fourth, only those patients and partners who volunteered to complete the questionnaires were included in the analyses. It is possible that volunteers had more intense feelings (positive or negative) about their cancer experience, and thus were more willing to answer questions about it. Fifth, participants may have answered the questions in a socially desirable manner. For example, they may have believed that cancer patients and their partners should think positively about their illness. Sixth, those patients who were sickest may not have had the ability or the energy to complete the questionnaires; therefore, the experiences of such individuals may not have been represented. Seventh, only patients and partners who were able to read English were included. This meant that non-English speaking individuals and those who were unable to read did not participate. Finally, the cross-sectional design of the study did not permit examination of changes in either the
meaning attached to the illness or psychosocial adjustment to the illness over time. It seems possible that changes in one also lead to changes in the other.

IMPLICATIONS

Implications for Practice

When individuals are facing advanced lung cancer, the options for forms of coping that attempt to change external stressors become increasingly limited as the illness progresses because the primary stressor, the lung cancer itself, cannot be changed. Given this fact, the construction of positive meaning is likely to be of even greater importance in the context of advanced lung cancer. The results of this study seem to support such a contention for both lung cancer patients and their partners. These findings strongly suggest that couples facing lung cancer could benefit from therapeutic intervention. In addition, psychosocial interventions developed for these couples should include a component that allows both patients and partners to explore issues related to the meaning of the illness. Those who hold a highly negative view of the illness may be appropriate targets for intervention.

In some instances, one or both may need assistance finding more positive meaning in the illness. When working with couples, clinicians might emphasize potential benefits resulting from the lung cancer illness, such as a more intimate relationship between the patient and partner (meaning-as-significance). When working with only the patient or the partner, clinicians might assist individuals in assimilating the lung cancer illness into their existing worldviews so that the experience seems less random (meaning-as-comprehensibility).

The finding that individuals’ (patients and partners) meaning attached to the lung cancer illness has no influence on the psychosocial adjustment of their partner might have implications for those partners who believe they must remain positive for their ill partners. It is possible that clinicians’ sharing of this information with partners of lung cancer patients will lessen the burden these individuals perceive. However, removing this barrier to a negative view of the illness may negatively affect the psychosocial adjustment of the partner.

White and Klein (2002) argued that effective relationships are “dependent on nurturing a culture of shared meanings” (p. 63), which suggests that couples must have relatively similar meanings of the illness in order to adjust to the demands associated with the experience. In this study, although patients and partners on average reported quantitatively different meanings of the illness, couples varied greatly in the degree of similarity between patients’ and their partners’ meanings. Whereas some had no difference in meaning scores, some differed drastically. Still, this degree of difference did not significantly influence the psychosocial adjustment of either patients or their partners to the lung cancer illness, suggesting that clinicians should assist patients and partners find some positive meaning in the illness rather than working to help them create a shared meaning.

Negative meanings attached to the illness seem to be more likely in patients with lung cancer and their partners than those facing other types of cancer and are negatively related to the adjustment of both patients and partners. Therefore, interventions aimed at
promoting psychosocial adjustment of patients and partners facing lung cancer should focus on reframing the illness as a challenge, rather than a threat to their relationship. For example, clinicians may point out to couples that, although they spend a great deal of time in medical settings waiting to see a physician, they likely spend more time together than many healthy couples. It does not appear to be important that patients and partners are congruent in their meanings attached to the illness. For this reason, although working with the couple would be ideal, interventions might also be successful when clinicians are working with only the patient or the partner. For example, clinicians might work with partners while patients are receiving chemotherapy. This may be especially important when barriers (e.g., lack of childcare, work schedules, room constraints, partner afraid of hospitals) to working with both partners together exist.

Finally, the findings of this study emphasize the importance of how the meaning attached to the illness in planning evidence-based interventions for lung cancer patients and their partners. Many clinicians currently working with these individuals must rely on clinical assumptions, rather than empirical evidence, to guide their treatment. This study serves as a foundation for future research that can be used in planning empirically-validated treatments for couples facing lung cancer.

Implications for Research

As previously stated, future researchers might strive to address some of the limitations of this study. Studies designed to sample consecutive patients in committed relationships seeking treatment at lung cancer clinics would be ideal to limit volunteer bias. In addition, a multi-site study sampling couples facing lung cancer from multiple oncology clinics in multiple cities, both urban and rural, would be helpful to enhance the generalizability of findings. Future researchers might also focus on lung cancer patients and their partners being treated on inpatient oncology units. Also, exploration of lung cancer patients are their partners who have decided against western medicine in favor of complementary medicines is needed. Further, the experience of couples with one or both partners being members of minority racial/ethnic groups, particularly those who do not read and/or speak English, has been neglected in the research. Well-designed studies, including those that utilize interview formats, that account for language and literacy barriers are needed. Finally, longitudinal studies examining lung cancer patients’ and their partners’ meanings of the illness and psychosocial adjustment would greatly enhance our understanding of the relationship between these two variables. In addition, researchers might focus not only on how meaning influences psychosocial adjustment, but also on how psychosocial adjustment influences meaning. It seems likely that the relationship between these variables is bidirectional.

Qualitative studies might also be helpful in aiding our understanding of both meaning attached to the lung cancer illness and psychosocial adjustment in couples. It is possible that meaning is best understood using qualitative rather than quantitative data. In addition, studies exploring how lung cancer patients and their partners negotiate the meaning attached to the illness and under what conditions, if any, conversations on the topic occur are needed.

This study appears to be the first to examine the impact of couple congruence related to patients’ and partners’ meanings of the lung cancer illness on psychosocial
adjustment to lung cancer. Carefully designed quantitative and qualitative research studies that further examine this issue are warranted. In addition, the development of an instrument that appropriately measures the construct of couple congruence in the context of serious illness is needed.

CONCLUSION

In spite of the fact that lung cancer is the most commonly diagnosed and most fatal cancer, very little is known about how individuals in intimate relationships experience the illness. The findings of this study indicate that the meaning patients and their partners attach to the lung cancer illness has a significant influence on their own psychosocial adjustment, with individuals viewing the illness more positively reporting better adjustment. Additional research on this relationship is warranted so that evidence-based interventions can be formulated to promote higher levels of psychosocial adjustment in both lung cancer patients and their partners.
APPENDIX A

HUMAN SUBJECTS COMMITTEE APPROVAL LETTERS

28
APPROVAL MEMORANDUM

Date: 5/4/2007

To:
Tara Lehan
2819 North Fitzhugh Ave. #1139
Dallas, TX 75204

Dept.: FAMILY & CHILD SCIENCE

From: Thomas L. Jacobson, Chair

Re: Use of Human Subjects in Research
The Importance of Shared Meaning in Couples Facing Lung Cancer

The forms that you submitted to this office in regard to the use of human subjects in the proposal referenced above have been reviewed by the Human Subjects Committee at its meeting on 4/11/2007. Your project was approved by the Committee.

The Human Subjects Committee has not evaluated your proposal for scientific merit, except to weigh the risk to the human participants and the aspects of the proposal related to potential risk and benefit. This approval does not replace any departmental or other approvals which may be required.

If the project has not been completed by 4/9/2008 you must request renewed approval for continuation of the project.

You are advised that any change in protocol in this project must be approved by resubmission of the project to the Committee for approval. The principal investigator must promptly report, in writing, any unexpected problems causing risks to research subjects or others.

By copy of this memorandum, the chairman of your department and/or your major professor is reminded that he/she is responsible for being informed concerning research projects involving human subjects in the department, and should review protocols of such investigations as often as needed to insure that the project is being conducted in compliance with our institution and with DHHS regulations.

This institution has an Assurance on file with the Office for Protection from Research Risks. The Assurance Number is IRB00000446.

cc: Lenore McWey
HSC No. 2007.151
TO: Tara Lehan  
Southwestern Temporary Services - 9023

FROM: George Buchanan, MD  
Institutional Review Board 2 Chairperson  
IRB - 8843

DATE: April 23, 2007

RE: Expedited Approval of Project Summary, Consent Form, HIPAA Authorization, Recruitment Material, and Questionnaire(s)  
IRB Number: 022007-034  
Title: The Importance of Meaning-Making in Couples Facing Lung Cancer

The Institutional Review Board reviewed this research activity via an expedited review procedure in accordance with 45 CFR 46.110(a)-(b)(1), 63 FR 60364, and 63 FR 60353. Having met the conditions as set forth by the IRB Chairman on February 28, 2007 your research protocol is now approved for a period of 12 months. This approval period will begin April 20, 2007 and last until February 27, 2008. If the research continues beyond approval period, the study will require continuing review from the IRB and a reminder will be mailed to you 60 days prior to the expiration date stated above.

Your approved subject sample size is 70 subjects.

Important Note: Unless a verbal consent process or waiver of consent was approved, you must use a photocopy of the attached IRB-approved and stamped consent form(s) to document each subject's willingness to participate. Use of a copy of any other version of the consent form is prohibited.

A photocopy of the signed consent form(s) and HIPAA Authorization should be given to each participant. The copy of the consent form(s) bearing original signatures should be kept with other records of this research for at least five years past the completion of the study. For research involving treatment or invasive procedures, a photocopy of the signed consent form(s) should be on file in a subject's medical record.

Federal regulatory law requires that you report to the Institutional Review Board any unexpected and/or serious adverse events/unanticipated problems, as defined on the IRB website at http://www.utsouthwestern.edu/irb, that occur to research subjects or others during the course of your study.

In the future, should you require a change or need to modify the research, including the informed consent document(s) and HIPAA Authorization, per federal regulation you must obtain prospective review and approval of the Institutional Review Board. For any change to the research, prior review and approval before implementing such changes is mandatory except when prompt implementation is necessary to eliminate apparent immediate hazard to a subject.
May 9, 2007

Tara Lehan, MS
Intern, Family Studies Center
UTSWMC
MC 9121

Dear Ms. Lehan,

Your site request for the study "The Importance of Meaning-Making in Couples Facing Lung Cancer" has been approved. This approval is contingent upon compliance with UTSWMC IRB rules and regulations. The research expense identified for this study is the administrative review fee. This study is student research and recruitment only, meeting the criteria for waiver of the administrative fee.

If your study period exceeds one year, send a copy of your annual IRB Continuing Review Form to Clinical Research. Also, please notify Clinical Research whenever the study is modified or closed. The Parkland Research Committee would like to invite you to present your research after completion of your dissertation. Please re-contact me at that time when you would be available. An informal presentation would be an excellent way to disseminate your study findings to continue improving patient care and to highlight research being done at Parkland.

All members of the research team that will be interacting with patients on the PHHS campus must have privileges to practice at Parkland and must wear current Parkland ID badges. This includes research nurses and assistants. For information on the process for obtaining privileges and/or a PHHS ID badge, contact the Office of Clinical Research & Data Management. Please do not hesitate to contact me if I can be of further assistance with this study. I can be reached at (214) 590-8966 or via e-mail at vhart@parknet.pmh.org. Good luck with your study!

Sincerely,

Valerie Hart, RN, PhD, MSN
Director, Clinical Research & Data Management
Parkland Health & Hospital System, MC 7750

cc
Randy Blanchard
April 10, 2007

Dear Tara Lehan:

It is my great pleasure to inform you that your protocol entitled, "Constructed Meaning and Adjustment in the Face of Lung Cancer" (PRMC Number: 0702261) has been approved by the Harold C. Simmons Comprehensive Cancer Center Protocol Review and Monitoring Committee (PRMC) as of April 10, 2007. You may submit your protocol to the University of Texas Southwestern Medical Center at Dallas Institutional Review Board. We wish you much success.

Sincerely,

James Huth, M.D.
Chairman
Simmons Protocol Review and Monitoring Committee
APPENDIX B

PARTICIPANT DEMOGRAPHIC FORM
PARTICIPANT INFORMATION FORM

Participant #

Age: _____  Race/ethnicity: _____  Sex: _____

Number of years of education: _________

Total family income: _________

Length of relationship: _________

Are you and your partner married? _________

If so, when did you get married? _________

How long have you and your partner been living together? _________

Date diagnosed with lung cancer: _________

Stage of lung cancer: _________

Treatment: ________________________________________

Have any treatments failed? _________

If so, which ones? ________________________________________

Family history of cancer: ________________________________________

Please help us understand your experience a little better by providing us with a metaphor or analogy that symbolizes what you are going through.

Facing lung cancer is like...

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

Thank you for your time!
APPENDIX C

CONSTRUCTED MEANING SCALE
CONSTRUCTED MEANING SCALE - PATIENT

The items below ask how you see life for your partner and yourself being affected by the illness. Circle the number that best describes how you have been feeling during the **past two weeks**.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel my illness is something I will never recover from.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I feel my illness is serious, but I will be able to return to life as it was before.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I often feel we are outsiders because of this illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I feel that my illness is changing our lives permanently so they will never be as good again.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. We do not have the same chance as others for satisfying lives due to my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I feel we are being victimized by the illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I feel I am making a complete recovery from the illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. The uncertainty of my illness is <strong>causing me</strong> great difficulty.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I feel my relationships with others have been negatively affected by my illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I feel my illness has permanently interfered with my ability to achieve the most important goals I have set for myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. My illness has a negative effect on the things I value most about our relationship.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
CONSTRUCTED MEANING SCALE - PARTNER

The items below ask how you see life for your partner and yourself being affected by the illness. Circle the number that best describes how you have been feeling during the past two weeks.

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. I feel my partner’s illness is something s/he will never recover from.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. I feel my partner’s illness is serious, but s/he will be able to return to life as it was before.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. I often feel we are outsiders because of this illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. I feel that my partner’s illness is changing our lives permanently so they will never be as good again.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. We do not have the same chance as others for satisfying lives due to my partner’s illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. I feel we are being victimized by the illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. I feel my partner is making a complete recovery from the illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. The uncertainty of my partner’s illness is causing me great difficulty.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. I feel my relationships with others have been negatively affected by my partner’s illness.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I feel my partner’s illness has permanently interfered with my ability to achieve the most important goals I have set for myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. My partner’s illness has a negative effect on the things I value most about our relationship.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
APPENDIX D

PSYCHOSOCIAL ADJUSTMENT TO ILLNESS SCALE
INSTRUCTIONS

The present form contains questions concerning the effects that your illness has had on you. We are interested in knowing what effects it has had on your relationships and your ability to perform at home and on your job. Also, we would like to know about effects on family and personal relationships. Other questions concern its effects on your social and leisure time activities, and how you have felt emotionally.

In answering each question, please put a check mark (√) in the box alongside the answer that best describes your experience. Please answer all the questions and try not to skip any. If none of the answers to a question match your experience exactly, please choose the answer that comes closest to the experience you have had.

The time we would like you to refer to is the past 30 days, including today. Answer each question in terms of what your experience has been like during this time frame. In the event you are presently a patient in the hospital, please report your experiences for the 30 days before entering the hospital.

Some questions on the form assume that you are married or have a steady partner you are close to. Other questions ask about family relationships. If these questions do not apply to you because you are unmarried, or you have no family or partner, please leave them blank. Try to answer all the questions that do apply to you, however.

Section II asks questions about your job performance. If you have either full-time or substantial part-time employment, please answer in terms of your job. If you are primarily a student, answer in terms of your school work. If you are a housewife, answer as though housework, neighbors, etc. are your work environment.

We appreciate the time you have taken to do this form. Please check again to make sure you have completed all the items. If you have any questions about the form, please ask. If you are responding by mail, please write them in the space provided below. Please return the form as soon as you have completed it.

Thank You.
SECTION I

(1) Which of the following statements best describes your usual attitude about taking care of your health?

[ ] a) I am very concerned and pay close attention to my personal health.
[ ] b) Most of the time I pay attention to my health care needs.
[ ] c) Usually, I try to take care of health matters but sometimes I just don't get around to it.
[ ] d) Health care is something that I just don't worry too much about.

(2) Your present illness probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction.

[ ] a) I do things pretty much the way I always have done them and I don't worry or take any special considerations for my illness.
[ ] b) I try to do all the things I am supposed to do to take care of myself, but lots of times I forget or I am too tired or busy.
[ ] c) I do a pretty good job taking care of my present illness.
[ ] d) I pay close attention to all the needs of my present illness and do everything I can to take care of myself.

(3) In general, how do you feel about the quality of medical care available today and the doctors who provide it?

[ ] a) Medical care has never been better, and the doctors who give it are doing an excellent job.
[ ] b) The quality of medical care available is very good, but there are some areas that could stand improvement.
[ ] c) Medical care and doctors are just not of the same quality they once were.
[ ] d) I don't have much faith in doctors and medical care today.

(4) During your present illness you have received treatment from both doctors and medical staff. How do you feel about them and the treatment you have received from them?

[ ] a) I am very unhappy with the treatment I have received and don't think the staff has done all they could have for me.
[ ] b) I have not been impressed with the treatment I have received, but I think it is probably the best they can do.
[ ] c) The treatment has been pretty good on the whole, although there have been a few problems.
[ ] d) The treatment and the treatment staff have been excellent.

(5) When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please check the statement below which comes closest to describing your feelings.

[ ] a) I am sure that I am going to overcome the illness and its problems quickly and get back to being my old self.
[ ] b) My illness has caused some problems for me, but I feel I will overcome them fairly soon, and get back to the way I was before.
[ ] c) My illness has really put a great strain on me, both physically and mentally, but I am trying very hard to overcome it, and feel sure that I will be back to my old self one of these days.
[ ] d) I feel worn out and very weak from my illness, and there are times when I don't know if I am really ever going to be able to overcome it.

(6) Being ill can be a confusing experience, and some patients feel that they do not receive enough information and detail from their doctors and the medical staff about their illness. Please select a statement below which best describes your feelings about this matter.

[ ] a) My doctor and the medical staff have told me very little about my illness even though I have asked more than once.
[ ] b) I do have some information about my illness but I feel I would like to know more.
[ ] c) I have a pretty fair understanding about my illness and feel that if I want to know more I can always get the information.
[ ] d) I have been given a very complete picture of my illness, and my doctor and the medical staff have given me all the details I wish to have.
(7) In an illness such as yours, people have different ideas about their treatment and what to expect from it. Please select one of the statements below which best describes what you expect about your treatment.

[  ] a) I believe my doctors and medical staff are quite able to direct my treatment and feel it is the best treatment I could receive.
[  ] b) I have trust in my doctor's direction of my treatment; however, sometimes I have doubts about it.
[  ] c) I don't like certain parts of my treatment which are very unpleasant, but my doctors tell me I should go through it anyway.
[  ] d) In many ways I think my treatment is worse than the illness, and I am not sure it is worth going through it.

(8) In an illness such as yours, patients are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about your treatment.

[  ] a) I have been told almost nothing about my treatment and feel left out about it.
[  ] b) I have some information about my treatment, but not as much as I would like to have.
[  ] c) My information concerning treatment is pretty complete, but there are one or two things I still want to know.
[  ] d) I feel my information concerning treatment is very complete and up-to-date.

SECTION II

(1) Has your illness interfered with your ability to do your job (schoolwork)?

[  ] a) No problems with my job
[  ] b) Some problems, but only minor ones
[  ] c) Some serious problems
[  ] d) Illness has totally prevented me from doing my job

(2) How well do you physically perform your job (studies) now?

[  ] a) Poorly
[  ] b) Not too well
[  ] c) Adequately
[  ] d) Very well

(3) During the past 30 days, have you lost any time at work (school) due to your illness?

[  ] a) 3 days or less
[  ] b) 1 week
[  ] c) 2 weeks
[  ] d) More than 2 weeks

(4) Is your job (school) as important to you now as it was before your illness?

[  ] a) Little or no importance to me now
[  ] b) A lot less important
[  ] c) Slightly less important
[  ] d) Equal or greater importance than before

(5) Have you had to change your goals concerning your job (education) as a result of your illness?

[  ] a) My goals are unchanged
[  ] b) There has been a slight change in my goals
[  ] c) My goals have changed quite a bit
[  ] d) I have changed my goals completely
(6) Have you noticed any increase in problems with your co-workers (students, neighbors) since your illness?

[ ] a) A great increase in problems
[ ] b) A moderate increase in problems
[ ] c) A slight increase in problems
[ ] d) None

SECTION III

(1) How would you describe your relationship with your husband or wife (partner, if not married) since your illness?

[ ] a) Good
[ ] b) Fair
[ ] c) Poor
[ ] d) Very Poor

(2) How would you describe your general relationships with the other people you live with (e.g., children, parents, aunts, etc.)?

[ ] a) Very Poor
[ ] b) Poor
[ ] c) Fair
[ ] d) Good

(3) How much has your illness interfered with your work and duties around the house?

[ ] a) Not at all
[ ] b) Slight problems, easily overcome
[ ] c) Moderate problems, not all of which can be overcome
[ ] d) Severe difficulties with household duties

(4) In those areas where your illness has caused problems with your household work, how has the family shifted duties to help you out?

[ ] a) The family has not been able to help out at all
[ ] b) The family has tried to help but many things are left undone
[ ] c) The family has done well except for a few minor things
[ ] d) No problem

(5) Has your illness resulted in a decrease in communication between you and members of your family?

[ ] a) No decrease in communication
[ ] b) A slight decrease in communication
[ ] c) Communication has decreased, and I feel somewhat withdrawn from them
[ ] d) Communication has decreased a lot, and I feel very alone

(6) Some people with an illness like yours feel they need help from other people (friends, neighbors, family, etc.) to get things done from day-to-day. Do you feel you need such help and is there anyone to provide it?

[ ] a) I really need help but seldom is anyone around to help
[ ] b) I get some help, but I can't count on it all the time
[ ] c) I don't get all the help I need all of the time, but most of the time help is there when I need it
[ ] d) I don't feel I need such help, or the help I need is available from my family or friends

(7) Have you experienced any physical disability with your illness?

[ ] a) No physical disability
[ ] b) A slight physical disability
[ ] c) A moderate physical disability
[ ] d) A severe physical disability
(6) An illness such as yours can sometimes cause a drain on the family's finances; are you having any difficulties meeting the financial demands of your illness?

[ ] a) Severe financial hardship
[ ] b) Moderate financial problems
[ ] c) A slight financial drain
[ ] d) No money problems

SECTION IV

(1) Sometimes having an illness can cause problems in a relationship. Has your illness led to any problems with your husband or wife (partner, if not married)?

[ ] a) There has been no change in our relationship
[ ] b) We are a little less close since my illness
[ ] c) We are definitely less close since my illness
[ ] d) We have had serious problems or a break in our relationship since my illness

(2) Sometimes when people are ill they report a loss of interest in sexual activities. Have you experienced less sexual interest since your illness?

[ ] a) Absolutely no sexual interest since illness
[ ] b) A marked loss of sexual interest
[ ] c) A slight loss of sexual interest
[ ] d) No loss of sexual interest

(3) Illness sometimes causes a decrease in sexual activity. Have you experienced any decrease in the frequency of your sexual activities?

[ ] a) No decrease in sexual activities
[ ] b) Slight decrease in sexual activities
[ ] c) Marked decrease in sexual activities
[ ] d) Sexual activities have stopped

(4) Has there been any change in the pleasure or satisfaction you normally experience from sex?

[ ] a) Sexual pleasure and satisfaction have stopped
[ ] b) A marked loss of sexual pleasure or satisfaction
[ ] c) A slight loss of sexual pleasure or satisfaction
[ ] d) No change in sexual satisfaction

(5) Sometimes an illness will cause interference in a person's ability to perform sexual activities even though the person is still interested in sex. Has this happened to you, and if so, to what degree?

[ ] a) No change in my ability to have sex
[ ] b) Slight problems with my sexual performance
[ ] c) Constant sexual performance problems
[ ] d) Totally unable to perform sexually

(6) Sometimes an illness will interfere with a couple's normal sexual relationship and cause arguments or problems between them. Have you and your partner had any arguments like this, and if so, to what degree?

[ ] a) Constant arguments
[ ] b) Frequent arguments
[ ] c) Some arguments
[ ] d) No arguments
SECTION V

(1) Have you had as much contact as usual (either personally or by telephone) with members of your family outside your household since your illness?

[  ] a) Contact is the same or greater since illness
[  ] b) Contact is slightly less
[  ] c) Contact is markedly less
[  ] d) No contact since illness

(2) Have you remained as interested in getting together with these members of your family since your illness?

[  ] a) Little or no interest in getting together with them
[  ] b) Interest is a lot less than before
[  ] c) Interest is slightly less
[  ] d) Interest is the same or greater since illness

(3) Sometimes, when people are ill, they are forced to depend on members of the family outside their household for physical help. Do you need physical help from them, and do they supply the help you need?

[  ] a) I need no help, or they give me all the help I need
[  ] b) Their help is enough, except for some minor things
[  ] c) They give me some help but not enough
[  ] d) They give me little or no help even though I need a great deal

(4) Some people socialize a great deal with members of their family outside their immediate household. Do you do much socializing with these family members, and has your illness reduced such socializing?

[  ] a) Socializing with them has been pretty much eliminated
[  ] b) Socializing with them has been reduced significantly
[  ] c) Socializing with them has been reduced somewhat
[  ] d) Socializing with them has been pretty much unaffected, or (I have never done much socializing of this kind)

(5) In general, how have you been getting along with these members of your family recently?

[  ] a) Good
[  ] b) Fair
[  ] c) Poor
[  ] d) Very poor

SECTION VI

(1) Are you still as interested in your leisure time activities and hobbies as you were prior to your illness?

[  ] a) Same level of interest as previously
[  ] b) Slightly less interest than before
[  ] c) Significantly less interest than before
[  ] d) Little or no interest remaining

(2) How about actual participation? Are you still actively involved in doing those activities?

[  ] a) Little or no participation at present
[  ] b) Participation reduced significantly
[  ] c) Participation reduced slightly
[  ] d) Participation remains unchanged

Please continue on the following page →
(3) Are you as interested in leisure time activities with your family (i.e., playing cards & games, taking trips, going swimming, etc.) as you were prior to your illness?

[ ] a) Same level of interest as previously
[ ] b) Slightly less interest than before
[ ] c) Significantly less interest than before
[ ] d) Little or no interest remaining

(4) Do you still participate in those activities to the same degree you once did?

[ ] a) Little or no participation at present
[ ] b) Participation reduced significantly
[ ] c) Participation reduced slightly
[ ] d) Participation remains unchanged

(5) Have you maintained your interest in social activities since your illness (e.g., social clubs, church groups, going to the movies, etc.)?

[ ] a) Same level of interest as previously
[ ] b) Slightly less interest than before
[ ] c) Significantly less interest than before
[ ] d) Little or no interest remaining

(6) How about participation? Do you still go out with your friends and do those things?

[ ] a) Little or no participation at present
[ ] b) Participation reduced significantly
[ ] c) Participation reduced slightly
[ ] d) Participation remains unchanged

SECTION VII

(1) Recently, have you felt afraid, tense, nervous, or anxious?

[ ] a) Not at all       [ ] b) A little bit       [ ] c) Quite a bit       [ ] d) Extremely

(2) Recently, have you felt sad, depressed, lost interest in things, or felt hopeless?

[ ] a) Extremely       [ ] b) Quite a bit       [ ] c) A little bit       [ ] d) Not at all

(3) Recently, have you felt angry, Irritable, or had difficulty controlling your temper?

[ ] a) Not at all       [ ] b) A little bit       [ ] c) Quite a bit       [ ] d) Extremely

(4) Recently, have you blamed yourself for things, felt guilty, or felt like you have let people down?

[ ] a) Extremely       [ ] b) Quite a bit       [ ] c) A little bit       [ ] d) Not at all

(5) Recently, have you worried much about your illness or other matters?

[ ] a) Not at all       [ ] b) A little bit       [ ] c) Quite a bit       [ ] d) Extremely

(6) Recently, have you been feeling down on yourself or less valuable as a person?

[ ] a) Extremely       [ ] b) Quite a bit       [ ] c) A little bit       [ ] d) Not at all

(7) Recently, have you been concerned that your illness has caused changes in the way you look that make you less attractive?

[ ] a) Not at all       [ ] b) A little bit       [ ] c) Quite a bit       [ ] d) Extremely
INSTRUCTIONS

The present form contains a set of questions concerning the effects that your partner's recent illness has had on you. We are interested in knowing what effects it has had on your relationships and performance at home and on your job, as well as on family and personal relationships. Other questions deal with its effects on your social and leisure time activities, and how you have felt emotionally.

In answering each question, please put a check mark (✓) in the box alongside the answer that best describes your experience. Please answer all the questions and try not to skip any. If none of the answers to a question match your experience exactly, please choose the answer that comes closest to the experience you have had.

The time we would like you to refer to is the past 30 days, including today. Answer each question in terms of what your experience has been like during this time frame. In the event your partner is a patient in the hospital, please report your experiences for the 30 days before he/she entered the hospital.

Some questions on the form assume that you are married; others ask about family relationships. If you are close to the patient but are not the patient's spouse, please answer questions that use the word "spouse", assuming the question to mean "partner". Try to answer all questions that do apply to you.

Section II asks questions about your job performance. If you have either part-time or full-time employment, please answer in terms of your job. If you are primarily a student, answer in terms of your school work. If you are a housekeeper, answer as though housework, neighbors, etc. are your work environment.

We appreciate the time you have taken to do this form. Please check again to make sure you have completed all the items. If you have any questions about the form, please ask. If you are responding by mail, please write them in the space provided below. Please return the form as soon as you have completed it.

Thank You.
SECTION I

(1) Which of the following statements best describes your usual attitude about taking care of your health?
   [ ] a) I am very concerned and pay close attention to my personal health.
   [ ] b) Most of the time I pay attention to my health care needs.
   [ ] c) Usually, I try to take care of health matters but sometimes I just don't get around to it.
   [ ] d) Health care is something that I just don't worry too much about.

(2) Your partner's illness probably requires some special attention and care on your part. Would you please select the statement below that best describes your reaction.
   [ ] a) I do things pretty much the way I always have done them and I don't worry or take any special considerations for my partner's illness.
   [ ] b) I try to do all the things I am supposed to do to take care of myself, but lots of times I forget or I am too tired or busy.
   [ ] c) I do a pretty good job taking care of my partner's present illness.
   [ ] d) I pay close attention to all the needs of my partner's present illness and do everything I can to take care of him/her.

(3) In general, how do you feel about the quality of medical care available today and the doctors who provide it?
   [ ] a) Medical care has never been better, and the doctors who give it are doing an excellent job.
   [ ] b) The quality of medical care available is very good, but there are some areas that could stand improvement.
   [ ] c) Medical care and doctors are just not of the same quality they once were.
   [ ] d) I don't have much faith in doctors and medical care today.

(4) During your partner's present illness they have received treatment from both doctors and medical staff. How do you feel about them and the treatment your partner has received from them?
   [ ] a) I am very unhappy with the treatment he/she has received and don't think the staff has done all they could have for my partner.
   [ ] b) I have not been impressed with the treatment he/she has received, but I think it is probably the best they can do.
   [ ] c) The treatment has been pretty good on the whole, although there have been a few problems.
   [ ] d) The treatment and the treatment staff have been excellent.

(5) When they are ill, different people expect different things about their illness, and have different attitudes about being ill. Could you please check the statement below which comes closest to describing your feelings.
   [ ] a) I am sure that my partner is going to overcome the illness and its problems quickly and get back to being his/her self.
   [ ] b) My partner's illness has caused some problems for me, but I feel he/she will overcome them fairly soon, and get back to the way he/she was before.
   [ ] c) My partner's illness has really been a great strain, both physically and mentally, but he/she is trying very hard to overcome it, and I feel sure that my partner will be back to his/her old self one of these days.
   [ ] d) My partner feels worn out and very weak from the illness, and there are times when I don't know if he/she is really ever going to be able to overcome it.

(6) Being ill can be a confusing experience, and some patients and the people close to them feel that they do not receive enough information and detail from their doctors and the medical staff about their illness. Please select a statement below which best describes your feelings about this matter.
   [ ] a) The doctor and the medical staff have told me very little about my partner's illness even though I have asked more than once.
   [ ] b) I do have some information about my partner's illness but I feel I would like to know more.
   [ ] c) I have a pretty fair understanding about my partner's illness and feel that if I want to know more I can always get the information.
   [ ] d) I have been given a very complete picture of my partner's illness and the doctor and the medical staff have given me all the details I wish to have.
(7) In an illness such as your partner's, people have different ideas about the treatment and what to expect from it. Please select one of the statements below which best describes what you expect about your partner's treatment.

[ ] a) I believe the doctors and medical staff are quite able to direct my partner's treatment and feel it is the best treatment he/she could receive.

[ ] b) I have trust in the doctor's direction of my partner's treatment however, sometimes I have doubts about it.

[ ] c) I don't like certain parts of his/her treatment which are very unpleasant, but the doctors say he/she should go through it anyway.

[ ] d) In many ways I think the treatment is worse than the illness, and I am not sure it is worth going through it.

(8) In an illness such as your partner's, patients and the people closest to them are given different amounts of information about their treatment. Please select a statement from those below which best describes information you have been given about their treatment.

[ ] a) I have been told almost nothing about my partner's treatment and feel left out about it.

[ ] b) I have some information about my partner's treatment, but not as much as I would like to have.

[ ] c) My information concerning their treatment is pretty complete, but there are one or two things I still want to know.

[ ] d) I feel my information concerning their treatment is very complete and up-to-date.

SECTION II

(1) Has your partner's illness interfered with your ability to do your job (schoolwork)?

[ ] a) No problems with my job

[ ] b) Some problems, but only minor ones

[ ] c) Some serious problems

[ ] d) Partner's illness has totally prevented me from doing my job

(2) How well do you physically perform your job (studies) now?

[ ] a) Poorly

[ ] b) Not too well

[ ] c) Adequately

[ ] d) Very well

(3) During the past 30 days, have you lost any time at work (school) due to your partner's illness?

[ ] a) 3 days or less

[ ] b) 1 week

[ ] c) 2 weeks

[ ] d) More than 2 weeks

(4) Is your job (school) as important to you now as it was before your partner's illness?

[ ] a) Little or no importance to me now

[ ] b) A lot less important

[ ] c) Slightly less important

[ ] d) Equal or greater importance than before

(5) Have you had to change your goals concerning your job (education) as a result of your partner's illness?

[ ] a) My goals are unchanged

[ ] b) There has been a slight change in my goals

[ ] c) My goals have changed quite a bit

[ ] d) I have changed my goals completely
(6) Have you noticed any increase in problems with your co-workers (students, neighbors) since your partner's illness?

[ ] a) A great increase in problems
[ ] b) A moderate increase in problems
[ ] c) A slight increase in problems
[ ] d) None

SECTION III

(1) How would you describe your relationship with your husband or wife (partner, if not married) since his/her illness?

[ ] a) Good
[ ] b) Fair
[ ] c) Poor
[ ] d) Very Poor

(2) How would you describe your general relationships with the other people you live with (e.g., children, parents, aunts, etc.)?

[ ] a) Very Poor
[ ] b) Poor
[ ] c) Fair
[ ] d) Good

(3) How much has your partner's illness interfered with your work and duties around the house?

[ ] a) Not at all
[ ] b) Slight problems, but easily overcome
[ ] c) Moderate problems, not all of which can be overcome
[ ] d) Severe difficulties with household duties

(4) In those areas where your partner's illness has caused problems with your household work, how has the family shifted duties to help you out?

[ ] a) The family has not been able to help out at all
[ ] b) The family has tried to help but many things are left undone
[ ] c) The family has done well except for a few minor things
[ ] d) No problem

(5) Has your partner's illness resulted in a decrease in communication between you and members of your family?

[ ] a) No decrease in communication
[ ] b) A slight decrease in communication
[ ] c) Communication has decreased, and I feel somewhat withdrawn from them
[ ] d) Communication has decreased a lot, and I feel very alone

(6) Some people with a partner who is ill like yours feel they need help from other people (friends, neighbors, family, etc.) to get things done from day-to-day. Do you feel you need such help and is there anyone to provide it?

[ ] a) I really need help but seldom is anyone around to help
[ ] b) I get some help, but I don't count on it all the time
[ ] c) I don't get all the help I need all of the time, but most of the time help is there when I need it
[ ] d) I don't feel I need such help, or the help I need is available from my family or friends

(7) Have you experienced any personal physical illness since your partner's illness was diagnosed?

[ ] a) No physical illness
[ ] b) Slight physical illness
[ ] c) Moderate physical illness
[ ] d) Severe physical illness
(8) An illness such as your partner’s can sometimes cause a drain on the family’s finances; are you having any difficulties meeting the financial demands of your partner’s illness?

[ ] a) Severe financial hardship
[ ] b) Moderate financial problems
[ ] c) A slight financial drain
[ ] d) No money problems

SECTION IV

(1) Sometimes having an illness can cause problems in a relationship. Has your partner’s illness led to any problems between the two of you?

[ ] a) There has been no change in our relationship
[ ] b) We are a little less close since his/her illness
[ ] c) We are definitely less close since the illness
[ ] d) We have had serious problems or a break in our relationship since my partner’s illness

(2) Sometimes when family members or close friends are ill, people report a loss of interest in sexual activities. Have you experienced less sexual interest since your partner’s illness?

[ ] a) Absolutely no sexual interest since illness
[ ] b) Marked loss of sexual interest
[ ] c) Slight loss of sexual interest
[ ] d) No loss of sexual interest

(3) Illness sometimes causes a decrease in sexual activity. Have you experienced any decrease in the frequency of your sexual activities since your partner’s illness?

[ ] a) No decrease in sexual activities
[ ] b) Slight decrease in sexual activities
[ ] c) Marked decrease in sexual activities
[ ] d) Sexual activities have stopped

(4) Has there been any change in the pleasure or satisfaction you normally experience from sex due to your partner’s illness?

[ ] a) Sexual pleasure and satisfaction have stopped
[ ] b) A marked loss of sexual pleasure or satisfaction
[ ] c) A slight loss of sexual pleasure or satisfaction
[ ] d) No change in sexual satisfaction

(5) Sometimes an illness will cause interference in a person’s ability to perform sexual activities even though they are still interested in sex. Has this happened to you because of your partner’s illness, and if so, to what degree?

[ ] a) No change in my ability to have sex
[ ] b) Slight problems with my sexual performance
[ ] c) Constant sexual performance problems
[ ] d) Totally unable to perform sexually

(6) Sometimes an illness will interfere with a couple’s normal sexual relationship and cause arguments or problems between them. Have you and your partner had any arguments like this, and if so, to what degree?

[ ] a) Constant arguments
[ ] b) Frequent arguments
[ ] c) Some arguments
[ ] d) No arguments
SECTION V

(1) Have you had as much contact (either personally or by telephone) with members of your family outside your household since your partner's illness?
   [ ] a) Contact is the same or greater since illness
   [ ] b) Contact is slightly less
   [ ] c) Contact is markedly less
   [ ] d) No contact since illness

(2) Have you remained as interested in getting together with these members of your family since your partner's illness?
   [ ] a) Little or no interest in getting together with them
   [ ] b) Interest is a lot less than before
   [ ] c) Interest is slightly less
   [ ] d) Interest is the same or greater since illness

(3) Sometimes, when people are ill, they are forced to depend on members of the family outside their household for physical help. Do you need physical help from them, and do they supply the help you need?
   [ ] a) I need no help, or they give me all the help I need
   [ ] b) Their help is enough, except for some minor things
   [ ] c) They give me some help but not enough
   [ ] d) They give me little or no help even though I need a great deal

(4) Some people socialize a great deal with members of their family outside their immediate household. Do you do much socializing with these family members, and has your partner's illness reduced such socializing?
   [ ] a) Socializing with them has been pretty much eliminated
   [ ] b) Socializing with them has been reduced significantly
   [ ] c) Socializing with them has been reduced somewhat
   [ ] d) Little or no socializing, or slight or no effect of illness.

(5) In general, how have you been getting along with these members of your family recently?
   [ ] a) Good
   [ ] b) Fair
   [ ] c) Poor
   [ ] d) Very poor

SECTION VI

(1) Are you still as interested in your leisure time activities and hobbies as you were prior to your partner's illness?
   [ ] a) Same level of interest as previously
   [ ] b) Slightly less interest than before
   [ ] c) Significantly less interest than before
   [ ] d) Little or no interest remaining

(2) How about actual participation? Are you still actively involved in doing those activities?
   [ ] a) Little or no participation at present
   [ ] b) Participation reduced significantly
   [ ] c) Participation reduced slightly
   [ ] d) Participation remains unchanged

Please continue on the following page
(3) Are you still interested in leisure time activities with your family (e.g., playing cards & games, taking trips, going swimming, etc.) as you were prior to your partner’s illness?

[ ] a) Same level of interest as previously
[ ] b) Slightly less interest than before
[ ] c) Significantly less interest than before
[ ] d) Little or no interest remaining

(4) Do you still participate in those activities to the same degree you once did?

[ ] a) Little or no participation at present
[ ] b) Participation reduced significantly
[ ] c) Participation reduced slightly
[ ] d) Participation remains unchanged

(5) Have you maintained your interest in social activities since your partner’s illness (e.g., social clubs, church groups, going to the movies, etc.)?

[ ] a) Same level of interest as previously
[ ] b) Slightly less interest than before
[ ] c) Significantly less interest than before
[ ] d) Little or no interest remaining

(6) How about participation? Do you still go out with your friends and do those things?

[ ] a) Little or no participation at present
[ ] b) Participation reduced significantly
[ ] c) Participation reduced slightly
[ ] d) Participation remains unchanged

SECTION VII

(1) Recently, have you felt afraid, tense, nervous, or anxious?

[ ] a) Not at all [ ] b) A little bit [ ] c) Quite a bit [ ] d) Extremely

(2) Recently, have you felt sad, depressed, lost interest in things, or felt hopeless?

[ ] a) Extremely [ ] b) Quite a bit [ ] c) A little bit [ ] d) Not at all

(3) Recently, have you felt angry, irritable, or had difficulty controlling your temper?

[ ] a) Not at all [ ] b) A little bit [ ] c) Quite a bit [ ] d) Extremely

(4) Recently, have you blamed yourself for things, felt guilty, or felt like you have let people down?

[ ] a) Extremely [ ] b) Quite a bit [ ] c) A little bit [ ] d) Not at all

(5) Recently, have you worried much about your partner’s illness or other matters?

[ ] a) Not at all [ ] b) A little bit [ ] c) Quite a bit [ ] d) Extremely

(6) Recently, have you been feeling down on yourself or less valuable as a person?

[ ] a) Extremely [ ] b) Quite a bit [ ] c) A little bit [ ] d) Not at all

(7) Recently, have you been concerned that coping with your partner’s illness has caused changes in your appearance that make you less attractive?

[ ] a) Not at all [ ] b) A little bit [ ] c) Quite a bit [ ] d) Extremely
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BIOGRAPHICAL SKETCH

TARA LEHAN

Education
2004-2007 Florida State University, Tallahassee, FL
Doctoral Candidate, Marriage and Family Therapy
Certificate: Measurement and Statistics
Dissertation: The Importance of Meaning in the Adjustment of Lung Cancer Patients and Their Partners
(Advisor: Lenore M. McWey)

2006-2007 University of Texas Southwestern Medical Center, Dallas, TX
Doctoral Internship
(Advisor: Wayne Denton)

2002-2004 East Carolina University, Greenville, NC
M.S., Marriage and Family Therapy
Thesis: Non-Sexual Touch Differences, Social Interest, and Relationship Adjustment in Committed, Intimate Relationships
(Advisor: Edward “Mel” Markowski)

1998-2002 College of William and Mary, Williamsburg, VA
B.S., Psychology

University Teaching Experience
2004-2006 Florida State University, Tallahassee, FL
Instructor
I was solely responsible for teaching an introductory and an upper-level course in the Department of Family and Child Sciences with an average of 65 students per semester for six semesters.
Courses Taught:
FAD2230 Family Relationships: A Lifespan Development Approach
FAD3271 Ecological Contexts

Research Experience
2006-present American Association for Marriage and Family Therapy
Intern, Virtual Intern Program, Journal of Marital and Family Therapy
Responsibilities: work on at least three manuscript reviews, one book review, two copyediting projects, one online resource development, and one special project.
2006-2007  University of Texas Southwestern Medical Center, Dallas, TX

*Researcher*

Responsibilities: conducted telephone interviews with prospective participants and live interviews with enrolled participants, entered all participant data in an SPSS database, and actively participated in weekly telephone supervision meetings with master Emotion-Focused Therapists as part of a federally funded research project.

2006  American Association for Marriage and Family Therapy

*Abstract Reviewer*

Responsibilities: reviewed and provided feedback on abstracts submitted for presentation at the 2007 national conference.

2004-2006  Florida State University, Tallahassee, FL

*Research Assistant*

Responsibilities: conducted participant interviews, transcribed and coded audio taped interviews, prepared papers and posters for national conferences, as well as manuscripts for publication.

2002-2003  East Carolina University, Greenville, NC

*Research Assistant*

Responsibilities: located relevant literature and coded qualitative data from a research study on family communication in Trinidad and Tobago.

2002-2003  East Carolina University, Greenville, NC

*Graduate Assistant for Assistant to the Dean for Undergraduate Studies*

Responsibilities: assisted in organizing the College of Human Ecology fall and spring graduation ceremonies and checked senior summaries to ensure students had fulfilled all graduation requirements.

**Peer Reviewed Publications**

*In Press:*


*Under Review*


In Process:

Professional Presentations
National:
Boalen, M., Lehan, T. J., & McWey, L. (October, 2006) Boundary Ambiguity for Families Involved in the Foster Care System. Presented at the American Association for Marriage and Family Therapy Annual Conference, Austin, TX.


Berarducci, N.S., & Lehan, T. J. (October, 2005) Do Graduate Students “Buy In” to Sprenkle and Blow’s Common Factors? Poster presented at the American Association for Marriage and Family Therapy Annual Conference, Kansas City, MO.

Lehan, T. J. (October, 2005) Reflections of Ambiguous Loss and Boundary Ambiguity in the Mother-Daughter Relationship. Poster presented at the Family Therapy Student Research Conference, Manhattan, KS.

State:
Lehan, T.J. (May, 2005) The Benefits of Medical Family Therapy with Oncology Patients and Their Families. Poster presented at the Florida Association for Marriage and Family Therapy Annual Conference, Ft. Lauderdale, FL.


Honors and Awards
Glenn Society Inductee (2007)

May Watson Connor Scholarship (2007)


Florida Association for Marriage and Family Therapy’s Student Paper Competition Winner (2005)
Ursich Graduate Scholarship (2004)

East Carolina University’s Marriage and Family Therapy Program Alumni Scholarship (2004)

**College and Departmental Service**
2005-2006  
Vice President, Graduate Student Advisory Council  
College of Human Sciences, Florida State University

2002-2004  
Treasurer, Marriage and Family Therapy Graduate Association  
College of Human Ecology, Department of Child Development and Family Relations, East Carolina University

**Clinical Experience**

2007  
*Family Therapist*  
Kids in Focus, Richmond, VA  
Responsibilities: provide individual, family, and group therapy in a group home facility for adolescent females, as well as collaborate with larger systems, including the legal system, and provide recommendations for future placement of the clients.

2006-2007  
Parkland Health and Hospital System Oncology, Dallas, TX  
Responsibilities: provided therapeutic services to underserved lung and breast cancer patients and their loved ones and participated in multidisciplinary treatment teams at an urban community hospital.

2006-2007  
Beavers Family Studies Center, Dallas, TX  
Responsibilities: provided couple and family therapy at a university-based clinic to clients primarily referred by two school districts and a hospital in the area from the initial contact through case planning, intervention, and termination.

2004-2006  
Center for Marriage and Family Therapy, Tallahassee, FL  
Responsibilities: worked with individual, couples, and families seeking treatment at a university-based clinic for a variety of issues from the initial contact through case planning, intervention, and termination, as well as provided therapeutic visitation services to families involved with the Department of Social Services.

2003-2004  
Pitt County Memorial Hospital Hematology-Oncology/Leo Jenkins Cancer Center, Greenville, NC  
Responsibilities: provided therapeutic services to inpatient and outpatient cancer patients and their loved ones and participated in multidisciplinary treatment teams at a rural hospital.
2003-2004  Family Therapy Clinic, Greenville, NC
Responsibilities: worked with diverse individuals, couples, and families who presented at a university-based clinic from the initial contact through case planning, intervention, and termination.

2001-2002  Colonial Services Board, Williamsburg, VA
Responsibilities: organized a directory of services for the community, with an emphasis on services for older adults and led two outreach groups for at-risk youths in the area.

2001-2002  Matthew Whaley Elementary School, Williamsburg, VA
Responsibilities: worked with an exceptional child and attending weekly meetings in collaboration with his parents, teacher, and school psychologist to determine the best way to serve him.

Professional Memberships
American Association for Marriage and Family Therapy (2002-present)
Texas Association for Marriage and Family Therapy (2006-2007)
Florida Association for Marriage and Family Therapy (2004-2006)
North Carolina Association for Marriage and Family Therapy (2002-2004)