PARTNER ADJUSTMENT AND RESPONSE TO YOUNG WOMEN WITH BREAST CANCER

by

GEORGE BOWDEN TEMPLETON

(Under the Direction of Stephanie Burwell)

ABSTRACT

Illness is a universal experience for families. In recent decades, increased attention has been paid to the role of the family in chronic illness and disability, as well as the impact of illness throughout the entire family system. The quality of relationships is being increasingly identified as a source of considerable influence in health and related adjustment. Drawing on a biopsychosocial framework (Rolland, 1994a, 1994b; Engel, 1977, 1978, 1979, 1980), the purpose of this research was to examine the impact of breast cancer on partners, identify factors associated with partner adjustment, and describe profiles of supportive partners. To address these aims, two related studies were conducted.

Study one reviewed literature examining the adjustment of partners to the diagnosis and treatment of breast cancer and answered two questions: (a) Do partners of women with BCA experience adjustment difficulties? and (b)What factors are associated with partner adjustment? This review determined that (a) partners experience physical health declines and are at risk for compromised immune functioning, (b) partners experience psychological distress that equal or exceeds that of patients, (c) partner experience disruptions at home, work, and in social activities, and (d) partners experience problems in their sexual relationship. Correlates of partner

adjustment included medical characteristics, coping strategies, thought content, communication patterns, and social support.

Study two investigated behaviors that young women perceive as supportive from their partners and factors that predicted partner support. Two questions were answered: (a) What partner behaviors do young women with BCA perceive as supportive? and (b) What factors predict the likelihood of partners being perceived as supportive? To address these questions, a series of two-step cluster analyses developed profiles of perceived partner behaviors in response to breast cancer, revealing two distinct groups: supportive and non-supportive. Binomial logistic regression determined that increases in patient symptom severity and psychological distress were associated with increased likelihood of patients perceiving partners as supportive, by factors of 1.83 and 1.97, respectively. In addition, patients reporting increased disruption of family life and their sexual relationship were less likely to perceive their partners as supportive, by factors of .28 and .35, respectively.

INDEX WORDS: breast cancer, spouse, partner adjustment, biopsychosocial, support

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CANCER

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INTRODUCTION

Illness is a universal experience that often presents major challenges to families. In recent decades, increased attention has been paid to the role of the family in chronic illness and disability, as well as the impact of illness throughout the family system (Campbell, 2003; Kiecolt-Glaser & Newton, 2001; McDaniel, Hepworth, & Doherty, 1992; Rolland, 1994a, 1994b; Weihs, Fisher, & Baird, 2001). While the illness experience can actually improve the quality of life among families who are resilient and thrive under difficult circumstances, others experience disruptions that impair even the most cohesive and flexible families. Weihs et al. (2001) summarized this growing body of research on the impact of illness on families, highlighting the relation of family dynamics to illness behavior, adherence, and the course of a disease. Close, connected families with a clear structural organization who use problem focused coping strategies and direct communication are more protected from the detrimental effects of illness than families characterized by criticism, hostility, blame, lack of support, rigidity, and psychological trauma.

Within families, marriage may be the relationship most influential on health (Campbell, 2003; Kiecolt-Glaser et al., 1987; Kiecolt-Glaser & Newton, 2001). Marriage has been identified as a protective factor as those who are married consistently have lower morbidity (Berkman & Syme, 1976) and mortality rates (Goodwin, Hunt, Key, & Samet, 1987) compared to people who are unmarried, particularly men. These rates are consistent across acute and chronic illnesses such as cancer, heart attack, and surgical procedures (Chandra, Szklo, Goldberg, & Tonascia, 1983; Goodwin et al., 1987; Gordon & Rosenthal, 1995; House, Landis, & Umberson, 1988).

Pathways between marital functioning and health have been identified as the nature and quality of marital problem-focused discussions, physiological reactivity to neutral or impersonal spousal disagreements, depression, trait hostility, and health habits (Kiecolt-Glaser & Newton, 2001).

Nowhere is the impact of illness on families and couples more evident than in the case of cancer. According to The American Cancer Society (ACS) (2007b), 1,444,920 new cases of cancer were expected to be diagnosed in 2007. In the same year, the ACS expected 559,650 Americans to die of cancer, making cancer the second leading cause of death in America following heart disease. Despite the large number of newly diagnosed cases and expected deaths, the five-year survival rate for all types of cancers for the period 1996-2002 is up 15% from the years 1975-1977. In sum, people are living longer with cancer placing an increased demand on families to care for chronically ill members.

Couples and Breast Cancer

Among women in the United States, breast cancer (BCA) is the most common type of cancer with 178,480 new cases expected in 2007 (ACS, 2007a). BCA accounts for nearly 1 in 3 cancers diagnosed in US women and this year alone will be responsible for an estimated 40,460 deaths (ACS, 2007a). Yet, early detection and advances in treatment have reduced the morbidity of breast cancer among women younger than 50 (decrease of 3.3% annually) as well as those aged 50 and older (decrease of 2.0% annually). Survival rates vary by location of cancer as 98% of women with localized malignant BCA attain 5 year survival rates that decline as the malignancy metastasizes to regional (83%) or distant (26%) tissues. Ten year survival rates for all stages of BCA are reported at 80% and may underestimate survival based on current medical advances (ACS, 2007a). Accordingly, BCA is an example of a chronic illness with significant impact not only on the life course of the patient but also on partners and family (Baider et al.,

2004a; Ben-Zur, 2001; Northouse, 1995; Northouse & Swain, 1987; Peteet & Greenberg, 1995; Shands, Lewis, Sinsheimer, & Cochrane, 2006). Through the study of BCA in younger couples we can further understand the impact of illness at specific life cycle stages and contribute to the body of knowledge regarding families and illness. This knowledge will be particularly useful in the development of appropriate interventions based on family structure and stage of the life cycle.

Need for the study

In light of the impact of chronic illness on family members (Weihs et al., 2001) and their role in the treatment of illness (Campbell, 2003), it is important to study family members, especially partners. Spouses and partners of women with breast cancer are often identified as the primary source of support, emergency contact, and health care proxy (Gass, Weitzen, Clark, & Dizon, 2007). Keicolt-Glaser and Newton (2001) highlight this influential role relationships play in health, describing the importance of differentiating between positive and negative dimensions of marital functioning. They conclude that negative dimensions of marital functioning have an indirect influence on health outcomes through depression and health habits and directly influence cardiovascular, endocrine, immune, neurosensory, and other physiological mechanisms (Kiecolt-Glaser & Newton, 2001). The study of how couples interact in the context of illness is therefore imperative. The investigation of partners of women with BCA is critical not only because of the distress they experience, but also because of their influence on women's adjustment (Holmberg, Scott, Alexy, & Fife, 2001; Manne, 1998; Manne, 1999; Ptacek, Ptacek, & Dodge, 1994; Segrin, Badger, Dorros, Meek, & Lopez, 2007; Vess, Moreland, Schwebel, & Kraut, 1988; Zunkel, 2002). Partners are in a unique position as they can have a positive or negative impact on patient outcomes. By caring for partners as well as women with BCA, healthcare providers stand to

exponentially increase the influence of their treatments. By identifying partner behaviors that women perceive as supportive and understanding the contextual factors that predict them, we may guide clinicians in their efforts to help partners be healthy and responsive to the needs of their ill spouses.

Statement of Purpose

Despite the recent increased attention paid to the role of family in cancer, there remains much to be learned about the impact of BCA on women's spouses or partners. The overarching goal of this research is to understand the impact of BCA on partners, identify factors associated with partner adjustment, and describe partner behaviors that women perceive as supportive. To accomplish this goal, two related studies were conducted.

Study One

The first article contains a review of the literature regarding the impact of BCA on spouses or partners of women with BCA and examines the following questions:

1. Do partners of women with BCA experience adjustment difficulties?

2. What factors are associated with adjustment among partners of women with BCA?

Study Two

The second article contains results from a study of the adjustment of younger couples to BCA. The objective of this study is to examine partner behaviors that younger women identify as supportive and identify predictors of these behaviors. The following questions are addressed in this study:

1. What partner behaviors do younger women with BCA perceive as supportive?

2. Do illness demands, patient psychological distress, family life, or the sexual relationship contribute to the likelihood of partners being perceived as supportive?

REVIEW OF THE LITERATURE

According to the most recent data reported by The Center for Disease Control (Kung, Hoyert, Xu, & Murphy, 2007), death rates from the three leading causes of death (heart disease, cancer, and cerebrovascular disease) decreased between 2004 and 2005. Heart disease accounted for 649,400 deaths in 2005, representing a 3.1% rate of decline. Death from cancer declined at a rate of 1.1%, accounting for 559,300 lost lives. The largest decline in death rate was related to cerebrovascular disease (-6.8%) that accounted for 143,500 reported deaths. Collectively, the 15 leading causes of death decreased by a rate of .2% annually in 2005, with 2,447,900 deaths reported. These data reflect the fact that Americans are living longer as the life expectancy at birth for Americans of all races increased from 77.8 to 77.9 years in 2005 (Kung et al., 2007). These facts, coupled with the aging of the baby boomer generation, create a situation wherein the care and treatment demands of illness are growing, yet shifting in ways that require reevaluation of our healthcare system. The role of family caregivers in healthcare is increasingly important.

Campbell (2003) asserts four important conclusions about the relationship between family and health. First, the influence of families on health is equal to traditional medical risk factors. Family support, for example, promotes better outcomes than those experienced by people who live in isolation. Second, the most important type of support in the context of family is emotional support. Blaming, criticism, and hostility in family relationships is more corrosive than supportive relationships are positive. Finally, Campbell declares that marriage is the most influential adult relationship on health. Further research is needed to document the relationship between family and health. These assertions are echoed in a report commissioned by the Committee on Health and Behavior at the National Academy of Sciences (Weihs, Fisher, & Baird, 2002). Weihs et al. point out that the impact of the demands placed on families by chronic illness are dependent upon the extent to which patients and family members are required to change their daily activities and how they relate to one another. Adaptive patients and family members will experience less distress than those who are more rigid. Likewise, distressed family members will be less able to meet patient needs and may require treatment themselves. Success in navigating these demands depends on close family relationships that are characterized by secure attachment, appropriate responsiveness, and engagement. This in turn influences the disease process through factors such as decision-making about compliance with medical interventions. Family relationships occupy a unique place in our healthcare system by providing the context, structure, belief systems, and day-to-day practices necessary to maintain health and treat disease. Collectively these findings suggest that although the family is a necessary complement to healthcare, it may be instructive to focus on the adult couple relationship.

The Impact of Couple Relationships on Illness

Within the family, the relationship of the adult couple is considered primary in its influence on health (Kiecolt-Glaser & Newton, 2001; Schmaling & Sher, 2000).¹ The impact of couples' relationships on illness has consistently demonstrated that married couples have lower mortality rates (Berkman & Syme, 1976) and higher survival rates following diagnosis of illness (Goodwin et al., 1987; Gordon & Rosenthal, 1995). Married couples are more likely to comply with treatment regimes (Goodwin et al., 1987). Kiecolt-Glaser and colleagues have demonstrated that partners who are separated or divorced have lower immune function than married partners

¹ Although this relationship has generally been conceptualized and studied as marriage, we believe this to include all committed adult partnerships. We use the term marriage not with the intent of excluding same-sex partnerships but rather to mean all committed relationships.

(Kiecolt-Glaser et al., 1988). Additionally, distressed marriages are known to reduce immune functioning, compromising health and increasing disease risk (Kiecolt-Glaser et al., 1987; Kiecolt-Glaser, Glaser, Cacioppo, MacCullum, & Snydersmith, 1997; Kiecolt-Glaser et al., 1988; Kiecolt-Glaser, Malarkey, Chee, Newton, & Cacioppo, 1993). Criticism from an intimate partner has been linked to disease activity and coping with illness (Manne, 1999; Zautra et al., 1998). Lastly, positive, caring, supportive spousal relationships are known to improve health (Helgeson & Cohen, 1996), decrease pain medication use and re-hospitalizations (Kulik & Mahler, 1989), and improve recovery following surgery (King, Reis, Porter, & Norsen, 1993). *The Impact of Illness on Couple Relationships*

The relationship between illness and family is reciprocal. Just as couple relationships affect illness, the illness affects the couple. Numerous studies have documented the negative impact of illness on each partners' psychological health including depression and anxiety (Baider, Goldzweig, Ever-Hadani, & Peretz, 2006; Derogatis et al., 1983a; Frances Marcus Lewis, Fletcher, Cochrane, & Fann, 2008; Manne, 1998; Northouse, 1989a; Northouse, 1992). However, some couples actually benefit from the distress by making significant positive life changes (Manne, Ostroff, Winkel et al., 2004; Weiss, 2002, 2004a, 2004b). For some couples, marital satisfaction declines while, for others, it increases (Schmaling & Sher, 2000). Rolland (Rolland, 1994a) proposed that this may be due to the type of illness, the demands it places on couples, and how these characteristics interact with family dynamics and individual and family life cycles. Rules, roles, and responsibilities are also affected by illness. Many spouses assume additional responsibilities when their partners are ill (Helgeson, 1993), placing burden on caregivers (Coyne et al., 1987). Rules of interaction may change in the context of the illness (Burwell, Brucker, & Shields, 2006). Lastly, illness can have a detrimental affect on social

support. Hegelson (1993) found that as the illness affected adjustment in both patients and their spouses, their distress subsequently influenced spousal availability to provide support to the patient. This, in turn, affected the patient's symptoms, increasing the need for support from a spouse who is less available to provide it, creating a cycle in which no one received the care and support they required for recovery and improved health.

The Biopsychosocial Framework

In 1977, George Engel challenged the biomedical framework that was dominate in medicine at the time (Engel, 1977). In Engel's view, medicine's concentrated focus on the physical or biological dimensions of disease did not allow for the conceptualization or treatment of behavioral or psychological problems and considered this a significant shortcoming in healthcare (Engel, 1977, 1978, 1979). The reductionist and dualistic, biomedical model operates from the stance that medical problems can be reduced to a molecular level that distinguishes between mind and body. Engel cited diabetes as an example of an illness for which there may be molecular evidence for disease despite a patient's lack of awareness of the physical evidence for the diabetic condition. Conversely, schizophrenia may not demonstrate molecular evidence but is outwardly visible to the patient or an objective observer. According to Engel, consideration of psychological, social, and cultural factors concurrent with biological factors is important in treating disease (Engel, 1977, 1978, 1979), a framework he termed the biopsychosocial model. Accordingly, to determine the etiology and appropriate treatment of disease, medicine must account for the person, the social context in which they interact, and how the healthcare providers and system perceive disease.

Couples and Breast Cancer

The diagnosis and treatment of BCA in women is a particularly distressing experience that affects both women and their partners. This may be particularly salient for young couples. A recent review of the literature on the psychosocial issues confronting young women with BCA concluded that young women report a lower quality of life than older women (Baucom, Porter, Kirby, Gremore, & Keefe, 2005). This may in part be due to the aggressive medical treatments young women are exposed to and their resulting physical side effects (Campora et al., 1992; Ganz, Rowland, Meyerowitz, & Desmond, 1998; Stanton et al., 1998). Aggressive medical treatments in young women may also bring about premature menopause and ovarian failure, creating family planning and infertility problems (Dow & Kuhn, 2004; Ganz, Rowland, Meyerowitz et al., 1998; Mor, Malin, & Alien, 1994; Schover, 1999). Other factors contributing to lower quality of life in young women include psychological distress (Derogatis et al., 1983a; Meyerowitz, 1980; Northouse, 1992) and the disruption of family life (Baider & De-Nour, 1984; Baider & Kaplan De-Nour, 1986), particularly in families who are already in the initial stages of negotiating rules, roles, and boundaries (Carter & McGoldrick, 1989; Carter & McGoldrick, 1999). Further, the impact of BCA treatment is disruptive to the sexual functioning of young women (Bakewell & Volker, 2005; Barni & Mondin, 1997; Bransfield, 1982; Burwell, Case, Kaelin, & Avis, 2006; Front, 1999; Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999; Henson, 2002). These findings are reiterated in a report from the Institute of Medicine and National Research Council National Cancer Policy Board (Hewitt, Herdman, & Simone, 2004).

Partners of women with BCA also confront a host of psychosocial issues similar to those of their ill spouses. Several studies document high positive correlations between the emotional distress of women and their partners (Baider, Koch, Esacson, & De-Nour, 1998; Baider, Rizel, &

De-Nour, 1986; Ben-Zur, 2001; Ben-Zur, Gilbar, & Lev, 2001) and illustrate the reciprocal nature of spousal influence. Northouse and colleagues (2001), for example, found that each partner's level of psychological adjustment over time had a direct effect on the other person's adjustment over time. The aggressive surgical and adjuvant treatments of young women with BCA and its associated symptom severity (fatigue, sleep disturbance, or pain) are associated with increased partner distress (Baider & De-Nour, 1984; Baider & Kaplan De-Nour, 1986). Likewise, partners may become preoccupied with and the myriad responsibilities resulting from BCA diagnosis and treatment that disrupt family and marital life (Hewitt et al., 2004; Hilton, Crawford, & Tarko, 2000), creating a situation wherein s/he is unavailable to meet patient's needs. Finally, problems in the sexual relationship have been identified as one of the major stressors in young couples confronting BCA (Baider & De-Nour, 1984; Bakewell & Volker, 2005; Hewitt et al., 2004). While partners clearly express priority for their spouse to heal over continuation of sexual activity (Holmberg et al., 2001), communication about sexual needs and concerns often goes unaddressed in even the closest relationship.

Social Support

Supportive behaviors play a crucial role in a woman's adjustment to BCA (Arora, Finney Rutten, Gustafson, Moser, & Hawkins, 2007; Davis, Williams, Parle, Redman, & Turner, 2004; Luszczynska, Boehmer, Knoll, Schulz, & Schwarzer, 2007; Manning-Walsh, 2005; Ringdal, Ringdal, Jordhoy, & Kaasa, 2007; Sammarco, 2001; Weber et al., 2007). Social support has been alternately conceptualized as the nature and structure of social ties with significant others such as marital status or involvement in community organizations (Eaton, 1978; Sandler, 1980), perceptions of the supportiveness of social relationships (emotional support, instrumental support, information provision, marital cohesion) (Moos, 1974, 1975), or the actual behaviors that individuals receive (Gottlieb, 1978). Manne and colleagues (Manne, Taylor, Dougherty, & Kemeny, 1997) have also explored the role of problematic aspects of social relationships in dealing with cancer concluding that perceived critical and avoidant responses were significantly correlated with lower well-being and higher distress in women with BCA. Negative or unhelpful interactions have been described as physical avoidance of the patient, avoidance of open communication, and minimization of the illness and its experience (Wortman, 1984; Wortman & Dunkel-Schetter, 1979, 1987). These and other authors proposed that negative responses by significant others result in patients feeling abandoned or rejected (Burwell, Brucker et al., 2006). Others developed a typology of helpful and unhelpful behaviors categorizing negative responses as unhelpful emotional, informational, and tangible support (Dakof & Taylor, 1990).

Symptom Severity

Aggressive treatments of young women with BCA including chemotherapy, radiation, and hormonal therapy, are commonly associated with general weakness, fatigue, and vaginal dryness (Ganz, Rowland, Meyerowitz et al., 1998; Holmberg et al., 2001). Symptom severity is related to increased distress in women and partners alike. In a study of 20 couples coping with BCA in which women were treated with chemotherapy or radiotherapy and chemotherapy, patients and their partners were more likely to report distress than those who received no treatment (Baider & De-Nour, 1984; Baider et al., 1986).

Psychological Distress

Along with initial diagnosis and treatment, women with BCA experience psychological distress that has been defined and studied in terms of anxiety, depression, shock, numbness, and sleep disturbance (Glanz & Lerman, 1992; Meyerowitz, 1980; Northouse, 1992). Estimates suggest that 20% to 38% of women with BCA experience high levels of psychological distress

following diagnosis (Hann, Winter, & Jacobsen, 1999; Irvine, Brown, Crooks, Roberts, & Browne, 1991; Maguire, 1995). Younger age has been identified by some researchers as a variable associated with psychological distress (Kroenke et al., 2004).

Family Life

In addition to psychological distress, the family life of couples managing BCA is dramatically disrupted. Women and partners experience problems in the area of family relations though partners may experience more disruption (Baider & De-Nour, 1984; Baider & Kaplan De-Nour, 1986; Baider et al., 1986). In a longitudinal study assessing partners at 3 and 30 days and 18 months post surgery, Northouse (1989b) found disruptions of partners' family lives though partners experienced fewer role adjustment problems over time than patients. This finding is consistent with Hoskins' (1995a) longitudinal study of 128 breast cancer patients and 121 partners assessed at six time points from diagnosis to one-year post surgery. Both patients and partners reported disruption of the domestic environment though again it improved over the year.

Sexual Relationship

The sexual relationship of young couples is also affected by the diagnosis and treatment of BCA (Bakewell & Volker, 2005; Barni & Mondin, 1997; Bransfield, 1982; Front, 1999; Ganz et al., 1999; Henson, 2002). Relationships of shorter duration may be particularly vulnerable to sexual problems since sexual patterns are not yet well established. Another concern among young women is fearing rejection by a sexual partner due to surgical disfigurement (Henson, 2002). Also, aggressive treatment with chemotherapy, radiation, and hormonal therapy is associated with decreases in sexual interest, desire, and responsiveness (Burwell, Case, et al., 2006; Ganz et al., 1999; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998; Holmberg et al., 2001). Finally, some partners have difficulty accepting the missing, new, or scarred breasts (Nissen, Swensen, & Kina) and may avoid looking at or discussing these changes.

In summary, the literature documents that relationships affect illness and illness affects relationships. Relationship status, relationship quality, and specific behaviors are associated with adjustment to chronic illness and disease and can be either beneficial or detrimental to health. People in relationships, particularly married couples, characterized by support, emotional availability, and responsiveness are likely to be defended against health risks. Conversely, criticism, negativity, blaming, and hostility increase risk for disease and are associated with poor treatment related outcomes. Reciprocally, illness affects relationships in ways that also can be beneficial or detrimental. Illness is associated with psychological distress, though in some, it produces personal growth and significant life change. Illness can bring about changes in marital satisfaction by pushing some partners apart and pulling others closer together. Social support is an important variable in investigations of the relationship between illness and couples as it represents one of the primary processes through which interaction occurs.

The biopsychosocial model provides a comprehensive framework for the investigation of couples and breast cancer. The model illustrates the mutual influence of biological, psychological, and social factors in the adjustment of partners to the diagnosis and treatment of breast cancer. It highlights many of the challenges faced by couples confronting breast cancer and offers possibilities for support and intervention and is used as a framework to guide the subsequent research.

CHAPTER 3

THE INVISIBLE PATIENT: A REVIEW OF ADJUSTMENT IN PARTNERS OF WOMEN WITH BREAST CANCER 2

² Templeton, G. B. and Burwell, S. B. To be submitted to *Psycho-Oncology*.

ABSTRACT

A biopsychosocial framework was used to examine a) whether spouses or partners of women with breast cancer experience adjustment difficulties and b) what factors are associated with variations in adjustment. Searches were conducted in Medline, PsycInfo, Biological Abstracts, Sociological Abstracts, and Cumulative Index to Nursing and Allied Health. A sparse literature suggests that partners of women with breast cancer experience biological, psychological, and social distress that parallels and at times exceeds that of patients and the normal population. Partners of patients with breast cancer are an often overlooked group in need of psychosocial intervention. Directions for future research are suggested.

Keywords: oncology, breast cancer, couple, review, spouse, marriage, biopsychosocial, partner adjustment

The Invisible Patient: A Review of Adjustment in Partners of Women with Breast Cancer

Breast cancer (BCA) is the most common type of cancer among women in the United States (US) with 178,480 new cases expected in 2007 (ACS, 2007a). BCA accounts for nearly 1 in 3 cancers diagnosed in US women and this year alone will be responsible for an estimated 40, 460 deaths (ACS, 2007a). Yet, early detection and advances in treatment have reduced the morbidity of breast cancer among women younger than 50 (decrease of 3.3% annually) as well as those aged 50 and older (decrease of 2.0% annually). Survival rates vary by location of the cancer as 98% of women with localized malignant BCA attain 5 year survival rates that decline as the malignancy metastasizes to regional (83%) or distant (26%) tissues. Ten year survival rates for all stages of BCA are reported at 80% and may underestimate survival based on current medical advances (ACS, 2007a). Accordingly, BCA may be best understood as a chronic illness with significant impact not only on the life course of the patient but also on partners and family (Baider et al., 2004a; Ben-Zur, 2001; Northouse, 1995; Northouse & Swain, 1987; Peteet & Greenberg, 1995; Shands et al., 2006).

The impact of the diagnosis and treatment of BCA on partners is particularly salient as they often adopt a caregiving role (Walsh, Manuel, & Avis, 2005). Studies show that partners of breast cancer patients are at increased risk for depression (Maguire, 1981; Omne-Ponten, Holmberg, Bergstram, Sjoden, & Burns, 1993), anxiety (Baider & De-Nour, 1984; Baider et al., 1986), sexual problems (Maguire, 1981; Wellisch, Jamison, & Pasnau, 1978), disruption in quality of life (Wagner, Bigatti, & Storniolo, 2006), compromised health status (Blake Mortimer et al., 2005), and having problems in their vocational and social environments (Maguire, 1981; Northouse, Laten, & Reddy, 1995). Despite these findings, much remains to be learned about the impact of BCA on partners.

The influence of BCA on partners is critical not only due to the distress *they experience* but also *their influence* on the adjustment of the patient (Holmberg et al., 2001; Manne, 1998; Manne, 1999; Ptacek et al., 1994; Segrin et al., 2007; Vess et al., 1988; Zunkel, 2002). Among married and partnered women with cancer, partners may represent the most proximal source of support (Ell, Nishimoto, Mantell, & Hamovitch, 1988; Helgeson & Cohen, 1996) and the majority of partnered women with BCA identify the partner as their primary support, emergency contact, and health care proxy (Gass et al., 2007). Moreover, partner support exceeds that of other sources of support including family, friends, and health care professionals (Neuling & Winfield, 1988; Northouse, 1988). In caring for patients with cancer, partner support predicts lower levels of depression and anxiety and better quality of life (Alferi, Carver, Antoni, Weiss, & Duran, 2001; Helgeson & Cohen, 1996; Manne, 1994; Peters-Golden, 1982). These findings are consistent with other health related literatures (e.g. cancer and coronary disease) and evidence the importance of marital quality in chronic illness (Badr & Acitelli, 2005; Berg & Upchurch, 2007; Campbell & Sprenkle, 2002; Kiecolt-Glaser et al., 1987; Kiecolt-Glaser & Newton, 2001; Rolland, 1994b; Skerrett, 2003).

A growing body of literature has begun to document the impact of BCA on partners (see Table 3.1) and the factors that are associated with partner adjustment during the diagnosis and treatment of BCA (see Table 3.2). Despite the importance of understanding partners' adjustment to BCA and their influence on the adjustment of patients, no comprehensive and systematic summary of the literature has been undertaken. Therefore, the purpose of this paper is to review and critically examine the literature on the adjustment of partners of women with BCA using a biopsychosocial framework. Engel (1977, 1980) originally proposed the biopsychosocial model in response to the biomedical conceptualization of disease and its treatment suggesting that it did

not adequately account for the personal characteristics of the patient or his or her social and familial context. A biopsychosocial framework provides a comprehensive lens from which to conceptualize partner adjustment to BCA and guides this review that addresses the following questions:

1. Do partners of women with BCA experience adjustment difficulties?

2. What factors are associated with adjustment among partners of women with BCA?

METHOD

To identify relevant literature, searches were conducted using Medline, PsycInfo, Biological Abstracts, Sociological Abstracts, and Cumulative Index to Nursing and Allied Health (CINALH) for the period 1970-2007. Multiple combinations of search terms were used and included breast cancer (carcinoma, neoplasm), partner, spouse, married, marital, biopsychosocial, psychiatric, psychological, psychosocial, morbidity, distress, depression, anxiety, coping, adjustment, social support, and quality of life. From these initial searches, additional studies were identified in the reference sections of specific journal articles.

For inclusion in this review, studies met three criteria. First, each study reported outcomes of the biopsychosocial adjustment of the partner of a BCA patient. Biological outcomes included physical health status and chronic stress responses. Psychological outcomes included mental health (e.g., depressive symptoms and disorders, anxiety symptoms and disorders, mood state, distress) and posttraumatic growth. Social outcomes included aspects of role functioning (e.g., vocational, domestic, social/leisure) and marital adjustment. Second, partners' outcome data were obtained through self-report or clinician interviews. Partner perceptions of psychosocial adjustment to breast cancer may differ from those of other reporters (Baider & Sarell, 1984; Carlson, Ottenbreit, St. Pierre, & Bultz, 2001; Clipp & George, 1992) and proxy raters are known to be more accurate raters of concrete, observable factors rather than subjective, psychological factors (Sprangers & Aaronson, 1992). Third, only articles published in English were included in this review. The review focused primarily on quantitative studies although qualitative studies (see Table 3.3) were used to assist in the interpretation and overall synthesis.

From the initial searches, a total of 42 studies met criteria for this review. Once the studies were identified, indicators and correlates of adjustment were grouped into coherent and mutually exclusive categories using the biopsychosocial framework (see Table 3.4). Each research question is addressed below along with considerations for future research and clinical implications.

RESULTS

Research Question One: Do Partners of Women With BCA Experience Adjustment Difficulties? Description of Studies

Sixteen studies addressed this question (see Table 3.1). The first study of partner adjustment to the diagnosis and treatment of BCA was published in the late 1970's. It was followed by six studies in the 1980's, 10 studies in the 1990's, and one study in the current decade. Ten studies were cross sectional and six were longitudinal. Fourteen studies employed between groups designs comparing partner adjustment to that of patients or normal populations. Two studies contrasted partner adjustment across type of disease and type of medical procedure. Partner adjustment was assessed from initial diagnosis to 5 years post surgery. Study sample sizes ranged from 10 to 265 and comprised partners who were well educated, had middle to higher incomes, and were aged 25 to 86, the majority being in their early to middle fifties. Relationship length ranged from a few months to 45 years though most had been in the relationship for 25 years. Sampled partners were overwhelmingly heterosexual as only one study noted a lesbian partner.

Outcomes examined in these studies were grouped by a) biological adjustment (four studies), b) psychological adjustment including global distress, depression, or anxiety (18 studies), and c) social adjustment including marital adjustment (six studies), family functioning (two studies), and role functioning (12 studies).

Partner Outcomes in Response to Women with BCA

Biological Adjustment

Four studies addressed the biological adjustment of partners of women with BCA yielding consistent results. Partners of women with BCA experience greater frequency and intensity of physical symptoms (Hoskins, 1995a; Hoskins, Baker, Sherman, & Bohlander, 1996; Wagner et al., 2006) and are vulnerable to the suppression of their immune system through exposure to chronic stress (Blake Mortimer et al., 2005). In a sample of 121 partners of women with BCA assessed longitudinally at 1 week and at 1, 2, 3, 6, and 12 months post surgery, Hoskins (1995a) found that partners generally perceived themselves as having fewer physical health problems than patients. This variable was conceptualized as over-all general health and whether or not health problems prevented partners from engaging in activities they wished to undertake at specific times during the illness. Yet, this changed at 12 months, and the more dissatisfied a partner was in marriage, the greater the report of physical health problems. Further, partners of women with positive node status had greater frequency and intensity of physical symptoms on the Physical Symptoms subscale of the Profile of Adaptation to Life Clinical Scale (PAL-C) (Ellsworth, 1981) than partners of women with negative node status (Hoskins, Baker, Sherman, & Bohlander, 1996).

Wagner, Bigatti and Storniolo (2006) compared the general health of partners of women with BCA (n = 79) to an age matched group of partners of healthy wives (n = 79). Patients in the BCA group were in cancer stages I – IV, diagnosed within a period of less than one year to more than ten years, and had a variety of treatments including lumpectomy, mastectomy, and adjuvant therapy. Using the Medical Outcomes Study (MOS) SF-36 (Ware & Sherbourne, 1992) to assess quality of life, partners of BCA patients were more likely to report physical health problems than partners of healthy wives and endorsed items associated with less general health and vitality.

Blake-Mortimer and colleagues (2005) have shown that partners of women with BCA experience declines in their physical health when exposed to chronic stress. In a sample of 34 partners of women with recurrent BCA an average of 2.3 years post recurrence, increased levels of intrusive thoughts were associated with suppression of the Cutaneous Delayed Type Hypersensitivity response (DTH) illustrating that exposure to chronic stress compromised the immune system of partners in this sample. Further, this suppression of the DTH response was associated with symptoms of depression in partners.

Together, these findings establish links between BCA and partner biological adjustment and provide evidence that partners of women with BCA experience decreases in their general physical health and immune function when compared to partners of healthy women. These studies also illustrate the importance of relationship quality in partner adjustment to breast cancer and are supported by a comprehensive review by Kiecolt-Glaser and Newton (2001) showing that marital quality influences physical health. Further, partner outcomes are consistent with the outcomes of adult daughters of BCA patients who experience immune function declines as a result of exposure to chronic stress associated with high levels of emotional distress and perceived disease risk (Cohen & Pollack, 2004).

Psychological Adjustment

The majority of studies on partner adjustment to BCA were focused on psychological adjustment. Of these, 15 indicated elevated symptoms of psychological distress among partners while three studies did not support the view that partners of women with BCA are psychologically distressed. Two studies suggested that the partners' experience of BCA was associated with increases in posttraumatic growth, or positive changes made in response to a traumatic event and are described below.

Distress.

Eighteen studies examined psychological distress in partners of women with BCA. Partner distress was apparent when compared to BCA patients, normative samples, and other comparison groups. Generally, there is agreement that partners experience distress at levels equal to, and at times, exceeding that of patients' (Baider & De-Nour, 1984; Ben-Zur et al., 2001; Hoskins, 1995a; Lewis & Deal, 1995; Maguire, 1981; Northouse, 1989b; Northouse, Laten et al., 1995; Northouse & Swain, 1987; Sabo, Brown, & Smith, 1986; Wellisch et al., 1978). However, others (Carter & Carter, 1993; Carter, Carter, & Siliunas, 1993) found no indication of psychological distress when comparing partner scores to the normal population, even though similar measures were used to assess distress (Symptom Check List 90-R vs Brief Symptom Inventory). This discrepancy may be attributed to small sample sizes and time since diagnosis as studies by Carter (Carter & Carter, 1993; Carter et al., 1993) comprise samples of only 14 and 20 couples, at 2 to 3 years post-mastectomy. Distress in response to BCA is known to decrease over time (Hoskins, 1995a), and at 2 to 3 years post surgery it would not be unusual to find distress scores within range of the normal population reflecting positive adjustment. An early cross sectional study (Wellisch et al., 1978) examined the psychological consequences of BCA on 31 partners an average of 22 months post mastectomy and found that partners experienced sleep disturbance, appetite loss, difficulty with concentration and disruption in their jobs. Partners retrospectively reported distress at the time of surgery and discharge. Several investigators subsequently identified similar adjustment patterns. Maguire's (1981) longitudinal study examined distress at three time points in partners of women with malignant breast cancer (n = 52) and partners of women with benign breast disease (n = 40). Partners in the malignant group (77%) were moderately to markedly distressed prior to surgery as compared to 35% of the partners in the benign group and only 7% of distressed partners reported talking with anyone about the situation. These findings are echoed by partners of mastectomy patients who experienced anxiety and depressive symptoms and felt ill-prepared to care for their wives and inadequate in offering protection, even though they wanted to be "protective guardians" of patient well being (Sabo et al., 1986).

Other early studies continued to provide evidence of partner distress. Baider and De-Nour (1984) compared 34 partners to BCA patients 8 to 34 months post mastectomy and found that patient and partner psychological distress scores were highly correlated and that distress increased steadily over time for partners. When later comparing the adjustment of partners of women post lumpectomy and partners of women post mastectomy, both groups reported distress though the post lumpectomy group experienced slightly higher levels of anxiety and poorer coping abilities (Baider et al., 1986). This reflects the uncertainty associated with the partial removal of a breast and fear that cancerous tissue remains. Northouse and Swain (1987) also found partners' distress levels to be similar to those of patients, both of which are higher than the mean levels reported by nonpatient populations. Their sample consisted of 50 partners assessed

at 3 and 30 days post-surgery for mood state, symptom distress and role functioning using the Affects Balance Scale, Brief Symptom Inventory, and Psychosocial Adjustment to Illness Scale, respectively. In evaluating the same sample at 18 months, improvement in mood scores were evident though younger partners and those in relationships of shorter duration reported more negative mood states (Northouse, 1989b). This is discrepant when compared to Maguire's (1981) findings that partners of patients with malignant BCA continued to report greater distress than partners in the benign group on measures of anxiety and depression for up to 1 year. Despite this discrepancy in the duration of distress, it is evident that the impact of BCA affected partners and extended over time.

Posttraumatic growth in partners.

More recent studies of psychological adjustment of partners have focused on posttraumatic growth (Manne, Ostroff, Winkel et al., 2004; Weiss, 2002, 2004a) defined as the spectrum of positive changes an individual may experience in response to a traumatic event (Tedeschi & Calhoun, 1996). Weiss (2002) identified that 88% of the partners of women with BCA experienced positive changes in response to the illness including a renewed enjoyment of life and positive changes in interpersonal relationships. Long term effort to find meaning in the illness experience, referred to as *constructive rumination*, brings about new cognitive schemas that decrease psychological distress (Weiss, 2004a). Manne (2004) also concluded that partners of women with BCA experience posttraumatic growth in response to illness though the growth is reported to be less than that of patients. Partners reported the most growth in personal strength, envisioning new possibilities for the future, and having an increased appreciation for life, relationships with others, and spirituality (Manne, Ostroff, Winkel et al., 2004). In sum, partners of women with BCA experience psychological distress that is equal to, and, at times, exceeds that of patients. Yet, for some, this distress contributes to post traumatic growth as partners actively engage the intrusive thoughts and feelings associated with the BCA experience. Psychological distress is a broad term that has been described and measured in a variety of ways, while post traumatic growth is a newer construct that has recently been applied to BCA patients and partners.

Social Adjustment

Role functioning.

Four studies investigated the role functioning of partners of women with BCA and concluded that there was a significant disruption of domestic, vocational, social and sexual roles. Maguire (1981) first identified disruptions in the lives of partners of women with BCA in terms of work (26%) and sexual (21%) roles when compared to partners of women with benign breast disease. At one year, disruptions continued for partners of malignant patients while disruptions declined for those in the benign group. Baider and colleagues found that levels of role disruptions were highly correlated between partners and patients and that partners experienced more problems in the area of family relations and the social environment (Baider & De-Nour, 1984; Baider et al., 1986). However, in a longitudinal study by Northouse (1989b) assessing partners at 3 and 30 days and 18 months post surgery, disruptions existed primarily in the domestic, sexual, and leisure roles but partners experienced fewer role adjustment problems over time than patients, a finding supported by Hoskins (1995a).

Marital adjustment.

Four studies have examined the marital adjustment of partners of women with BCA, concluding that the onset and treatment of BCA creates significant relational distress. In a

sample of 20 partners of women who had a mastectomy and were an average of 2.5 years post diagnosis, Carter and Carter (1993) found couple cohesion scores on the Dyadic Adjustment Scale (DAS) (Spanier, 1989) and FACES-III (Olson, Portner, & Lavee, 1985) indicated poor marital adjustment though measures of individual adjustment did not differ from the normal population. Lewis and Deal (1995) reported that 40% of partners of recurrent BCA patients indicated marital dissatisfaction. The Carters concluded that whereas individual adjustment was proceeding in a positive manner, the marital relationship was too enmeshed, and thus distressed and dysfunctional. A later interpretation of these data proposed that although couples managing BCA were enmeshed and strongly connected, this was a natural and appropriate response to the stress of a life threatening illness (Carter et al., 1993).

Summary of Partner Outcomes in Response to Women with BCA

In reviewing the literature on partner adjustment to the diagnosis and treatment of women with BCA, it is evident that partners are patients in their own right. A biopsychosocial framework reveals that adjustment problems are manifest across biological, psychological, and social domains of partner functioning. Biologically, partners face declines in their general physical health and are vulnerable to suppression of their immune system when exposed to chronic stress associated with BCA. Evidence of compromised partner psychological health is seen in their reports of general distress, anxiety, and depression. Yet, some partners of women with BCA are able to find benefit from these difficult circumstances by reevaluating priorities, renewing their enjoyment of life, and transforming interpersonal relationships. Finally, partners face disruption in their roles and relationships. Partners have difficulty concentrating at work and often have less time to devote to friendships and leisure activities. Family life is seriously disrupted as partners assume additional responsibility for instrumental household tasks. Problems
in the sexual relationship are also paramount. Although family and healthcare professionals have largely overlooked partners, partners are also in need of support and intervention. We contend that partners who become visible and receive effective intervention and support will be healthier and better positioned to respond to the needs of women with BCA.

Research Question Two: What Factors are Associated With Adjustment Among Partners of

Women With Breast Cancer?

Description of Studies

Nineteen studies addressed this question (see Table 3.2), the first being published in 1991. Of these, 13 studies were cross sectional and six were longitudinal. Two studies employed between groups designs comparing partner adjustment to healthy partners and type of BCA treatment. Studies described partner adjustment from one week to 5 years post surgery. Correlates examined in these studies were organized into categories including a) person and biological factors (demographics and medical/illness), b) psychological factors (coping strategies and cognition), and c) social factors (concurrent stress, relationship, family functioning, communication patterns, social support). Sample sizes ranged from 22 to 265 and were comprised of well educated, middle to higher income partners aged 25 to 84, the majority being in their early to middle fifties. Relationship length ranged from a few months to 45 years though most had existed for approximately 25 years. Sampled partners were overwhelmingly in heterosexual relationships.

Correlates of Partner Adjustment to BCA

Person and Biological Factors

Demographics.

There was little evidence for associations between demographic factors and the adjustment of partners of women with BCA. The majority of studies found no association between age, education, or length of marriage and partner adjustment though two exceptions were noteworthy. Northouse and colleagues (Northouse, 1989b; Northouse & Swain, 1987) followed 41 partners of women treated primarily with mastectomy and found that partners who were younger and married for shorter periods of time reported less positive mood states on the Affects Balance Scale (Derogatis, 1975a). In a separate sample of 127 partners of early stage BCA patients, being older and longer relationship duration were significantly related to less partner distress nine months following surgery (Manne et al., 2006). Additional evidence is provided by a study of 84 partners ranging in age from 40 to 70 (M = 58) whose wives were treated with mastectomy (71%) and lumpectomy (29%) (Kilpatrick, Kristjanson, Tataryn, & Fraser, 1998). In this study, partners completed the Family Inventory of Needs-Husbands and those at greatest risk for not having their needs met were retirees or laborers, living in rural areas, over age 60, and having less than a high school education. While partners' needs were not linked to indicators of distress outcomes, this study is one of few that showed significance between demographic characteristics and partner adjustment.

These findings contrast those on women with BCA who experience differences in adjustment as a function of age. Compared to women over 50, younger women with breast cancer generally have more problems adjusting to and coping with cancer, undergo more aggressive treatments for breast cancer, have poorer quality of life and survival rates, and have psychosocial problems encountered less often by older women (Avis, Crawford, & Manuel, 2004; Baider et al., 2004b; Cordova et al., 1995; Ganz, Rowland, Desmond et al., 1998; Ganz, Rowland, Meyerowitz et al., 1998; King, Kenny, Shiell, Hall, & Boyages, 2000; Manuel et al., 2007; Nixon et al., 1994; Swanson & Lin, 1994). From a family lifecycle perspective (Carter & McGoldrick, 1989; Carter & McGoldrick, 1999), it is conceivable that the partners of younger women would experience distress as they negotiate new rules, roles and boundaries and navigate movement of members into and out of the family (Burwell, Templeton, Stidham, & Zak-Hunter, in press; Kiecolt-Glaser & Newton, 2001). We suspect that the lack of evidence to date regarding the influence of demographic variables on partner adjustment is likely a reflection of the paucity of research.

Medical factors.

Several investigators have identified medical factors associated with partner adjustment. Maguire (1981) compared the adjustment of partners of women with malignant cancer to partners of women with benign breast disease and found that partners in the malignant group were more distressed and at 3 months post surgery reported more anxiety, depression, and decline in sexual activity. At 1 year, the malignant group continued to report more distress than the benign group on anxiety, sexual activity, and problems with work. Northouse et al., (1998) also found greater distress in partners of patients with malignant BCA who reported consistent levels of concurrent stress, greater decreases in marital and family functioning, more uncertain appraisals of the illness, and more emotional distress over the course of the 1 year assessment period. Positive node status was also found to be associated with higher levels of emotional distress for partners at 1 week, 1, 2, 3, 6, and 12 months (Hoskins, Baker, Budin et al., 1996). Partners in the benign group experienced decreases in reported concurrent stress.

Type of BCA treatment has also been associated with partner adjustment. Northouse, Laten, and colleagues (1995) found that partners of women in treatment were more emotionally distressed than partners of women not undergoing treatment. However, studies have shown conflicting results in regard to the impact of being treated with breast conserving or nonconserving surgery. Omne-Ponten (1993) reported that partners of patients in both breast conserving surgery and mastectomy groups were distressed four months following treatment. At 13 months, however, partners in the mastectomy group reported greater frequency of illness related disturbances and more frequent depression, yet reported improvement in their marriages. Baider (1986) also found no differences between groups (lumpectomy vs mastectomy) in terms of role functioning and depression but partners of lumpectomy patients had slightly higher levels of anxiety and were not coping as well. Breast conserving surgery has been associated with fear of recurrence (Yeo et al., 2004) and higher levels of anxiety. Yet, others (Segrin, Badger, Sieger, Meek, & Lopez, 2006) report that partners of patients with greater symptom distress and undergoing mastectomy had higher symptoms of depression. Finally, in terms of adjuvant treatment, study results remain fairly consistent in regard to partner adjustment. Partners of women treated with chemotherapy or radiotherapy were more likely to report distress (Baider & De-Nour, 1984; Baider et al., 1986) while partners of women with less extensive treatments were less likely to report fear of recurrence (Walker, 1997).

Psychological Factors

Coping strategies.

Four studies addressed the relationship between coping strategies and partner outcomes focusing on both individual and dyadic coping strategies. Individual coping strategies included problem focused (active coping, planning, suppression, instrumental support) and emotion focused strategies (ventilation, denial, behavioral disengagement). In general, partners and their wives who used more problem focused strategies reported better outcomes. Further, partners who used coping strategies such as support seeking and less blaming and avoidance reported better mental health outcomes (Ptacek et al., 1994). Other studies found that patient and partner coping strategies were interrelated as partners who perceived higher levels of emotion focused coping in patients reported higher distress scores on the Brief Symptom Inventory (BSI) (Ben-Zur, 2001; Ben-Zur et al., 2001). Patients perceived as using more problem focused strategies had partners who reported less distress.

Dyadic coping has also been associated with partner adjustment in regard to negative relational coping strategies. In a sample of 71 partners of newly diagnosed patients undergoing treatment, Feldman and Broussard (2006) established that hostile dyadic coping, operationalized as distancing, ridicule, or sarcasm in response to a partner's signal for assistance, accounted for 33% of the variance in illness intrusiveness scores (Feldman & Broussard, 2006). Further, partner report of lower levels of mutuality (reciprocal expression of feelings, thoughts and activities) was associated with greater use of negative dyadic coping strategies (Feldman & Broussard, 2005). This is consistent with Manne and colleagues (2006) who found that mutually avoidant and demand withdraw communication patterns were associated with higher distress and lower relational satisfaction among couples coping with BCA.

Cognition.

Four studies evaluated the associations between partner adjustment and cognitive factors, including appraisal of the illness situation (Manne, Ostroff, Winkel et al., 2004), uncertainty associated with BCA (Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris, 1995; Northouse, Laten et al., 1995) and feelings of hopelessness (Northouse et al., 1998). Together

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these studies show that positive evaluations of the BCA experience were associated with positive partner outcomes while increased uncertainty and hopelessness in partners was associated with increased distress (Northouse, Jeffs et al., 1995; Northouse, Laten et al., 1995; Northouse et al., 1998). Manne and colleagues (2004) illustrated that exposure to intrusive thoughts coupled with willingness to engage the thoughts (rather than avoid them) and positively reappraise the situation was associated with partner posttraumatic growth. While feelings of uncertainty and hopelessness were natural responses to a stressful event, the meaning partners made of the situation was more predictive of their adjustment (Manne, Ostroff, Winkel et al., 2004). *Social Factors*

Communication patterns.

Several investigators have evaluated the role of communication in partner adjustment (Hodgson, Shields, & Rousseau, 2003; Manne et al., 2006). Hodgson (2003) compared 20 BCA partners to 22 non-BCA partners and found that partner disengaging communication (e.g. withdrawal or avoidance) was negatively correlated with partner marital satisfaction. No difference was found in the influence of disengaging communication on depression and perceived health between the cancer and control groups. In this sample, partners were generally martially satisfied, had low depression scores, and had positive views of their health. Manne (2006) evaluated the impact of mutual constructive, mutual avoidant, and demand withdraw communication patterns on the psychological and marital adjustment of 127 partners of women with early stage BCA during treatment (Time 1) and at nine months post treatment (Time 2). Communication patterns did not change significantly over time after accounting for age, Time 1 distress level, and physical impairment. Partners who reported more mutually constructive communication had less distress whereas partners who reported avoidance of problem discussions and greater use of demand withdraw communication had higher levels of distress at Time 2. This finding is interesting in light of other research documenting that 28% of the variance in partners' fear of recurrence was accounted for by the amount and degree of satisfaction with illness-related communication (Walker, 1997). Partners who reported frequent communication about the illness also report higher levels of fear of recurrence (Walker, 1997).

Social support.

Social support has been identified as a major factor in partner adjustment to the diagnosis and treatment of BCA (Baider et al., 2004a; Hoskins, Baker, Sherman, & Bohlander, 1996; Northouse, 1988; Northouse, Jeffs et al., 1995; Northouse, Laten et al., 1995; Ptacek, Pierce, Dodge, & Ptacek, 1997; Wagner et al., 2006; Weiss, 2004a). In a study of 50 partners of BCA patients treated primarily with mastectomy (Northouse, 1988), partners reported social support from patients and family at levels similar to that of patients, but significantly less than the social support received from friends, nurses, and physicians. Partners with high levels of social support had fewer adjustment difficulties than partners with lower levels of social support as measured by the BSI and Psychosocial Adjustment to Illness Scale (PAIS). In a sample of 121 partners assessed at six time points over the course of a year, 21% of the variance in partner adjustment at one year post diagnosis was accounted for by marital support (Hoskins, Baker, Sherman et al., 1996). In sum, studies show a strong positive relationship between support both from within and outside the marital relationship and partner emotional and physical adjustment.

Summary of Correlates of Partner Adjustment to BCA

This review identified several important correlates of partner adjustment that assist in identifying invisible partners. As family members and health care professionals recognize these factors, they may accurately focus their support and intervention efforts. Correlates of partner

adjustment to women with BCA include demographic and medical characteristics, psychological factors (coping strategies and cognition), and social factors (communication patterns and social support). There is little evidence for associations between age, education, or length or marriage and partner adjustment though one study reports that older partners and those in relationships of longer duration are less distressed. Illness characteristics including malignancy and positive node status are positively related to greater partner distress. In addition, type of BCA treatment is associated with partner adjustment. Although both breast conserving and non-conserving surgical procedures increase partner distress, partners of women treated with lumpectomy have higher levels of anxiety and fear of recurrence. Psychological factors including positive appraisals of the cancer experience and the use of problem focused coping strategies are associated with better partner adjustment outcomes. Conversely, partner feelings of uncertainty and hopelessness are related to increased distress. In addition, partners of women using emotionfocused coping strategies such as ventilation, denial, and disengagement report greater distress. Finally, social support and how couples communicate about the cancer experience are correlated with partner adjustment. Partners with higher levels of social support report fewer adjustment difficulties than those with lower levels of social support. Withdrawal or avoidance of problem discussions is negatively correlated with partner marital satisfaction whereas partners who report more mutually constructive communication have less distress.

DISCUSSION

Marriage is considered the most influential adult relationship on health (Kiecolt-Glaser & Newton, 2001). Partners of women with BCA experience psychosocial distress and are at risk for general symptom distress, depression, and anxiety. Partners chronically exposed to stress are vulnerable to compromised immune functioning. Many partners of women with BCA experience

disruption in their marriages and their roles at work and in the family. These findings are not surprising given the increased caregiving demands placed on partners. Partners often assume extra responsibility for instrumental family tasks such as providing transportation to medical appointments and keeping up with household responsibilities. They also take on much more of the care and nurturance of children than they had before the onset of BCA. Distress in partners is greatest at the time of diagnosis and initial treatment when they were unprepared and overwhelmed by illness demands.

Although there is clear evidence to support our finding that partners of women with BCA are distressed, several other factors appear to be associated with partner functioning. Partners report better outcomes when they actively confront illness demands and when they perceive their spouses as doing the same. Emotional coping strategies are associated with increased distress whereas problem focused coping is linked with decreased distress. Partners who are able to work through the distress related to uncertainty and hopelessness are likely to experience post traumatic growth (Manne, Ostroff, Winkel et al., 2004; Weiss, 2002, 2004a). Some may actually find benefits, such as new meaning in life or deeper appreciation for things that previously may not have been viewed as important. (Tallman, Altmaier, & Garcia, 2007). Couples have the potential to grow closer to one another and more research is needed to understand the particular mechanisms by which couple relationships become stronger as a result of BCA (Omne-Ponten et al., 1993; Walsh et al., 2005). Much more research is needed on the multidimensional and biopsychosocial processes of strengthening couple relationships following BCA. This involves understanding couples' histories, their personalities, coping strategies, and their support systems.

Consistent with patient outcomes related to social support, partners who receive ongoing support from their spouses and from family, friends, and health care professionals report better

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adjustment in terms of less overall distress; they experience less depression and anxiety, and they are likely to experience consistent improvement in role functioning at home, work, and in leisure activities. This suggests that partners, who typically receive much less support than patients, need to become a priority in the treatment of young women with BCA. Partners need support for their own well-being, but they also need support to manage the monumental task of supporting their wives, while maintaining their work and domestic roles.

Collectively, these findings add to a growing understanding of the relevance of the social and family context in the treatment of patients in healthcare. Engel's (Engel, 1977, 1980) biopsychosocial model typifies this understanding and offers a useful framework from which to emphasize the interrelatedness of individuality and relationships in the care and treatment of BCA. This review demonstrates that partners of women with BCA are substantially affected by the illness experience as they are physically and psychologically distressed, and their lives are significantly disrupted. Yet, similar literature addressing the quality of life among women with BCA indicates that partners have a significant influence on patient adjustment and outcomes (Eldridge, Sevier, Jones, Atkins, & Christensen, 2007; Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000; Hoskins, 1995b; Manne, 1998). This suggests that illness is a mutual, inter-related and reciprocal process, congruent with Engel's biopsychosocial framework.

Study	Design	Characteristics of	of the sample	Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Wellisch et al., 1978	 Cross sectional, descriptive No comparison group Locke-Wallace Marital Adjustment Test, Rotter Locus of Control Scale, Eysenck Personality Inventory, and eight pages of open and close-ended researcher designed questions 	• $n = 31$ partners ages 34- 74 yrs. (M = 54.4); high school to doctoral level education, most with some college; income range \$2K-\$60K (M = \$20K); 94% Caucasian, 3% Black, 3% Oriental	• Patients within five years post mastectomy (M = 22 months)	 Partners viewed relationship more positively than the wives. Data point to husband's need to be involved in decision-making regarding treatment. Those that were less involved wished for greater involvement. Those that found the relationship rewarding tended to be more involved in the decision making. Distress primarily associated with time period prior to surgery and until discharge from the hospital. Partners report feeling polarized in regard to the surgeons. Some saw physician in negative light, others as an ally.
Maguire, 1981	 Longitudinal, descriptive; assessed preoperative, one month postoperative, and at 1 yr Compares partners of patients with benign disease to partners of mastectomy patients No data provided about instrumentation 	• $n = 52$ partners of women treated for breast cancer (BC) and $n = 40$ partners of women treated for benign breast disease (control); no specific demographic data is reported though the authors indicate that the partner groups were matched for age, social class, and stage of cancer	• Patients with malignant breast disease treated with mastectomy and radiation; no information provided about treatment of benign disease group	 77% of partners of BC patients reported moderate to marked distress between hospital admission and surgery compared to only 35% of partners of control group. Only 7% of distressed partners reported discussing this with anyone. At 3 months, 57% of the BC partners reported some degree of anxiety compared to only 7% in control group (p < 0.001). 33% of BC partners reported some degree of depression compared to only 7% in control group p < 0.01). 21% of BC partners reported sexual decline compared to only 6% in the control group (p < 0.001). 26% of employed BC partners reported difficulty at work compared to only 6% of employed partners in the control group (p < 0.05). Few in either group had depressive symptoms 6% and 3%, respectively. 29% of BC partners reported sexual difficulties compared to only 5% in the control group (p < 0.05). Ew in either group had depressive symptoms 6% and 3%, respectively. 29% of BC partners reported sexual difficulties compared to only 5% in the control group (p < 0.05). Z5% of employed BC partners indicated that their work was being adversely affected compared to 2% in control group (p < 0.05).

Table 3.1. Characteristics of Studies Documenting Adjustment in Partners of Women With Breast Cancer.

Study	Design	Characteristics	of the sample	Major findings	
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis		
Baider & De-Nour, 1984	 Longitudinal; assessed 3 consecutive years post enrollment in study Compares partner and patient scores Psychosocial Adjustment to Illness Scale, Brief Symptom Inventory, Family Environment Scale 	• <i>n</i> = 20 partners ages 40- 66 yrs. (M = 51.7); education (M = 14.2); no other demographic data provided	• Patients 8 to 34 months post mastectomy (M = 19.3 months) with no evidence of metastatic involvement; $n = 7$ received no further treatment than mastectomy, $n = 6$ received only chemotherapy, $n = 7$ received chemotherapy and radiation, $n = 3$ in treatment at time of study	 Partners' reports highly correlated with patients' reports, partners specifically noting almost as many problems from the mastectomy as the patients and more problems than the patient in the areas of family relations and social environment. Partners report somewhat high psychological distress scores that are positively correlated with those of patients. Partners of patients receiving radiation and chemotherapy reported far more problems role functioning than partners of patients receiving no treatment or chemotherapy alone. Partners' scores of distress and problems with role functioning increase steadily over time. 	
Baider et al., 1986	 Cross sectional, descriptive Compares partners of post lumpectomy patients to partners of post mastectomy patients Spielberger State-Trait Anxiety Scale, Beck Depression Inventory, Psychosocial Adjustment to Illness Scale, Shanan's Sentence Completion Test, Moos Family Environment Scale 	• $n = 21$ partners of women postlumpectomy; age (M = 53.2); education (M = 14.9); no other demographic data provided • $n = 20$ partner of women postmastectomy; age (M = 48.5); education (M = 13.1); no other demographic data provided	 Patients post lumpectomy (M = 17.2 months) and treated with or without chemotherapy Patients post mastectomy (M = 21.2 months)and matched to postlumpectomy group by age, time since operation, and postoperative treatment None of the patients had active signs of disease and all had been out of treatment for at least six months 	 No differences found between groups of partners regarding role functioning or depression. Post lumpectomy partners reported slightly higher levels of trait and state anxiety than the post mastectomy group. Post lumpectomy partners report coping less well than the post mastectomy partners. Post mastectomy partners report significantly greater cohesion (p < 0.055). 	

Study	Design	Characteristics	of the sample	Major findings
		Partners <i>n</i> ; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Northouse & Swain (1987)	 Longitudinal, assessed at 3 and 30 days post surgery Compares partner, patient and normative data Affects Balance Scale, Brief Symptom Inventory, Psychosocial Adjustment to Illness Scale 	• <i>n</i> = 50 partners ages 27 – 78 yrs. (M = 52.3); education range 8 - 20 yrs (M = 13.4); 68% working, 30% retired; 100% Caucasian	• 92% of patients treated with mastectomy, 2% lumpectomy; 32% received chemotherapy while 8% received radiation	 Partners' mood and distress scores were similar to those of patients and higher than the mean levels reported by the normal nonpatient population. Patient and partner balance of mood states scores improved from Time 1 to Time 2. There were differences in role adjustment with partners reporting fewer problems than patients at Time 2.
Northouse (1989b)	 Longitudinal, assessed at 3 days, 1 month and 18 months post surgery Compares partner and patient scores Affects Balance Scale, Brief Symptom Inventory, Psychosocial Adjustment to Illness Scale Prediction 	• <i>n</i> = 41 partners with complete data from Northouse & Swain (1987) sample	• Same sample as Northouse & Swain (1987)	 Younger partners and those married for a shorter period of time reported less positive mood states. Partners whose wives had recurrent cancer or were undergoing chemotherapy indicated greater problems with role functioning. Patients and partners' mood scores did not differ significantly across time 1, 2, and 3. Mood scores improved significantly over time (patient and partner) with most of the change occurring between times 1 and 2 and leveling off at time 3. Husband's distress scores did not change over time and were similar to those of patients. At times 2 and 3, partners reported fewer role adjustment problems than their wives.

Study	Design	Characteristics	of the sample	Major findings
		Partners <i>n</i> ; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Carter et al., 1992	 Cross sectional, descriptive Compares partner and patient scores Symptom Check List 90-R, Psychosocial Adjustment to Illness Scale-Self Report, IPAT Anxiety Scale, Geriatric Depression Scale, Million Behavioral Health Inventory, Affect Balance Scale 	• <i>n</i> = 20 partners age (M = 55.7); education (M = 14.1); income (M = \$38K);	• Patients an average of 2.5 years post diagnosis, treated with single mastectomy for Stage I or II disease, and not involved in or planning adjuvant treatment	 Partners significantly more Confident (p < 0.001) and Forceful (p < 0.001) than patients. Confident/Forceful and Sociable/Respectful partners scored significantly higher on Chronic Tension while Respectful/Introversive partners scored significantly higher on Somatic Anxiety.
Carter & Carter, 1993	 Cross sectional Compares partner, patient and normative data Anxiety Scale Questionnaire, Geriatric Depression Scale, Symptom Check List 90-R, Psychosocial Adjustment to Illness Scale-Self Report, The Pessimism/Optimism Scale, Quality of Life Scale, Dyadic Adjustment Scale, Family Adaptability and Cohesion Evaluation Scale - III, Breast Cancer Incomplete Stems 	• Same sample as Carter et al., (1992)	• Same sample as Carter et al., (1992)	 Husband ratings of individual adjustment (anxiety, depression and role functioning) were not significantly different than normal population. Husband optimism increased over time. Husband ratings of perceived and total cohesion fell within an extreme range, suggesting poor marital quality. Husband ratings were significantly less than those of wives. Husband scores were significantly lower on consensus and significantly higher on cohesion than those in published norms. Suggests that while individual adjustment may have been successful, marital adjustment was still problematic.

Study	Design	Characteristics	of the sample	Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Carter et al., 1993	 Cross sectional, observational Compares partner and patient scores Symptom Check List 90-R, Psychosocial Adjustment to Illness Scale-Self Report, Dyadic Adjustment Scale, Family Adaptability and Cohesion Evaluation Scale - III and Clinical Rating Scale (CRS) 	• <i>n</i> = 14 partners ages (M = 57.7); education (M = 13.7); income (M = \$34K)	• Patients with single mastectomy for Stage I or II disease, not involved or planning adjuvant treatment, 2 to 3 years (M = 2.6) post mastectomy	 Partners ratings of individual adjustment (anxiety, depression and role functioning) were not significantly different than normal population. Husband reports of consensus significantly lower than norms for married couples. On ratings of ideal cohesion, partners fell into the enmeshed range. On ratings of perceived and ideal adaptability, partners fell into the range of chaotic flexibility. Clinical Rating Scale scores indicated strong connectedness, moderate flexibility, and moderate to high facilitation for partners. Suggests that couples are quite enmeshed and that this is a natural response to the stress of a life threatening illness.
Omne-Ponten et al., 1993	 Longitudinal, assessed at 4 and 13 months post surgery; descriptive Compares partners of women receiving breast conserving surgery with partners of women treated with mastectomy Social Behavior Assessment Scale, researcher designed assessment to evaluate psychiatric symptoms of anxiety, depression, marital relations, sexual relations, and social network 	• $n = 20$ partners aged 40 – 76 (M = 58.05) of women treated with breast conserving surgery and $n = 36$ partners aged 40- 81 (M = 58.15) of women treated with mastectomy	• Patients treated with breast conserving surgery or mastectomy	 No differences in impact of the illness found between partner groups at 4 months, both distressed. At 13 months, partners in the mastectomy group reported a greater frequency of disturbances related to wife's illness than the breast conserving group. Depression was more frequent in the mastectomy group at 4 and 13 months. Partners in the mastectomy group were more negatively affected (assoc/D, p = 0.04; distress/D p = 0.03), more depressed (p = 0.03), yet had improvements in their marriages (p = 0.04). In the complete sample, 48% of partners reported emotional distress over the 13 month period. Of those reporting, 38% reported disturbance of their sexual activity though others reported improvements. 5% of partners reported problems with work outside the home.

Study	Design	Characteristics	of the sample	Major findings
		Partners <i>n</i> ; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Hoskins, 1995	 Longitudinal, assessed at 1 to 7 days, at 1, 2, 3, and 6 months, and 1 year post surgery; descriptive Compares partner and patient scores Partner Relationship Inventory, Psychosocial Adjustment to Illness Scale, Profile of Adaptation to Life Clinical Scale, Self-rated Health Subscale of the Multilevel Assessment Instrument 	 n = 121 partners age (M = 54.2); no education data; 86% income < \$20K and 47% < \$40K; 78% employed outside of home 	• No data provided regarding treatments received	 At 7 to 10 days, partners were less satisfied with the extent to which respondents (both partners and wives) met their Interactional and Emotional Needs. These scores decreased over time. Negative emotions are high post surgery but significantly decline between 7 to 10 days post surgery and 1 year. Psychological Well-being increased over the course of the year. Partner's scores were lower than partner at every point in time. Psychological Distress declined over the course of the year and partner's scores were less than those of patients at each point. Partners' vocational, domestic, and social role performance improved steadily over time.
Lewis & Deal, 1995	 Cross sectional, descriptive, mixed methods: qualitative interview with survey Compares partner, patient and normative data Marital Dyad Interview, Dyadic Adjustment Scale, Center for Epidemiological Studies Depression Scale 	• $n = 15$ partners aged $25 - 64$ (M = 43); 93% with some college or post high school training; income range $$25 - 70K$, with 27% in \$40 - \$50K range	• Patients diagnosed with recurrent breast cancer (M = 10 months past diagnosis of the recurrence)	 Domains of the couples' experience with recurrent breast cancer: a) managing the woman's everyday illness (talking about treatment and the disease, educating ourselves about the disease, interpreting her symptoms, not dwelling on it, feeling down, and hitting the unknowns and uncertainties), b) surviving (learning to live with it, struggling with the relational parts, talking about the kids, and being in control), c) healing (making progress and moving on, maintaining optimism, keeping stress down), and d) preparing for death (talking about dying, talking about afterwards). 20% of partners at or above cutoff points for depression. 40% of partners 1 standard deviation below referent sample on marital satisfaction. 60% of couples are out of normative ranges on either mood or marital adjustment. Couples may be avoiding difficult topics which contributes to dissatisfaction with marriage and depressed mood.

Study	Design	Characteristics	of the sample	Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Northouse, Laten, et al., 1995	 Cross sectional, exploratory, descriptive Compares partner and patient scores Beck Hopelessness Scale, Mishel Uncertainty in Illness Scale, Social Support Questionnaire, Symptom Distress Scale, Brief Symptom Inventory, Psychosocial Adjustment to Illness Scale 	• <i>n</i> = 74 partners aged 31 – 81 years (M = 56.9); education range 6 – 2 years (M = 14); 66% employed outside of home, 91% Caucasian	• Patients with recurrent breast cancer 1 month to 3 years post recurrence	 Partners reported low to moderate emotional distress but difficulty in psychosocial role functioning. Partners whose wives were currently in treatment were more emotionally distressed than those whose wives were not in treatment. Partners with more personal health problems reported more problems with role functioning. Partners reported more uncertainty about the illness than patients. Higher levels of distress were found in partners who reported more symptom distress in their wives. Partners role functioning difficulties were in the areas of domestic roles, sexual relationship, and leisure time activities.
Kilpatrick et al., 1998	 Cross sectional, descriptive No comparison group Convenience sample recruited from four hospitals Family Inventory of Needs-Husbands 	• $n = 84$ partners aged > 40 - < 70 (M = 58); 33% with less than high school education and 67% with high school or greater education; 44% retired; 29% European, 35% British Isles, 10% French, and 27% other	• Patients newly diagnosed with Stage 0 – 4 breast cancer; treated with 71% mastectomy and 29% lumpectomy	 Partners' need 1) honest answers to their questions, 2) to know their wives are being given the best care, 3) to know the likely outcome of the illness, 4) to know about the future, and 5) to know when their wives' condition changes. Partners identified care needs and communication issues as their most important information needs. Partners classified as retired or laborer, living in rural areas, over age 60, and with less than a high school education were at greatest risk for not having their needs met.
Ben-Zur et al., 2001	 Cross sectional, survey data Compares partner scores to patients scores 30 item shortened Hebrew version of the COPE scale, Brief Symptom Inventory, Psychosocial Adjustment, Demographic and Madical Questionnaire 	• $n = 73$ partners aged $33 - 86$ (M = 55.6); education range $4 - 21$ years (M = 12.92); 74% employed; 49% born in Israel, 35% Europe or America, 14% Asia or Africa, and 5% elsewhere	• Patients with Stage I or II breast cancer 2 to 6 months after diagnosis; 79% lumpectomy and 29% mastectomy	 Partner scores on psychological and psychosocial adjustment were positively correlated with patient scores. Partners scored lower than patients on problem focused coping. Patient and partner emotional focused scores were similar and significantly correlated.

Study	Design	Characteristics of the sample		Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Weiss, 2004	 Cross sectional, explanatory No comparison group Posttraumatic Growth Inventory, Social Support Questionnaire-Brief, Quality of Life Inventory 	• $N = 72$ partners aged $35 - 84$ years (M = 56.8); education range $10 - 20$ years (M = 16.2); 93% income < \$60K; primarily Caucasian	• Patients 1 – 5.5 years post diagnosis of Stage 0 (19%), I (49%), or II (21%) breast cancer	 Partners' posttraumatic growth positively related to perceived social support, support and depth of commitment in the marital relationship, and breast cancer meeting DSM-IV criteria as a traumatic stressor accounting for 42% of the variance in this sample. Partners' posttraumatic growth positively related to patient growth scores. 42% of variance in partners' posttraumatic growth accounted for by depth of marital commitment, patient's posttraumatic growth, and breast cancer perceived as a DSM-IV trauma.

Table 3.2.

Characteristics of Studies Documenting Factors Associated With the Adjustment of Partners of Women With Breast Cancer.

Study	Design	Characteristics	of the sample	Major findings
		Partners <i>n</i> ; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Hannum et al., 1991	 Cross sectional, quantitative survey, qualitative interview, observation of interactional behavior No comparison group Researcher designed marital and family history questionnaire, Symptom Check List 90-R, Marital Adjustment Test, Family Adaptability and Cohesion Scale, Health Symptom Checklist, Friendship Scale, Philosophies of Marriage Scale 	• N = 22 partners ages 30 – 75 (M = 56); no data regarding education; per Hollingshead's four-factor system classified as second level SES (medium business, minor professional, technical); 100% Caucasian	• Patients with Stage I (91%) or Stage II (9%) breast cancer diagnosed within the past 9 – 12 months;	 73% of the variance of husband distress is accounted for husband denial as reported by wife, husband's observed confronting behavior, and wife's self reported optimism. Husband's distress negatively correlated with wife's ratings of cohesion. Points out that adjustment to stress is a two way interaction.
Northouse et al., (1995).	 Cross sectional, exploratory, predictive Social Support Questionnaire, Spanier Dyadic Adjustment Scale. Family APGAR, Beck Hopelessness Scale, Smilkstein Stress Scale, Mishel Uncertainty in Illness Scale, Brief Symptom Inventory 	• N = 265 partners ages 26 - 83 years (M = 50); 82% working outside of the home; education range 8 – 25 years (M = 15); 95.7 % Caucasian	• Patients scheduled for breast biopsy and with no prior history of cancer	 Mean partner distress higher than norm for population but lower than patient distress, primarily in the areas of anxiety and obsessive compulsive reflecting problems with decision-making and concentration. Some partners report low distress, some high (range = 0 – 1.92). Education, age, number of years married, employment status, income, and patient medical factors were not related to partner distress. 42% of the variance in partner distress explained by concurrent stress, hopelessness, and family functioning. Partner distress was not related to patient distress.

Study	Design	Characteristics	of the sample	Major findings	
		Partners <i>n</i> ; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis		
Hoskins et al., 1996	 Longitudinal, assessed at 7 – 10 days, 1, 2, 3, 6, and 12 months post surgery Compares breast conserving to non breast conserving surgical procedure groups Partner Relationship Inventory, Psychosocial Adjustment to Illness Scale, Profile of Adaptation to Life Clinical Scale, Multilevel Assessment Instrument 	• N = 121 partners age (M = 54.2 years); education (M = 15.6 years); 91% income < \$20K and 71% income < \$40K; "largely" Caucasian	• Patients with primary breast cancer post treatment by breast conserving surgery and radiation or nonconserving surgery that may or may not have been followed up with chemotherapy	 Support within the marital relationship was positively related to emotional adjustment. Support from extramarital relationships was positively related to emotional adjustment. Partners with less favorable attitudes about healthcare reported more health related problems. Partners reporting greater support from the marital relationship and from other adults have fewer indications of emotional and physical distress. 21% of husband adjustment at 1 year accounted for by marital support. Partners of women with positive node status reported higher levels of physical symptoms and at 1 and 3 months and higher levels of emotional distress at every data point. 	
Walker, 1997	 Cross sectional, descriptive, explanatory No comparison group Family Adaptability and Cohesion Evaluation Scale - III, 20 item couples version), Perceived Social Support-Family Scale, Communication measured by five items adapted from Sabo et al., 1986, Fear of Recurrence Questionnaire, Profile of Mood States 	• N = 58 partners aged 28 – 81 years (M = 50.5); 66% completed 4 or more years of college; 95% Caucasian	• Patients who had undergone total (14%), modified radical (83%), or radical mastectomy (3%) and completed adjuvant treatment 3 months to 3 years prior to the study	 Partners with wives reporting greater flexibility had lower levels of emotional distress. Partners have less fear of recurrence as more time elapses since treatment. Partners whose wives underwent less extensive follow-up treatment had reduced levels of fear of recurrence approaching significance. For partners, increases in support are associated with less frequent emotional distress. Partners' reports of frequent illness related communication are associated with their increased fear of recurrence. 28% of the variance in partner's fear of recurrence was accounted for by the perceived amount of communication and satisfaction with it. 	

Study	Design	Characteristics	of the sample	Major findings
		Partners <i>n</i> ; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Northouse (1988)	 Longitudinal, assessed at 3 and 30 days post surgery; descriptive No comparison group Affects Balance Scale, Brief Symptom Inventory, Psychosocial Adjustment to Illness Scale, Social Support Questionnaire 	• Same sample as Northouse & Swain (1987)	• Same sample as Northouse & Swain (1987)	 Partners with high levels of social support reported fewer adjustment difficulties than partners with lower levels of social support. At Time 1, partners report social support from spouse and family at levels similar to that reported by patients but significantly less than the social support received from friends, nurses, and physicians. At Time 2, partners continue to report less social support from friends, nurses, and physicians.
Ptacek et al., 1994	 Cross sectional, descriptive, correlational No comparison group Ways of Coping Checklist- Revised, Dyadic Adjustment Scale, Mental Health Inventory 	• <i>n</i> = partners age (M = 57.65); 42% completed college; income range \$20K - \$70K; 86% Caucasian, 14% Native American	• Patients with Stage I (64%) or Stage II (36%) breast cancer and treated with radiotherapy following lumpectomy (89%) or mastectomy (11%)	 Partners report using coping strategies (problem-focused, seeking support, blaming self, wishful thinking, and avoidance) less frequently than patients. Partners report using more problem focused coping, less wishful thinking, and less avoidance over time. Partners report better mental health over time. Partners using more support seeking strategies and less avoidant and blaming strategies reported better mental health. Partners of wives reporting greater use of problem focused coping and less avoidance were more satisfied with the marital relationship and reported higher levels of mental health.
Northouse, Laten, et al., 1995	 Cross sectional, exploratory, descriptive Compares partner and patient scores Beck Hopelessness Scale, Mishel Uncertainty in Illness Scale, Social Support Questionnaire, Symptom Distress Scale, Brief Symptom Inventory, Psychosocial Adjustment to Illness Scale 	• $n = 74$ partners aged 31 – 81 years (M = 56.9); education range 6 – 2 years (M = 14); 66% employed outside of home; 91% Caucasian	• Patients with recurrent breast cancer 1 month to 3 years post recurrence	 Partners reported low to moderate emotional distress but difficulty in psychosocial role functioning. Partners whose wives were currently in treatment were more emotionally distressed than those whose wives were not in treatment. Partners with more personal health problems reported more problems with role functioning. Partners reported more uncertainty about the illness than patients. Higher levels of distress were found in partners who reported more uncertainty, more hopelessness, and who perceived more symptom distress in their wives. Partners role functioning difficulties were in the areas of domestic roles, sexual relationship, and leisure time activities.

Study	Design	Characteristics	of the sample	Major findings	
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis		
Kilpatrick et al., 1998	 Cross sectional, descriptive No comparison group Convenience sample recruited from four hospitals Family Inventory of Needs- Husbands 	• $n = 84$ partners aged > 40 - < 70 (M = 58); 33% with less than high school education and 67% with high school or greater education; 44% retired; 29% European, 35% British Isles, 10% French, and 27% other	• Patients newly diagnosed with Stage 0 – 4 breast cancer; treated with 71% mastectomy and 29% lumpectomy	 Partners' need 1) honest answers to their questions, 2) to know their wives are being given the best care, 3) to know the likely outcome of the illness, 4) to know about the future, and 5) to know when their wives' condition changes. Partners identified care needs and communication issues as their most important information needs. Partners classified as retired or laborer, living in rural areas, over age 60, and with less than a high school education were at greatest risk for not having their needs met. 	
Northouse et al., 1998	 Longitudinal, assessed at time of diagnosis, 60 days, and 1 year; survey data Compares partners of women with breast cancer and partners of women with benign breast disease Smilkstein Stress Scale, Dyadic Adjustment Scale, Family APGAR, Social Support Questionnaire, Mishel Uncertainty in Illness Scale, Brief Symptom Inventory, Psychosocial Adjustment to Illness Scale 	• $n = 58$ partners of women with breast cancer aged and $n =$ 73 partners of women with benign breast disease; cancer group reported being older than benign group (M = 53 and 49 years respectively) and less educated (M = 15 and 16.4 years respectively)	• Cancer patients received lumpectomy (62%) and adjuvant therapy (75%)	 Partners in malignant group reported greater decreases in marital and family functioning, more uncertain appraisals, and more emotional distress and role functioning problems than partners in the benign group and this continues at 60 days and 1 year. Social support decreased at 60 days for partners. 	

Study	Design	Characteristics	of the sample	Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Ben-Zur, 2001	 Cross sectional, explanatory No comparison group 30 item shortened Hebrew version of the COPE scale, Brief Symptom Inventory, Psychosocial Adjustment, Demographic and Medical Questionnaire 	• $N = 73$ partners aged (M = 55.6); education (M = 12.92); 74% employed; 49% Israeli, 24 % Europe/America, 22% Asia/Africa, 5% other	• Patients with Stage I or II breast cancer two to six months after diagnosis	 Partner perceptions of higher levels of Emotion Focused coping (i.e. ventilation, denial, behavioral disengagement, religion, and restraint) in patients were related to higher Global Severity Index scores and lower Psychosocial Adjustment scores in partners. Husband perceptions of higher levels of Problem Focused coping (i.e. active coping, planning, suppression, instrumental support, emotional support, and positive reinterpretation) in patients were related to higher functioning in work, family, social relations, house care, and self care roles but not to global distress indicators. Partners who perceive their wives as using active coping and planning had less distress and higher functional levels.
Baider et al., 2004	 Longitudinal, randomized, prospective, explanatory; quantitative interviews 1 to 5 years post diagnosis (Time 1) and 6 to 8 months later (Time 2) Brief Symptom Inventory, Impact of Event Scale, Perceived Family Support 	• $N = 71$ partners in Graz, Australia and 101 partners in Jerusalem at Time 1, and 55 and 65 spouses, respectively, at Time 2; no demographic data provided	• Patients 1 – 5 years post initial breast cancer diagnosis, with no adjuvant therapy in past 6 months and no current disease	 Partners' mean levels of emotional distress decreased from Time 1 to Time 2. 54% (Graz sample) and 58% (Jerusalem sample) of the variance in partners' GSI at Time 2 accounted for by GSI at Time 1. Only family support added to the prediction of partners' GSI, accounting for 3.4% of the explained variance in the Jerusalem sample.
Weiss, 2004	 Cross sectional, explanatory No comparison group Posttraumatic Growth Inventory, Social Support Questionnaire-Brief, Quality of Life Inventory 	• $N = 72$ partners aged $35 - 84$ years (M = 56.8); education range 10 - 20 years (M = 16.2); 93% income < \$60K; primarily Caucasian	• Patients 1 – 5.5 years post diagnosis of Stage 0 (19%), I (49%), or II (21%) breast cancer	 Partners' posttraumatic growth positively related to perceived social support, support and depth of commitment in the marital relationship, and breast cancer meeting DSM-IV criteria as a traumatic stressor accounting for 42% of the variance in this sample. Partners' posttraumatic growth positively related to patient growth scores. 42% of variance in partners' posttraumatic growth accounted for by depth of marital commitment, patient's posttraumatic growth, and breast cancer perceived as a DSM-IV trauma.

Study	Design	Characteristics of the sample		Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Blake Mortimer et al., 2005	 Cross sectional No comparison group Stress Chronicity defined as the number of days from diagnosis of recurrence to participation in research assessment, Center for Epidemiological Studies Depression Scale, Impact of Event Scale, Multitest Cell Mediated Immunity which measures response to seven antigens: tuberculin, tetanus, diptheria, Streptococcus, Candida, Trichophyton, and Proteus 	• <i>N</i> = 34 partners aged 35 – 78 (M = 57); education (M = 16.7); income range \$60K - \$80K; 94% Caucasian	• Patients with recurrent breast cancer (M = 2.3 years post diagnosis of recurrence)	 Living with an ill spouse for longer periods of time may bring about suppression of cell mediated immunity. Partners increased levels of intrusive thoughts were associated with suppression of the DTH response (size of induration and number of positive responses). Partner depressive symptoms were associated with suppression of the DTH response.
Butler et al., 2005	 Cross sectional, explanatory, survey data No comparison group Impact of Event Scale, Life Events Scale, Perceived Stress Scale, Anticipation of Loss Inventory 	• $N = 50$ partners (1 lesbian) aged 30-79 (M = 56.5); education range 8 – 20 years (M = 16); median household income \$60K – \$79K; 94% Caucasian, 6% Asian-American	• Patients with metastatic or recurrent breast cancer	 34% of partners' IES scores indicated clinically significant stress responses to breast cancer. Partners' perceptions of stress and anticipation of the impact of the loss were positively and significantly related to intrusive symptoms. Partners anticipation of the impact of the loss of his wife was significantly and positively related to avoidance symptoms. Higher levels of pre loss intrusive symptoms and the influence of past deaths were each related to higher levels of post loss intrusive symptoms. Higher levels of pre loss past deaths and the anticipation of the loss of his wife were related to higher levels of post loss avoidance symptoms.

Study	Design	Characteristics	of the sample	Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Feldman & Broussard, 2005	 Cross sectional; survey data No comparison group Quality of Life Spouses Scale, Illness Intrusiveness Rating Scale, Mutual Psychological Development Questionnaire, Dyadic Coping Scale 	• N = 71 partners aged 26 – 78 years (M = 51); 80% college graduates; 61% income < \$90K; 89% Caucasian	• Patients diagnosed with primary, non- metastatic breast cancer within past 3 months, undergoing treatment	 Mutuality was not a significant predictor of partners' emotional wellbeing. Mutuality predicted both common and positive dyadic coping in partners. Partners using lower levels of mutuality had greater use of negative dyadic coping strategies.
Wagner et al., 2006	 Cross sectional, survey data Compares partners of women with breast cancer and partners with healthy wives Medical Outcomes Study MOS SF-36, Illness Impact Form, Ways of Coping Questionnaire, Interpersonal Support Evaluation List 	 Partners of breast cancer group: N = 79 partners age (M = 50.76); 56% college and beyond, 44% below college grad; 83% income < \$40K; 94% Caucasian Partners of healthy wives: N = 79 partners age (M = 49.45); 54% college and beyond, 46% below college grad; 80% income < \$40K; 90% Caucasian 	• Patients currently being treated for BCA and recruited from infusion centers	 Partners of BCA patients reported needing to provide significant assistance to patients in terms of ADLs and IADLs. Greater impact in terms of providing ADLs and IADLs correlated with lower vitality, more role limitations, and lower mental health QOL. Disease characteristics did not correlate with QOL outcomes. Social support positively correlated with mental health. Higher use of emotion focused coping negatively correlated with role physical, general health. Higher use of problem focused coping negatively correlated with role physical and social functioning. Illness impact, emotional focused coping and social support accounted for 26% of the variance in partner mental health.
Manne et al., 2006	 Longitudinal, survey data assessed during treatment and 9 months later Adaptation of the Communication Patterns Questionnaire, Mental Health Inventory- 18, Dyadic Adjustment Scale, Cancer Rehabilitation and Evaluation System, and medical data from patient's chart. 	• N = 127 partners age (M = 52.7; 90% with some or completed college; 75% income < \$60K; 94% Caucasian	• Patients with early stage BCA who had undergone surgery	 Communication did not significantly change over time. Partner age and length of relationship were significantly associated with less partner distress at Time 2. After accounting for age, Time 1 distress and physical impairment, partners reporting more mutual constructive communication had less distress at Time 2. Partners reporting that they avoid discussions of problems and stressors or more use of demand withdraw communication had higher levels of distress at Time 2.

Study	Design	Characteristics	of the sample	Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Segrin et al., 2006	 Longitudinal, survey data assessed at recent diagnosis (T1), T1 + 6 weeks and T1 + 10 weeks. Center for Epidemiological Studies-Depression Scale, Positive and Negative Affect Scale, Mental Health subscale of the Medical Outcomes Study-Short Form, Index of Clinical Stress, Relationship Assessment Scale, Index of Socially Supportive Behaviors 	• N = 63 partners age (m = 55.54; 60% with Bachelors degree of higher; 58% working; 89% Caucasian, 8% Hispanic	• Patients with Stage I – III BCA	 No effect for Stage of BCA. Partners of patients reporting greater symptom distress and undergoing a mastectomy had higher symptoms of depression. Interpersonal well being improved across time. Social support declined significantly though in the context of a supportive relationship. Symptoms of depression declined significantly over the 10-week period. However, 20 – 24% of partners remained depressed. Negative and positive affect both declined during this same period. Greater relationship satisfaction is associated with better mental health at all time points. Higher social support was associated with lower mental health scores. Partners with better relationship satisfaction reported improved global mental health and decreases in stress from T1 to T2. Partners with more T1 social support reported significant decreases in stress at T2. Better T1 relationship satisfaction predicted less negative affect and improved mental health over 10-week period, T1 – T3. Better T1 social support predicted increased positive affect and decreased stress over the 10-week period, T1 – T3.
Feldman & Broussard, 2006	 Cross sectional, assessed within 3 months of patient diagnosis Quality of Life Spouses Scale, Illness Intrusiveness Rating Scale, Dyadic Coping Scale 	• N = 71 partners age 26 to 78 years (M = 51); 80% college graduates; 61% with income < \$90K	• Patients diagnosed with primary, non- metastatic BCA within the past 3 months and currently undergoing treatment	 Positive dyadic coping strategies did not predict higher levels of partner adjustment. Hostile dyadic coping accounted for 33% of the variance in illness intrusiveness.

Table 3.3.

Qualitative Studies Documenting the Experiences of Partners of Women With Breast Cancer.

Study	Design	Characteristics	of the sample	Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Sabo et al., 1986	 Longitudinal, assessed at enrollment in study and completion of 10 week support group; mixed methods including interview data, observation of group dynamics, and written questionnaires No comparison group Participants filled out 37 item questionnaire measuring gender expectations, self esteem, depression, sexual compatibility, frequency of verbal communication about mastectomy, and supportive attitude toward patient 	• $n = 24$ partners completed semistructured interview and survey questionnaire; sub sample $n = 6$ then participated in 10 week support group; $n =$ 23 of total initial participants completed follow up survey upon completion of 10 week support group; no demographic data provided	• Patients treated with mastectomy; no other patient medical data provided	 Partners feared the death of the patient and not being able to provide adequate support. Partners developed sense of themselves as "protective guardians" of patients' well being. Partners developed capacity to deny their own feelings that contributed to anxiety. At post test, support group participants were talking frequently about the mastectomy than nonparticipants.
Northouse (1989a)	 Longitudinal, assessed days and 30 days post surgery; descriptive; No comparison group Qualitative interviews 	• Same sample as Northouse & Swain (1987)	• Same sample as Northouse & Swain (1987)	 At Time 1, partners' primary concerns are with his wife's surviving the disease and her ability to cope with the emotional upheaval of the illness. At Time 2, partners' are still primarily concerned with survival, but also begin to consider the affect of life style changes. Coping was less of a concern at Time 2. 24% of partners reported mild (12%) to a great deal (12%) of difficulty seeing the surgical incision. 50% of partners reported the presurgery phase as most stressful while 44% indicated the treatment phase as most stressful. Partners identified emotional support as the most important factor related to their coping at both Times 1 (64%) and 2 (49%). Information and attitude were also important though less so at Time 2. and 0% at Time 1.

Study	Design	Characteristics	of the sample	Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Hannum et al., 1991	 Cross sectional, quantitative survey, qualitative interview, observation of interactional behavior No comparison group Researcher designed marital and family history questionnaire, Symptom Check List 90-R, Marital Adjustment Test, Family Adaptability and Cohesion Scale, Health Symptom Checklist, Friendship Scale, Philosophies of Marriage Scale 	• $N = 22$ partners ages 30 – 75 (M = 56); no data regarding education; per Hollingshead's four-factor system classified as second level SES (medium business, minor professional, technical); 100% Caucasian	• Patients with Stage I (91%) or Stage II (9%) breast cancer diagnosed within the past 9 – 12 months;	 73% of the variance of partner distress is accounted for partner denial as reported by wife, partner's observed confronting behavior, and wife's self reported optimism. Partner's distress negatively correlated with wife's ratings of cohesion. Points out that adjustment to a stress is a two way interaction.
Zahlis & Shands, 1991	 Cross sectional, descriptive No comparison group Qualitative interviews; Demands of Illness Interview 	• $N = 67$ partners ages 28 to 63 (M = 44); 70% with some college or college degree; 73% income > \$35K; 90% Caucasian	• 60% of patients treated with mastectomy, 40% lumpectomy; time since diagnosis 35 – 984 days (M = 395 days)	• Identified 7 domains of the demands of breast cancer on the partner: Reacting to the patient's illness (93%), negotiating the illness experience (52%), adapting the lifestyle to meet the demands of the illness (61%), being sensitive to the patient's needs (57%), thinking about the future (52%), attempting to minimize the effects of the illness (34%), and feeling the impact on the relationship (16%).
Zahlis & Shands, 1993	 Cross sectional, descriptive; some participants' interviews compared longitudinally No comparison group Qualitative interview, Demands of Illness Interview 	• N = 30 partners aged 31 – 63 years; no additional demographics provided	• Patients diagnosed with breast cancer within the past 2.5 years and treated with lumpectomy (50%), modified radical (40%), or radical (10%) mastectomy	 27% of partners report that negative feelings and effects of breast cancer remain a part of their daily lives 18 months post diagnosis. Partners primary concerns are with the recurrence of the breast cancer and marital problems (separation, communication, and lack of intimacy). There is a small group of men who continue to struggle to adjust to their wives' breast cancer 18 months post diagnosis.

Study	Design	Characteristics	of the sample	Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Lewis & Deal, 1995	 Cross sectional, descriptive, mixed methods: qualitative interview with survey Compares partner, patient and normative data Marital Dyad Interview, Dyadic Adjustment Scale, Center for Epidemiological Studies Depression Scale 	• $N = 15$ partners aged $25 - 64$ (M = 43); 93% with some college or post high school training; income range $$25 - 70K$, with 27% in $$40 - $50K$ range	• Patients diagnosed with recurrent breast cancer (M = 10 months past diagnosis of the recurrence)	 Domains of the couples' experience with recurrent breast cancer: a) managing the woman's everyday illness (talking about treatment and the disease, educating ourselves about the disease, interpreting her symptoms, not dwelling on it, feeling down, and hitting the unknowns and uncertainties), b) surviving (learning to live with it, struggling with the relational parts, talking about the kids, and being in control), c) healing (making progress and moving on, maintaining optimism, keeping stress down), and d) preparing for death (talking about dying, talking about afterwards). 20% of partners at or above cutoff points for depression. 40% of partners 1 standard deviation below referent sample on marital satisfaction. 60% of couples are out of normative ranges on either mood or marital adjustment. Couples may be avoiding difficult topics that contribute to dissatisfaction with marriage and depressed mood.
Samms, 1999	 Qualitative, two focus group interviews No comparison group 	• N = 9 partners age (M = 41.88); all with two or more years college; 77% income < \$70K	• Patients with early stage BCA	• Inductive coding yielded 4 domains: a) riding the roller coaster (feeling helpless, understanding personal emotions, feeling turned loose, protecting myself, noticing changes and thinking about loss), b) doing well by her (reading her, being there, getting back to normal, doing the right thing, and doing more), c) doing my duty (problem solving, communicating, assimilating medical information and protecting her) and d) what partners asked for (how to help, when to help, when not to help, what to help with). Deductive coding yielded 4 domains: a) at the time of diagnosis (feeling helpless, problem solving, assimilating medical information, protecting her, protecting myself, noticing changes, and understanding personal emotions), b) during treatment (reading her, being there, communicating, doing the right thing, doing more, getting back to normal, thinking about loss), c) after treatment ends (feeling turned loose) and d) programmatic feedback (how to help, when to help, when not to help, when to help, what to help with).

Study	Design	Characteristics of the sample		Major findings
		Partners n; age; education; income; ethnicity	Patients diagnosis or treatment; months since diagnosis	
Hilton et al., 2000	 Cross sectional; qualitative, semi structured interviews; grounded theory No comparison group 	• $N = 10$ partners aged $39 - 58$ years (M = 47.1); 60% with college preparation; income range $36 - 95K$ (Canadian dollars); 100% Caucasian	• Patients treated with chemotherapy within the past two years	• Two major themes related to men's coping: 1) a focus on their wives' illness and care and 2) a focus on their families and keeping life going. Further identified nine sub themes: 1) being there, 2) relying on health care professionals, 3) being informed and contributing to decision making, 4) trying to keep patterns normal and family life going, 5) helping out and relying on others, 6) trying to be positive, 7) putting self on hold, 8) adapting work life, and 9) managing finances.

Table 3.4. Biopsychosocial Domains of Indicators and Correlates of Partner Adjustment toBreast Cancer.

Domain	Indicators of Partner Adjustment to BCA	Correlates of Partner Adjustment to BCA
Biological	General health Immune functioning	Demographics Medical factors
Psychological	Distress Post-Traumatic growth	Coping strategies Cognition
Social	Role functioning Marital adjustment	Communication patterns Social support

CHAPTER 4

PROFILES OF SUPPORTIVE PARTNERS OF YOUNG WOMEN WITH BREAST CANCER³

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Abstract

The purpose of this study was to determine the characteristics and predictors of partner support as perceived by young women with breast cancer. Women aged 50 and younger diagnosed with primary breast cancer (n=111) completed a one-time survey containing the Partner Responses to Cancer Inventory, Initiator Style Questionnaire, Beck Depression Inventory-II, and the Domestic Environment and Sexual Relationship subscales of the Psychosocial Adjustment to Illness Scale. Cluster analyses revealed that patient ratings of partner behaviors fell into two distinct profiles that included supportive partner responses and non-supportive partner responses. Binomial logistic regression indicated that a large proportion of the variance in partner response profiles was determined by symptom severity, distress in family life, and the couple's sexual relationship. Clinical implications and directions for future research are discussed.

Profiles of Supportive Partners of Young Women with Breast Cancer

The most common type of cancer among women in the United States is breast cancer (BCA) as 178,480 new cases of breast cancer were expected in 2007 (ACS, 2007a). The needs of young women with breast cancer are receiving increased attention with at least one fourth of newly diagnosed women being aged 50 or younger (ACS, 2001). The diagnosis and treatment of BCA in young couples is a particularly distressing experience that affects both women and their partners. A recent review of the literature regarding the psychosocial issues confronting young women with BCA concluded that young women experience a lower quality of life than older women (Baucom et al., 2005). This may, in part, be due to the aggressive medical treatments young women are exposed to and their resulting physical side effects (Campora et al., 1992; Ganz, Rowland, Meyerowitz et al., 1998; Stanton et al., 1998). Aggressive medical treatments in young women may also bring about premature menopause and ovarian failure creating problems related to family planning and infertility (Dow & Kuhn, 2004; Ganz, Rowland, Meyerowitz et al., 1998; Mor et al., 1994; Schover, 1999). Other factors contributing to lower quality of life in young women may be psychological distress (Derogatis et al., 1983a; Meyerowitz, 1980; Northouse, 1992) and the disruption of home life (Baider & De-Nour, 1984; Baider & Kaplan De-Nour, 1986) in families who are already in the initial stages of negotiating rules, roles, and boundaries (Carter & McGoldrick, 1989; Carter & McGoldrick, 1999). Further, the impact of BCA treatment is associated with disruption of sexual functioning in young women (Bakewell & Volker, 2005; Barni & Mondin, 1997; Bransfield, 1982; Front, 1999; Ganz et al., 1999; Henson, 2002). These findings have been documented in a report from the Institute of Medicine and National Research Council National Cancer Policy Board (Hewitt et al., 2004).

The source and type of social support has been identified as an important variable in adjustment to a variety of cancers (Helgeson & Cohen, 1996), including BCA (Arora et al., 2007; Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Lindsey, Norbeck, Carrieri, & Perry, 1981). Women with BCA have consistently reported the benefits of supportive relationships with family, friends, nurses, physicians, BCA survivors, support groups, and a variety of mental and other healthcare professionals (Brady & Helgeson, 1999; Davis et al., 2004; Gass et al., 2007; Holland & Holahan, 2003; Hoskins, Baker, Sherman, & Bohlander, 1996; Kornblith et al., 2001; McLean, 1995; Neuling & Winfield, 1988; Northouse, 1988; Pistrang & Barker, 1998; Sammarco, 2001). Social support from such relationships is related to lower levels of depression and anxiety (Kornblith et al., 2001), lower levels of uncertainty about the illness (Sammarco, 2001), improved vocational, domestic, and social role functioning (Hoskins, Baker, Sherman, & Bohlander, 1996), improved sexual adjustment (Bakewell & Volker, 2005), and better quality of life (Carver, Smith, Petronis, & Antoni, 2006; Manning-Walsh, 2005).

Yet, the role of partners in women's adjustment to BCA is particularly germane (Jamison, Wellisch, & Pasnau, 1978; Pistrang & Barker, 1995; Vess, Moreland, & Schwebel, 1985). Women with breast and other cancers identify their partners as primary sources of support and often name them as emergency contacts and health care proxies (Ell et al., 1988; Gass et al., 2007; Helgeson & Cohen, 1996). Moreover, investigations of women's adjustment to BCA indicate that the influence of partners exceeds that of other sources of support including family, friends, and health professionals (Neuling & Winfield, 1988; Northouse, 1988). Among women with BCA, support from partners is related to improved role functioning (Hoskins, Baker, Sherman, & Bohlander, 1996) and better emotional adjustment (Hoskins, Baker, Sherman, Bohlander et al., 1996). Despite the importance of partner support in the adjustment of women to BCA, relatively little is known about what partners actually *do* that young women find supportive. In fact, as women express the importance of partner support in their adjustment, partners actually report feeling inadequate in their ability to help their wives cope with the diagnosis (Sabo, 1990) and are concerned that they won't be able to provide *enough* support (Sabo et al., 1986). Partners have described feeling ill-equipped and unprepared for the emotional upheaval following a breast cancer diagnosis, yet want to protect their wives from its emotional sequelae (Zahlis & Shands, 1991). Sabo and colleagues(1986) described partners taking on the role of "protective guardian" of women with BCA. Samms identified that husbands of early stage BCA patients needed information regarding "how to help, when to help, when not to help, and what to help with." (Samms, 1999, p. 1353).

Though partner support has often been investigated as it predicts patient outcomes (Cohen, Schaie, Blazer, & House, 1992; Kagawa-Singer & Wellisch, 2003; Northouse, 1988; Ptacek et al., 1997), it may also be instructive to consider the factors that predict partner support. In a recent review, patient symptom severity, psychological distress, home life, and a couple's sexual relationship were identified as four primary factors through which the lives of partners of women with breast cancer are disrupted (Templeton & Burwell, under review). These are consistent with psychosocial concerns identified in a report from the Institute of Medicine and National Research Council National Cancer Policy Board (Hewitt et al., 2004). For example, the aggressive surgical and adjuvant treatment of young women with BCA is associated with increased symptom severity (fatigue, sleep disturbance, or pain) and increased partner distress (Baider & De-Nour, 1984; Baider & Kaplan De-Nour, 1986). Partners are known to experience distress at levels equal to, and at times, exceeding that of patients (Baider & De-Nour, 1984;
Ben-Zur et al., 2001; Hoskins, 1995a; Lewis & Deal, 1995; Maguire, 1981; Northouse, 1989b; Northouse, Laten et al., 1995; Northouse & Swain, 1987; Sabo et al., 1986; Templeton & Burwell, under review; Wellisch et al., 1978). Likewise, partners may become overwhelmed by the myriad responsibilities taken on as a result of the disruption of family and marital life (Hewitt et al., 2004; Hilton et al., 2000). Finally, disruption of the sexual relationship has been identified as a major problem in young couples confronting BCA (Baider & De-Nour, 1984; Bakewell & Volker, 2005; Hewitt et al., 2004). While partners clearly express priority for their spouse to heal over continuation of sexual activity (Holmberg et al., 2001), communication about sexual needs and concerns often goes unaddressed in even the closest relationship. Collectively these risk factors warrant further investigation as they influence partner behaviors and represent potential targets for clinical intervention.

Given the increased illness demands placed on young couples with BCA, the salience of the partner's role in patient adjustment, partner distress and desire to be of assistance, and the lack of resources to guide partners, it is imperative that more effort be undertaken to investigate specific partner responses to the diagnosis and treatment of BCA. To date there is no literature describing profiles of partner behaviors in response to young women with BCA. Further, no data evidences the relative importance of partner behaviors to BCA patients or factors that contribute to the likelihood of their presence. Hypotheses grounded in family systems theory propose that relationships confronting increased symptom severity, psychological distress, disruption of family life, or a stressful sexual relationship would directly affect partner support of the needs of a spouse with BCA. Therefore, the purpose of this study is to examine partner behaviors and responses to BCA in young women and identify specific factors related to partner support by answering the following research questions: 1. What partner behaviors do young women with BCA perceive as supportive?

2. Do illness demands, patient psychological distress, home life, or the sexual relationship of the couple contribute to the likelihood of partners being perceived as supportive?

Method

One hundred and thirty-two women aged 50 and younger and within 36 months of a primary breast cancer diagnosis completed an online or written survey as part of a larger study investigating couples' adjustment to breast cancer. Patients completing the survey online were recruited from various cancer websites and support groups (e.g., the American Cancer Society and Young Cancer Survivors Coalition) and participated by following a link connecting them to an introduction to the study and eligibility, the informed consent form, and survey. The Principal Investigator's (SRB) contact information was provided with the study introduction and informed consent form so that participants could call or email for more information or to ask questions pertaining to the study. All procedures and materials were approved by the Institutional Review Board. Patients completing a written survey were recruited through local oncologists, surgeons, radiologists, hospitals, health departments and medical clinics. Four percent of participants completed and returned a mailed survey and the remainder (96%) completed the online survey. *Constructs and Measures*

Constructs relevant to this inquiry include demographics, cancer and health status, partner behaviors in the context of BCA, psychological distress, family life, and the couple's sexual relationship. Partners' behaviors include specific behaviors that partners employ in the context of BCA. Two scales measured partner behaviors, the Initiator Style Questionnaire (ISQ) (Denton & Burleson, 2007) and the Partner Responses to Cancer Inventory (PRCI) (Manne & Schnoll, 2001b). The combined 55 items of the ISQ and PRCI were used to develop profiles of partner support behaviors. Family life was conceptualized as global disruption of the day to day lives of the nuclear family and measured by the Domestic Environment subscale of the Psychosocial Adjustment to Illness Scale-Self Report (PAIS) (Derogatis, 1975b, 1986; Derogatis & Lopez, 1983). Changes in the sexual relationship of the couple were measured by the Sexual Relationship subscale of the PAIS. Psychological distress was conceptualized as depression and measured by the Beck Depression Inventory II (Beck & Beamesderfer, 1974; Beck, Steer, & Brown, 1996).

Demographics. Demographic variables included age, relationship status, length of relationship, previous marriage and divorce, number and ages of children, income, education level, and work status.

Cancer and health status. Medical variables included cancer stage, type of surgery (lumpectomy, mastectomy, breast reconstruction), adjuvant treatments (chemotherapy, radiation, hormone therapy), and time since diagnosis. An index of symptom severity was created from 14 items measuring the impact of current symptoms such as hair loss, nausea, and weight gain. Each response category has a 5-point Likert scale ranging from 1) not at all to 5) very much. The final scale score represented the mean of the fourteen responses. The symptom severity index had a reliability coefficient alpha of .73.

Partner Support Behaviors. Partner behaviors were measured by the ISQ and the PRCI. The ISQ measures the tendency to initiate or avoid discussions of relationship issues with one's partner (Denton & Burleson, 2007) and was conceptually derived from the Communication Patterns Questionnaire (Christensen & Sullaway, 1984). Two 10 item parallel scales comprise the ISQ and each has a 9-point Likert type scale ranging from strongly disagree to strongly agree. We utilized items from the partner subscale in which the patient is asked to rate her partner on how he/she typically responds to relationship problems. Higher scores represent a greater tendency to initiate relationship-focused discussions and lower scores suggest a greater tendency to avoid relationship discussions. The ISQ has good validity and test-retest reliability (Denton & Burleson, 2007). The estimated coefficient alpha for this study was .96 for the patient rating of partner scale.

The PRCI is a 45 item scale used to measure supportive and unsupportive responses from partners during the treatment of cancer (Manne & Schnoll, 2001a). The PRCI is derived from the Inventory of Socially Supportive Behaviors Scale (Barrera, Sandler, & Ramsey, 1981) and designed to measure specific supportive behaviors. The PRCI has four subscales that include Cognitive Information and Guidance, Emotional and Instrumental Support, Encouraging Distancing and Self-restraint, and Criticism and Withdrawal. Each response category has a 4-point Likert scale ranging from 1) never responds this way to 4) often responds this way. The PRCI has met the standard criteria for internal consistency and construct validity (Manne & Schnoll, 2001a). The estimated coefficient alpha for this study was .82.

Family Life. Family life was conceptualized as global disruption of a BCA patient's home and nuclear family and measured by the Domestic Environment subscale of the PAIS-SR. The PAIS-SR is a well known and widely used instrument designed to assess changes in functioning as a result of illness across 7 domains (Derogatis, 1975b; Derogatis & Derogatis, 1983). Responses are recorded on a 4-point scale (0-3) with higher scores indicating poorer adjustment to illness. Questions on the domestic functioning subscale ask about the quality of relationships with principal and additional cohabitants, domestic impairment, family adaptability and cohesion, family communication, dependency posture, physical disability and financial resources. In this study, the Chronbach's alpha for the Domestic Environment subscale was .82. *Couple's Sexual Relationship.* The couple's sexual relationship was conceptualized as changes in the sexual relationship and measured by the Sexual Relationship subscale of the PAIS-SR. Questions on the Sexual Relationship subscale ask about sexual interest, frequency, satisfaction, dysfunction, quality of the sexual relationship, and level of interpersonal conflict. Responses are recorded on a 4-point scale (0-3) and higher scores indicate poorer adjustment to illness. The PAIS and both relevant subscales meet criteria for reliability and validity among cancer patients (Derogatis & Derogatis, 1983; Derogatis et al., 1983b). In this study, the Chronbach's alpha for the Sexual Relationships subscale was .80.

Beck Depression Inventory II (BDI-II). The BDI-II is a 21-item measure commonly used to assess depressive symptoms (Beck et al., 1996). Response categories are on a 4-point Likert scale. The maximum score of the BDI-II is 63 with higher scores indicating more severe depressive symptoms (e.g., 0-13=minimal depression, 14-19=mild depression, 20-28=moderate depression, 29-63=severe depression). The BDI-II has been used with cancer populations and has demonstrated satisfactory psychometric properties (Baider & Kaplan De-Nour, 1986; Christensen, 1983; Hodgson et al., 2003). The reliability coefficient alpha for the BDI-II in this study was .92.

Participants

Women were eligible for participation in this study if they were (a) between 18-50 years of age, (b) in a committed relationship with the same partner since the time of diagnosis, (c) diagnosed with their first breast cancer within the past 3 years, (d) without cancer recurrence or an additional cancer site (e.g., lung cancer), and (e) completed initial surgery. Any major health condition in the spouse or partner (e.g., cancer) excluded participation. The analytic sample was comprised of 111 women whose descriptive characteristics are provided in Table 4.1. The mean age of participants was 41 (range = 23 to 50; SD = 7.30) and the mean age of partners was 43 (range = 23 to 67; SD = 8.58). Of the sample, 73% reported incomes greater than \$60,000. The majority of women (95%) and their partners (71%) were covered by medical insurance. Women were highly educated with 66% having attended some college or earning a college degree and 27% acquiring professional education or a graduate degree after college. The majority of women in this sample identified as White (88%), married (80%), and having children (72%). The average number of children per participant was 4 (range = 1 to 10; SD = 1.52). The mean length of the relationship with their spouse or partner was 160 months (SD = 104.42; median = 141). Online participants responded from 38 states.

In terms of medical characteristics (see Table 4.2), the average time since breast cancer diagnosis was 12.09 months (SD = 9.5). Fifty-four percent of the women underwent mastectomy, 54% underwent breast-conserving surgery. Thirty-five percent of participants underwent breast reconstruction surgery. Following surgery, most participants completed chemotherapy (71%), radiation therapy (49%), and/or hormonal therapy (53%).

Results

Analyses were conducted using the Statistical Package for the Social Sciences 15.0 (SPSS). Descriptive statistics were used to produce variable frequencies and means. Two-step cluster analyses identified profiles of partner behaviors. Binomial logistic regression predicted factors contributing to the likelihood of patients perceiving partner behaviors as supportive. *Profiles of Partner Behaviors*

Our initial interest was to develop profiles of partner behaviors among young women with BCA. A two-step cluster analysis using 55 z-scored variables measuring specific partner behaviors (45 items from the PRCI and 10 items from the partner subscale of the ISQ) was calculated. The analysis yielded two distinct profiles of partner behaviors, supportive and non-supportive. Seventy-three partners were classified into a profile comprised of supportive partner behaviors and 38 partners were classified into a profile comprised of non-supportive behaviors. Forty-one items from the PRCI and ISQ made significant contributions to the supportive partner profile and 33 items made significant contributions to the non-supportive partner profile and 33 items made significant contributions to the non-supportive and non-supportive profile (organized by supportive profile), whether or not the behavior makes an increased or decreased contribution to the profile (valence), centroid means, standard deviations, and *t*-tests of significance.

Predictors of Partner Behaviors

To better understand factors associated with partner behaviors, a second phase of analysis sought to identify predictors of perceived partner support. Partner behaviors were dummy coded so that 0 = non-supportive and 1 = supportive (Peng & So, 2002; West, Aiken, & Krull, 1996) and a binominal logistic regression model was fit to patient data to explain the predicted odds of partners being perceived as supportive. The model included four main effects measured continuously: a) symptom severity, b) psychological distress, c) disruption in family life, and d) sexual relationship (see Table 4.4). Variables were entered simultaneously, parameters thus express each variable's unique contribution to the regression equation while controlling for every other predictor variables. Hosmer and Lemeshow tests were significant and indicated good fit, $\chi 2$ (8) = 3.46, p = .90 (see Table 4.4). Pseudo R^2 values (Cox & Snell's = .25 and Nagelkerke's = .33) illustrated that the model accounted for a substantive proportion of variance in perceived partner support behaviors. Wald statistics identified symptom severity (Wald test = 3.93, *p* = .00), family life (Wald test = 11.85, p = .00), and the sexual relationship (Wald test = 9.65, p = .00) as significant predictors of partner supportive behaviors. Odds ratios indicate that as symptom severity or depression increased in young women with BCA, partners were more likely to be supportive, a likelihood that increased by factors of 2.00 and 1.72, respectively. Further, with increased disruption in family life and the sexual relationship, the likelihood of a partner being perceived as supportive decreased by factors of .29 and .38, respectively.

Discussion

The purpose of this investigation was to identify profiles of partner behaviors perceived by young women with BCA. Two unique profiles emerged and were identified as supportive and non-supportive. Supportive partners expressed interest and concern for their spouses and indicated that they would be around when needed. These partners reassured their spouses of their strength and competence and showed physical affection. Supportive partners encouraged spouses to express themselves and were accepting of them in the face of illness. Supportive partners wanted to spend time with their partners and enjoyed the interaction. In contrast, non-supportive partners were generally uncomfortable discussing relationship problems or expressing feelings about their relationship and kept feelings about the relationship private.

The profiles of partner support behaviors provide useful information to clinicians. Behaviors perceived by young women with BCA as supportive document the importance of couple communication and suggest that it is critical to assess the nature and quality of couple communication in general and specifically in the context of BCA. These data suggest that young women with BCA need partners who are willing and able to talk openly about their feelings and who also listen. Manne and colleagues have previously reported the influence of marital communication on the adjustment to cancer suggesting that negative communication patterns such as avoidance, withdrawal, and negativity are associated with adjustment problems (Manne, Ostroff, Rini et al., 2004; Manne et al., 2006; Manne et al., 1997). These point to the importance of coaching partners to listen and share feelings.

The influence of predictors on partner support behaviors also provides useful clinical information. Clinicians must assess the availability and willingness of extended family and other support systems to offer assistance to young couples as these data evidence the disruption of home life and its impact on partners. Extended family and friends represent sources of support in managing the day to day tasks of home life. Assistance with these seemingly mundane and instrumental tasks could mean the difference between maintaining some semblance of normal family life or disruption that increases distress and tension.

The sexual relationship of couples facing breast cancer requires special consideration. These data indicate that disruptions in the sexual relationship of young couples are associated with a decreased likelihood of partners being supportive. Given that partner support is crucial in patient adjustment, it is imperative to find ways to enhance couples' sexuality despite decreased desire and increased treatment related symptoms such as vaginal dryness. Education regarding alternative means of enjoying sexual intimacy is necessary.

Several important limitations much be considered when interpreting these data. First, the study uses cross sectional data and correlational analyses which prohibit establishing causality. Future analyses with longitudinal data would strengthen these findings. In addition, these data represent only the woman's perspective, many of whom are distressed. Future investigations should include partner report. Agreement between provision of partner support behaviors and patient perceptions would be an important area of inquiry. In addition, as with other BCA samples (Ganz et al., 1999; Ganz et al., 2002; Northouse, Jeffs et al., 1995; Northouse & Swain,

1987) this sample is comprised of women who are primarily white, middle to upper class, and highly educated, limiting generalizibility. These data also were primarily collected online which prevents the ability to determine a response rate.

Table 4.1.

Variable		Supportiv	ve(n = 73)	3)	Non-supportive $(n = 38)$				
	<u>n</u>	%	М	SD	<u>n</u>	%	М	SD	
Participant age			41	6.54			41	7.61	
24-30	4	6.2			4	11.1			
31-40	24	36.9			12	33.3			
41-50	37	56.9			20	55.5			
Partner age			43	7.72			43	8.86	
23-30	5	7.5			2	5.50			
31-40	17	25.8			10	27.7			
41-50	35	53.0			17	47.2			
51 and above	9	13.6			7	19.4			
Race/Ethnicity									
Caucasian	63	94.0			35	94.6			
African American	1	1.5			0				
Hispanic/Latino	2	3.0			0				
Other	1	1.5			2	5.4			
Education									
High school and/or Vocational School	12	17.9			6	16.2			
Some college to college degree	37	55.2			19	51.4			
College degree and professional school	10	14.9			5	13.5			
Master's or doctoral degree	8	11.9			7	18.9			
Employment									
Working	46	68.7			24	64.9			
Not working – retired, illness, searching	13	19.4			5	13.5			
Other – stay home mom, disabled	8	11.9			8	21.6			
Income									
less than \$10,000 - \$39,999	4	5.9			3	8.1			
\$40,000 - \$59,999	12	17.9			7	18.9			
\$60.000 - \$74.999	12	17.9			5	13.5			
\$75,000 and above	39	58.2			22	59.5			
Relationship status									
Number of children			4	1.58			4	1.30	
Months in relationship			160	110			160	102	
Health insurance									
Patient	73	100			35	97.2			
Partner	54	74.0			25	69.4			

Demographic Characteristics of Participants by Perceived Partner Support Profile (n = 111).

Table 4.2.

Medical Characteristics of Participants by Partner Support Profile (n = 111).

Variable		Supp	ortive		Non-supportive				
	<u>n</u>	%	М	SD	<u>n</u>	%	М	SD	
Surgery									
Lumpectomy	39	67.2			21	65.6			
Mastectomy	39	60.0			21	56.8			
Breast reconstruction	25	43.9			14	45.2			
Adjuvant Treatment									
Chemotherapy	52	77.6			27	73.0			
Radiation	34	57.6			20	64.5			
Hormone therapy	36	58.1			23	63.9			
Months since diagnosis			11.37	9.79			12.62	8.14	

Table 4.3

Rank of Variable Importance and Centroid Means of Partner Support Behaviors Perceived by Young Women With Breast Cancer

Behavior	Rank of Variable Importance and Valence of Partner Support Behaviors					Centroid Means and Tests of Significance					
-	Supportive		Non-supportive		Supportive			Non-supportive			
-	Rank	Valence	Rank	Valence	<u>M</u>	<u>SD</u>	Student's t [*]	M	<u>SD</u>	Student's t [*]	
Reassured your partner that she remained a competent and strong person	1	+	18	-	.61	.36	11.56	71	1.07	-4.80	
Was right there with you in the stressful times of her breast	2	+	40	-	.41	.29	9.94	49	1.24	-2.83	
Did you a favor	3	+	34	-	.45	.34	9.34	56	1.22	-3.22	
Wasn't emotionally supportive of you when you were	4	-	17	+	55	.43	-9.33	.73	1.03	4.82	
Let you know that he would always be around if you needed	5	+	29	-	.51	.43	8.88	70	1.13	-4.18	
Did not seem to respect your feelings.	6	-	8	+	59	.52	-8.42	.78	.89	5.95	
Listened to you confide your worries or concerns about	7	+	26	-	.52	.45	8.40	66	1.06	-4.33	
Seemed less accepting of you since you got breast cancer.	8	-	38	+	44	.37	-7.64	.46	1.20	2.91	
Shouted or yelled at you.	9	-	28	+	52	.51	-7.60	.70	1.10	4.31	
Joked and tried to cheer you up.	10	+	21	-	.50	.51	7.52	70	1.02	-4.58	
Seemed not to enjoy being around you.	11	-	30	+	53	.49	-7.42	.62	1.08	4.13	

Behavior	Rank of Variable Importance and Valence of Partner Support Behaviors					Significar	nce			
-	Supportive		Non-supportive		Supportive			Non-supportive		
-	Rank	Valence	Rank	Valence	<u>M</u>	<u>SD</u>	Student's t [*]	<u>M</u>	<u>SD</u>	Student's t [*]
When I want to talk about a relationship problem, my partner usually tries to get out of the discussion.	12	+	3	-	.60	.62	7.32	83	.83	-6.65
When I want to talk about a relationship problem, my partner	13	+	2	-	.60	.64	7.07	84	.83	-6.74
Said things that made your situation clearer and easier to	14	+	4	-	.60	.65	6.91	79	.84	-6.43
Avoided being around you when you were not feeling well.	15	-	31	+	46	.55	-6.61	.68	1.12	3.99
Encouraged you to keep your feelings to yourself.	16	-	45	+	39	.41	-6.34	.43	1.23	2.59
Encouraged you to let your feelings out	17	+	1	-	.60	.69	6.30	77	.79	-6.79
Comforted you by showing you some physical affection.	18	+	32	-	.49	.53	6.27	56	1.04	-3.89
Gave the idea he really didn't want to talk about your	19	-	16	+	49	.61	-6.23	.71	.96	4.85
problem. Asked you how you were feeling.	20	+	12	-	.57	.65	6.23	69	.97	-5.06
When my partner becomes aware of a problem in our relationship, my partner usually tries to start a	21	+	5	-	.62	.72	6.09	76	.83	-6.42
discussion of the problem. Helped come up with a solution to a problem you encountered.	22	+	6	-	.57	.69	6.06	75	.84	-6.09

Behavior	Rank of Variable Importance and Valence of Centroid Means and Tests of Sign Partner Support Behaviors Centroid Means and Tests of Sign					Significar	nce			
-	Supportive		Non-supportive		Supportive			Non-supportive		
	Rank	Valence	Rank	Valence	<u>M</u>	<u>SD</u>	Student's t [*]	<u>M</u>	<u>SD</u>	Student's t [*]
When discussing a relationship problem, my partner usually tries to keep the discussion going until we settle the issue.	23	+	7	-	.60	.70	5.99	71	.84	-6.08
My partner usually keeps feelings about our relationship	24	+	11	-	.54	.71	5.47	68	.93	-5.12
My partner is the kind of person who generally feels	25	+	9	-	.58	.72	5.46	65	.88	-5.45
Comfortable discussing relationship problems. You had to wait a long time for help when you needed it.	26	-	10	+	49	.72	-5.40	.73	.92	5.13
My partner is the kind of person who generally does not feel	27	+	20	-	.52	.71	5.07	61	.96	-4.59
Helped you analyze a problem you were having to help you understand it better	28	+	14	-	.53	.75	5.04	67	.95	-4.90
Seemed impatient with you.	29	-	13	+	55	.74	-4.84	.58	.89	4.91
When my partner becomes aware of a problem in our relationship, my partner usually does not say anything about it	30	+	15	-	.49	.80	4.53	66	.92	-4.88
Seemed uncomfortable talking to you about your breast	31	-	43	+	39	.57	-4.48	.42	1.19	2.63
Seemed angry or upset with you when she/he did things to	32	-	35	+	43	.66	-4.25	.45	1.07	3.21
My partner usually expresses any feelings about our relationship to me.	33	+	23	-	.47	.82	4.19	61	.93	-4.54

Behavior	Rank of Variable Importance and Valence of Partner Support Behaviors					Centroid Means and Tests of Significance					
	Supportive		Non-supportive		Supportive			Non-supportive			
	Rank	Valence	Rank	Valence	<u>M</u>	<u>SD</u>	Student's t [*]	M	<u>SD</u>	Student's t [*]	
Did household chores or errands that you found difficult to	34	+	39	-	.39	.69	4.07	49	1.18	-2.91	
Encouraged you to look on the bright side of things.	35	+	37	-	.41	.73	3.97	50	1.12	-3.15	
Criticized the way you handled your disease and/or its treatment.	36	-	42	+	33	.63	-3.73	.41	1.09	2.64	
Complained about your breast cancer or helping you with a difficult task	37	-	49	+	30	.47	-3.71	.25	1.17	1.82	
Encouraged you to make a plan of action and follow it.	38	+	22	-	.44	.90	3.55	56	.86	-4.57	
Checked to see if you followed advice she/he gave you.	39	+	19	-	.45	.88	3.55	54	.81	-4.75	
Pitched in to do something that needed to be done.	40	+	44	-	.33	.72	3.49	46	1.18	-2.60	
If my partner and I are discussing an important relationship issue, my partner usually tries to keep discussing it even if it seems we are beginning to become emotional	41	+	27	-	.43	.91	3.43	56	.89	-4.32	
Encouraged you to talk to other family and friends about how you were feeling	42	+	25	-	.41	.93	3.00	46	.78	-4.36	
Encouraged you to express anger towards someone who caused a problem (eg. insurance company)	43	+	24	-	.36	1.00	2.93	56	.79	-4.53	
Told you not to worry because everything would turn out alright.	44	+	41	-	.37	.84	2.74	35	1.04	-2.71	

Behavior	Rank of Variable Importance and Valence of Centroid Means and T Partner Support Behaviors					Fests of Significance				
-	Supportive		Non-supportive		Supportive			Non-supportive		
-	Rank	Valence	Rank	Valence	<u>M</u>	<u>SD</u>	Student's t [*]	M	<u>SD</u>	Student's t [*]
Encouraged you to stand your ground and fight for what you wanted (pursue a medical treatment).	45	+	36	-	.28	.96	2.41	44	.89	-3.17
Handled or cleared up money matters (e.g. insurance or monthly bills).	46	+	46	-	.27	.91	2.15	34	1.06	-2.24
Encouraged you to go on as if nothing had happened.	47	-	48	+	26	.84	-2.07	.29	1.10	1.94
Encouraged you to keep others from knowing how bad things were.	48	-	53	+	18	.79	-1.70	.24	1.18	1.38
Provided you with transportation.	49	+	51	-	.25	.89	1.62	20	1.05	-1.68
Encouraged you not to think too much about problems you were encountering with breast cancer.	50	-	52	+	20	.93	-1.38	.20	1.04	1.51
Encouraged you to keep your feelings from interfering too much with other things.	51	-	54	+	15	.91	-1.37	.24	1.14	1.33
Encouraged you to talk to someone (another physician, cancer agency) to find out more about the problems you were encountering with your disease	52	+	50	-	.20	1.02	1.33	23	.91	-1.82
Encouraged you to take a chance on something risky (eg: try a new treatment)	53	+	47	-	.11	1.12	1.22	32	.78	-2.16
Suggested some action you should take.	54	-	55	+	11	.96		.03	1.03	0.52
Expressed interest or concern for your well-being.	55		33		.52	.00		48	1.09	-3.57

Table 4.4

Pearson Correlations Between Perceived Partner Supportive Profile and Predictor Variables.

Variable	1	2	3	4	5
1. Profile	1				
2. Symptom Severity	021	1			
3. Psychological Distress	187*	.336**	1		
4. Family Life	386**	.290**	.683**	1	
5. Sexual Relationship	340**	.464**	.525**	.421**	1

Note. Partner profile coded as 0 = non-supportive and 1 = supportive. ** p < .01

Table 4.5.

Binomial Logistic Regression of Perceived Partner Support Profile on Predictor Variables.

Predictors	В	SE	Wald	Significance	Odds Ratio	959	% CI		
						Lower	Opper		
Constant	.41	.20	4.14	.04	1.50				
Symptom Severity	.54	.27	3.93	.05	1.72	1.01	2.95		
Psychological Distress	.69	.38	3.37	.07	2.00	.96	4.19		
Family Life	-1.23	.36	11.85	.00	.29	.15	.59		
Sexual Relationship	98	.32	9.65	.00	.38	.20	.70		
Likelihood ratio test						$\chi^2(4) = 29$	0.65, p = .00		
Score Test							26.63		
Homer & Lemeshow goodness of fit sta	atistic					$\chi^2(8) = 3$	8.46, <i>p</i> = .90		
Cox & Snell R ²							.25		
Nagelkerke R ² (max rescaled R ²)							.33		
Percentage of correct overall classification of entries									

CHAPTER FIVE

CONCLUSION

Using a biopsychosocial framework, the purpose of this research was to examine the impact of BCA on partners, identify factors associated with partner adjustment, and describe profiles of supportive partners. A review of the relevant literature concluded that partners of women with BCA experience both beneficial and detrimental changes as a result of this experience that manifest biologically, psychologically, and socially. Empirical data from a study of young couples and breast cancer subsequently documents specific behaviors that young women with BCA perceive as supportive from their partners. Four factors were shown to predict the likelihood of partners being perceived as supportive. These factors included the severity of patients' symptoms, the patients' level of depression, disruption of the couples' family life, and changes in their sexual relationship. In sum, partners of women with BCA have largely been invisible, despite their needs and the important role they play in patient care and treatment. Further attention must be paid to the interaction of illness and relationships across couples, families, and treatment systems in order to meet the ever-growing demands of today's healthcare system.

Partners of women with BCA experience decreases in their general physical health and immune function when compared to partners of healthy women. This is a natural consequence of partners' increased workload and lack of stress reduction outlets such as leisure pursuits, support networks to talk with and who will share in the increased burden. Effort must be made to guard against the physical decline associated with exposure to the demands created by BCA. To accomplish this, we must understand the mechanisms associated with this decline and look for ways to change the process. Declines in immune functioning, for example, may be changed through appropriate diet and exercise minimizing the effects of stress. Appropriate intervention by a partner's primary care physician may be warranted to check for infection resulting from declines in immune functioning or increases in blood pressure due to stress. Partners also report disturbance of sleep patterns resulting in fatigue. Mindfulness based practices can be helpful as they are known to be associated with reductions in the anxiety and intrusive thought processes contributing to insomnia (Benson et al., 1978). On the other hand, if sleep disturbance is positively associated with patient symptom severity, temporary reorganization of sleeping arrangements may be useful. Rested and physically healthy partners will be much more available to provide emotional and instrumental support.

Partners of women with BCA are also at risk for depression and anxiety. They worry excessively about their wife's death or feel sad and hopeless. Given the invasive nature of surgical procedures associated with breast cancer and the long-term adjuvant treatments associated with it, these feelings are natural. Further investigation of the specific concerns experienced by partners will shed light on how to support and intervene on their behalf. Physicians must address provide information about patient care and treatment as it relates to the patient's medical condition, treatment, and prognosis. Other healthcare professionals are needed to treat depression and anxiety and provide spiritual support and guidance.

Not all partners experience psychological distress. In fact, a small percentage of them develop resilience and find new meaning through the experience, reinvesting in relationships and life pursuits. Investigation of the biopsychosocial factors that contribute to this resilient process constitutes a fruitful area of inquiry. Lee and colleagues (Lee et al., 2004) have proposed that

resilience relates to flexibility, adaptability, a positive outlook, the use of problem solving coping strategies, having a sense of control of the situation, and being resourceful and socially integrated. These factors mirror many of those related to positive adjustment to BCA by partners and their investigation will help determine whether an illness has beneficial or detrimental effects.

Many partners of women with BCA experience disruption in their leisure, work, family, and sexual activities, contributing to their distress. While confronting the demands of BCA, partners are not able to spend as much time with friends and pursue their typical social activities. These activities provide the relationships and physical outlets through which partners reduce the negative impact of BCA, and when time spent in these pursuits is reduced, distress is compounded. During leisure activities, men often share stories about their work and families. Leisure time pursuits help bind these relationships. Problems can be created when partners of women with BCA need someone to talk with about the emotional aspects of BCA, only to find that many of their friends are not able to listen. These friends are timid and fearful of the heightened affect associated with partner conversations about the effect of BCA in their lives and give signals that they cannot tolerate these conversations and don't want to or can't listen. For their part, partners are often reluctant to talk about the impact of BCA in their lives feeling like it detracts from care that could be given to the BCA patient. Social support of partners therefore is more difficult than just having access to close friends.

One of the greatest challenges faced by partners of women with BCA is navigating the multiple social roles they occupy. BCA requires a temporary reorganization of these priorities, putting partners in the position of being pulled by the responsibilities associated with multiple social roles. Partners are husbands, significant others, best friends, and sexual partners. Findings

from the profile of partner support behaviors suggest that young women with BCA want a partner who will listen and be available when needed. They want a partner who will be there and share the experience with them. But this task is complicated because partners occupy additional roles in life. Partners may also be fathers who are increasingly counted on to attention to the emotional and instrumental needs of their children. At home, partners often assume extra responsibility for instrumental tasks such as providing transportation to medical appointments and keeping up with household responsibilities. Partners are also colleagues and co-workers who are counted on to contribute in the workplace where their ability to concentrate is disrupted.

The couple's sexual relationship may reflect how well they manage BCA. These data are consistent with other studies finding that the couple sexual relationship is seriously disrupted by a woman's BCA and imply that partners are perceived as more supportive when there is less disruption of their sexual relationship. Both spouses are concerned about the possibility of death or the recurrence of cancer. Patients experience pain and a host of undesirable symptoms and side effects related to the cancer and its treatment (Campora et al., 1992; Ganz, Rowland, Meyerowitz et al., 1998), each contributing to decreased sexual interest and increased sexual discomfort. Young women fear that their partners will reject them because they cannot perform adequately or their bodies are disfigured. In their role, risk for partner distress and role disruption was greatest at the time of diagnosis and initial treatment when partners are overwhelmed by illness demands. Some partners will stop initiation of sexual activity out of concern for their partner's psychological distress and fears of rejection at the hands of an altered body image. Each of these factors diminishes sexual excitement and arousal and can leave young couples concerned that disruption of their sex lives threatens the integrity of their relationship. In short, a perpetual downward spiraling cycle of dissatisfaction with the sexual relationship emerges. As

women fear rejection and alteration of their body image and partners fear initiating sex, each position in the cycle is reinforced and the cycle begins again.

To address these concerns, couples need care firmly grounded in a biopsychosocial framework. Effort should be made to minimize the impact of treatment side effects so that their influence on a couple's sexuality is simultaneously reduced. Healthcare professionals are encouraged to ask about sexuality and set the tone of these conversations by gently inquiring about the presence of side effects and how they disrupt sexual functioning. Likewise, both spouses should focus attention on any cognitive distortions that support unfounded interpretations. Much of this distress can be diffused through open, honest, and candid communication.

Several factors were identified as correlates of partner adjustment and warrant further consideration. Coping strategies were identified as important to partner adjustment. Partners using problem focused strategies reported better outcomes. It is important to note that coping strategies between partners and patients are interrelated with greater use of emotional coping strategies (ventilation, denial, and behavioral disengagement) by patients associated with greater partner distress. This implies that better partner outcomes are associated with patient willingness and ability to confront their illness and its demands without disengaging from relationships. Our data indicate that young women want something quite similar. Young women want partners who express concern for them, start discussions of problem issues, are there for them, and talk when patients listen. But the issue is not that simple. Although mutually constructive communication is associated with decreased partner distress (Manne et al., 2006), partners also report that frequent communication about the illness is associated with increased fear of recurrence (Walker, 1997). Partners may need additional outlets to express fear.

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Social support has also been identified as influential in partner adjustment as increasing levels of support are associated with less adjustment difficulties. Yet, partners may steadfastly remain in the guardian role (Sabo et al., 1986), not realizing the importance of self care as it relates to being effective caregivers. A biopsychosocial model may best inform strategies to assist couples dealing with BCA. First, expand the family system looking for ways to assist in meeting the day-to-day demands of family life. Assess the availability and willingness of extended family and other support systems to offer assistance to younger couples. Extended family and friends represent sources of support in managing the day to day instrumental tasks of home life and could mean the difference between maintaining stability in family life or dealing with disruption that increases distress and tension.

It is interesting that increases in patient symptom severity and psychological distress were associated with increased likelihood of patients perceiving partners as supportive while increased disruption of family life and the couples sexual relationship were associated with decreased likelihood of a patients perceiving partners as supportive. Helgeson (1993) found that partners were less supportive of patients as their distress increased, primarily in the context of shifting of responsibilities in the home. Partner role as "protective guardian" may shed light on these findings. As protectors, partners may be more focused on what they can do for patients, thinking that attending to their immediate needs is primary. They may try to minimize the side effects of treatment or improve the patient's mood. In short, dealing with daily instrumental tasks may be given less priority until they pile up to such a degree that they cannot be ignored, thus forcing partners to shift their focus away from the patient wherein they will be perceived as less supportive. Given the myriad demands that partners are undertaking, it is natural that there will be times when they are solely focused on the emotional and physical needs of their patient wives

and times when they are focused on instrumental tasks in the home and at work. More research is needed to clarify the discrepancies in these findings. Unfortunately our data do not provide information about the preexisting state of the patient distress or the couple relationship that would clarify these findings.

These discrepancies are also interesting from the patient's perspective. Patients who report greater disruption of their family life are less likely to perceive their partners as supportive. This suggests that partner behaviors perceived as supportive would be more instrumental in nature, though our data do not support this notion. In fact, several of the 10 items that we dropped from our final cluster calculation because they were considered not important by patients, were instrumental items such as providing transportation and dealing with money matters. Patients may be sending mixed messages to partners wanting them to keep day to day life moving forward with the least possible disruption while also being responsive and available to meet their needs.

Many other directions for future research are indicated. Our finding that increased patient symptom severity predicted the increased likelihood of partners being perceived as supportive warrants more attention. Helgeson (1993) found an inverse relationship between spousal distress and social support provided when assessed at hospitalization, 3 months, and 1 year. Increased partner distress was associated with decreased provision of social support. Helgeson described a pattern wherein as illness affected partner adjustment, support of patients reduced, in turn increasing patient physical symptoms. Increased symptomology in turn decreased support, and the pattern is established. One likely candidate for understanding these discrepant findings is methodological in that our cross-sectional design cannot assess how distress contributes to

support over time. It is possible that disease characteristics or access to resources contributes to the differences between the groups.

Future research is also needed to understand partner social role disruption as well as how this disruption influences partner adjustment. Reciprocally this will inform partner availability to provide care and support for patients. Partners of women with BCA experience tremendous shifts in the demands placed on them in the roles they occupy in society. What resources from family and community are available for partners to allow them to continue to pursue some degree of leisure activity and diffuse distress? What types of support do partners of women with BCA need from their friends and social networks? While patients express the importance of emotional support, is this also the case for partners or are they best supported instrumentally? Does the nature and quality of a partner's workplace contribute to differences in partner adjustment or support provision? Do partners whose workplaces accommodate increased family demands related to illness experience better adjustment that those in less flexible workplaces? Investigations of partner friendship networks and how they respond will also provide data useful in targeting support efforts.

In sum, this work has direct implications for our healthcare delivery system. It implies that resources must be allocated to assess and treat the whole person within the context of her or his family and social condition. Physicians and allied healthcare professionals must be trained to acquire and interpret biopsychosocial data. This does not mean that everyone becomes and expert in every area related to healthcare. It does indicate, however, that while practitioners specialize in a particular topic or treatment such as oncology, they maintain working knowledge of other domains. For example, oncologists need working knowledge of the psychological and social aspects of cancer to effectively treat it with a biomedical emphasis. Likewise, those specializing in psychological or social aspects of oncology need to have working knowledge of biological functioning including basic disease process, human anatomy and physiology, and pharmacological intervention. Oncologists who recognize that partners of women with BCA represent a tremendous resource for the health and recovery of their patient will attend to their well-being and strive to access a vital component of the treatment team. Partners will become visible members of treatment appreciated for the impact BCA has on them and for their impact in fighting BCA.

The biopsychosocial model grounded in systems theory continues to acquire evidence that must tailor our approach to healthcare. If we move forward with an understanding that biological, psychological, and social systems mutually influence one another, then our approach to healthcare must continue to shift. This entails a reassessment of what defines disease, who constitutes the patient and patient system, who intervenes and under what circumstances. Family members play a critical role in the development, course, and outcomes of illness and constitute the primary context within which we learn health behaviors and make decisions. Patients' partners, children, parents, and extended family, social networks must be evaluated for their own needs as well as how they can contribute to treatment of the patient. Some family members will be treated as "patients"; other family members will join the treatment team. The roles of members of the healthcare team must also be considered as we identify the limitations and strengths of each person in the healthcare system and how they can contribute to care and treatment. No one individual can undertake the monumental task of providing for the care and treatment of a woman's BCA or the family members that are affected. Partners and family must become visible patients and trusted members of the treatment team.

In conclusion, this work contributes to the growing body of knowledge detailing the reciprocal influence of chronic illness and close relationships. Using a biopsychosocial framework, we examined the impact of BCA on partners, identified factors associated with partner adjustment, and described profiles of supportive partners. A review of the relevant literature concluded that partners of women with BCA experience both beneficial and detrimental changes as a result of this experience that manifest biologically, psychologically, and socially. Empirical data from a study of young couples and breast cancer subsequently documented specific behaviors that young women with BCA perceive as supportive from their partners. Four factors were shown to predict the likelihood of partners being perceived as supportive. These factors included the severity of patients' symptoms, the patients' level of depression, disruption of the couples family life, and changes in their sexual relationship. BCA adversely affects the psychological distress of patients and partners. Young women who perceive greater symptom severity and psychological distress perceive their partners as more likely to be supportive. BCA also shifts the roles and responsibilities of family members, placing a burden on caregivers that subsequently affects relationship quality. Women who perceive greater disruption of their family and sexual relationship perceive their partners as less likely to be supportive. In sum, partners of women with BCA have largely been invisible, despite their tremendous needs and the important role they play in patient care and treatment. Further attention must be paid to the interaction of illness and relationships across couples, families, and treatment systems in order to meet the ever-growing demands of today's healthcare system

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APPENDICES

The University of Georgia

Office of The Vice President for Research DHHS Assurance ID No. : FWA00003901 Institutional Review Board Human Subjects Office **117** 612 Boyd GSRC Athens, Georgia 30602-7411 (706) 542-3199 Fax: (706) 542-3360 www.ovpr.uga.edu/hso

APPROVAL OF RENEWALS / CHANGES

Request Date: 2007-11-19 Project Number: 2006-1			10783-3			
Name	Title	Dept/Phone	Address	Email		
Dr. Stephanie R. Burwell	PI	CHFD Family Science Center I 706-542-4897		sburwell@uga.edu		
Mr. George Bowden Templeton	СО	Child and Family Development 123 Dawson Hall 706-296-7987		bowdent@uga.edu		
Title of Study: The Psychosocial N	Title of Study: The Psychosocial Needs of Minority Women Aged 50 and Younger with Breast Cancer and their Partners					
45 CFR 46 Category: Continuing Review Renew : No Change(s) : Added Mr. George Templeton as co-researcher. Parameters: APPROVAL OF ABOVE NOTED CHANGES. New date-stamped Consent Documents not required: No changes to IRB-approved Consent Documents. Fragment 2007 11 20 Parameters in the 2007 04 04						
NOTE: Any research conducted before the a	pproval da	- te or after the end data collection date shown	above is not cov	vered by IRB approval, and	cannot be retroactively approved.	
Number Assigned by Sponsored I	Progran	ns:		NANNA 44960 (R.C. 1995) (NAC 3000) (NC 1995) (R. 1995)	Funding Agency:	
Your request for approval of rene You must report any adverse even	ewal and	d/or changes has been approved. nanticipated risk to the IRB with	in 24 to 72 l	nours Refer to the	IRB Guidelines for additional information	
Use the attached Researcher Requ Keep this original approval form fo	aest Foi or your i	rm for requesting renewals, chan <i>records</i> .	ges, or closu	ires.	Chairberson or Designee, Institutional Review Board	

The University of Georgia

Office of The Vice President for Research DHHS Assurance ID No. : FWA00003901

RESEARCHER REQUEST FORM

Request Date: 2007-11-19 Project Number: 2006-10783-3					
Name	Title	Dept/Phone	Address	Email	
Dr. Stephanie R. Burwell	PI	CHFD Family Science Center I 706-542-4897		sburwell@uga.edu	
Mr. George Bowden Templeton	СО	Child and Family Development 123 Dawson Hall 706-296-7987		bowdent@uga.edu	
Title of Study: The Psychosocial N	eeds of]	Minority Women Aged 50 and You	inger with B	reast Cancer and the	r Partners
45 CFR 46 Category: Continuing Review Renew: No Change(s): Added Mr. George Templeton as co-researcher. Approved: 2007-11-29 Begin date: 2007-11-29 Expiration date: 2008-06-04 NOTE: Any research conducted before the approval date or after the end data collection date shown above is not covered by IRB approval, and cannot be retroactively approved.					
Number Assigned by Sponsored	Prograi	ns:			Funding Agency:
Attention, Principal Investigator! You must complete and return this form before the expiration date shown above. Failure to receive a notification that it is time to renew does not relieve you of your responsibility to provide our office with a request to renew in a timely manner.					
1. Changes		For approval of changes you must complete and sign the back of this form. (Also attach a copy of any revised instruments or consent forms, with changes highlighted, where applicable.)			
2. Renewals	For an extension of the approval period you must complete and sign the back of this form.				

3. Closure

Data collection has been completed as approved by the IRB, and this file can now be closed. Federal laws & UGA policies require notification of completion of data collection.

Respondent ID #

Appendix A

Couples Coping with Breast Cancer Patient Survey

Principal Investigator: Dr. Stephanie Burwell

BASELINE SELF ADMINISTERED QUESTIONNAIRE



Thank you for completing this survey. It should take no more than 30 minutes. For most questions, you will be asked to circle your answer. On some questions, you will be asked to write out your answer.

There is no right or wrong answer. Please answer each question as accurately as you can. It is important to the project goals that all information be as complete as possible. Your opinions are important to us, so please let us know what you think.

If you have any questions, please call Dr. Stephanie Burwell at (706) 542-4897. We appreciate your help with this important research.

1.a PATIENT Date of	Birth:	PARTNER Date of	Birth:
	Age:		Age:
1.b Gender:	Female	Male	
1.c Marital Status:	Married	Not Married	
1.d Length of relations	hip or marriag	e: (years/months)	
1.e Does your spouse of	or partner live	with you? Yes	No
2. Number of times yo	ou have been m	narried:	
0	2	4	
1	3	5 or more	
3. Number of times yo	ou have been d	ivorced:	
0	2	4	
1	3	5 or more	
4. Number of times yo	ou have been w	vidowed:	
0	2	4	
1	3	5 or more	

- 5.a Do you have children? Ses No
 - 5.b Please list the age(s) of your child(ren):

Females:

Males:

- 6. Approximate yearly income before taxes of self and partner combined:
 - \Box less than \$10,000
 - □ \$10,000 \$19,999
 - □ \$20,000 \$39,999
 - □ \$40,000 \$59,999
 - □ \$60,000 \$74,999
 - □ \$75,000 or above
- 7. What is the highest grade or year of school you have completed?
 - □ No formal education
 - □ Grade School (1-8 years)
 - □ Some High School (9-11 years)
 - □ High School graduate or equivalency (12 years or GED)
 - □ Vocational or Training School after High School Graduation
 - □ Some College
 - □ Associate Degree
 - □ College Graduate
 - □ Some College or Professional School after College Graduation
 - □ Completed a Master's Degree
 - Completed a Doctoral Degree (PhD, MD, DDS, JD, etc.)

- 8. How would you describe your racial or ethnic group? If you are of mixed blood, which group do you identify with most?
 - □ White (not of Hispanic origin)
 - □ Black or African-American (not of Hispanic origin)
 - □ Hispanic/Latino (ancestry is Mexican, Cuban, Puerto Rican, Central American, or South American)
 - □ American Indian or Alaskan Native
 - □ Asian or Pacific Islander (ancestry is Chinese, Indo-Chinese, Korean, Japanese, Pacific Islander, Vietnamese)
 - □ Other (please specify):_____
- 9. Which of the following best describes your work status?
 - □ Working full-time (35 hours or more)
 - □ Working part-time (less than 35 hours)
 - □ Stopped working due to ill health
 - □ Retired
 - □ Was never in paid employment
 - □ Unemployed or searching for work
 - □ Student
 - □ Other, please specify: _____

A.1 When	was your breast cancer first diagnosed?	MONTH	YEAR
A.2 Since (please	the time of diagnosis have you had any of the follow se circle "yes" or "no" for each type of treatment)	ving? •	
A.2.a.	Lumpectomy or partial mastectomy (<i>removal of a lump, with or without a wedge of normal tissue around it</i>) If yes, when was this?	1. NO	2. YES
A.2.b.	Axillary node dissection (<i>removal of underarm lymph nodes</i>) If yes, when was this?	1. NO	2. YES
A.2.c.	Mastectomy (complete removal of a breast) If yes, when was this?	1. NO	2. YES
A.2.d.	Breast reconstruction If yes, when was this?	1. NO	2. YES
A.2.e.	Chemotherapy If yes, when was this?	1. NO	2. YES
A.2.f.	Radiation Therapy If yes, when was this?	1. NO	2. YES
A.2.g.	Hormone Therapy If yes, when was this?	1. NO	2. YES
A.2.h.	Other treatment Please specify	1. NO	2. YES
A.3. Have If yes	e you developed any other type of cancer? s, what type and when was this diagnosed?	1. NO	2. YES
A.4. Have If yes	e you had a recurrence of breast cancer? s, when was this?	1. NO	2. YES

A.5. Are you currently undergoing any treatment for cancer? 1. NO 2. YES If yes, please describe your treatment:

Please add any explanation and/or additional comments about your cancer history

Symptoms

How much have you been bothered by any of the following problems during <u>the past 4 weeks?</u> (Please circle one number on each line)

In the past 4 weeks I have been bothered by	Not at all	A little	Some what	Quite a bit	Very much
1. Hot flashes	1	2	3	4	5
2. Nausea	1	2	3	4	5
3. Vomiting	1	2	3	4	5
4. Diarrhea	1	2	3	4	5
5. Difficulty with bladder control when laughing or crying	1	2	3	4	5
6. Difficulty with bladder control at other times	1	2	3	4	5
7. Vaginal discharge	1	2	3	4	5
8. Vaginal dryness	1	2	3	4	5
9. Pain with sexual intercourse	1	2	3	4	5
10. General aches and pains	1	2	3	4	5
11. Swelling of hands and feet	1	2	3	4	5
12. Weight gain	1	2	3	4	5
13. Weight loss	1	2	3	4	5
14. Unhappiness with the appearance of your body	1	2	3	4	5

Partner Response to Cancer Inventory—Patient Form

In the past month, how often would you say your partner has done the following:

1. Joked and tried to cheer you up.	Frequently 1	Occasionally 2	Rarely 3	Never 4
2. Let you know that she/he would always be around if you needed assistance.	1	2	3	4
3. Asked you how you were feeling.	1	2	3	4
4. Comforted you by showing you some physical affection.	1	2	3	4
5. Handled or cleared up money matters (e.g. insurance or monthly bills).	1	2	3	4
6. Provided you with transportation.	1	2	3	4
7. Pitched in to do something that needed to be done.	1	2	3	4
8. Did household chores or errands that you found difficult to do.	1	2	3	4
9. Seemed impatient with you.	1	2	3	4
10. Seemed angry or upset with you when she/he did things to help you.	1	2	3	4
11. Seemed not to enjoy being around you.	1	2	3	4
12. You had to wait a long time for help when you needed it.	1	2	3	4
13. Avoided being around you when you were not feeling well.	1	2	3	4
14. Gave you the idea she/he really did not want to talk about the problem you were having.	1	2	3	4
15. Shouted or yelled at you.	1	2	3	4
16. Did not seem to respect your feelings.	1	2	3	4

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		Frequently	Occasionally	Rarely	Never
17.	Complained about your breast cancer or about helping with a task that you found difficult to do yourself.	1	2	3	4
18.	Seemed uncomfortable talking to you about your breast cancer.	1	2	3	4
19.	Criticized the way you handled your disease and/or its treatment.	1	2	3	4
20.	Seemed less accepting of you since you got breast cancer.	1	2	3	4
21.	Was not emotionally supportive of you, when you were expecting some support.	1	2	3	4
22.	Encouraged you to keep your feelings to yourself.	1	2	3	4
23.	Suggested some action you should take.	1	2	3	4
24.	Encouraged you to talk to other family and friends about how you were feeling.	1	2	3	4
25.	Encouraged you to talk to someone (another physician, cancer agency) to find out more about the problems you were encountering with your disease.	1	2	3	4
26.	Encouraged you to stand your ground and fight for what you wanted (pursue a medical treatment).	1	2	3	4
27.	Helped you analyze a problem you were having to help you understand it better.	1	2	3	4
28.	Encouraged you to make a plan of action and follow it.	1	2	3	4
29.	Helped come up with a solution to a problem you encountered.	1	2	3	4
30.	Said things that made your situation clearer and easier to understand.	1	2	3	4
	Couples Coping with Breast Cancer	2006		9	

	Frequently	Occasionally	Rarely	Never
31. Checked to see if you followed advice she/he gave you.	1	2	3	4
32. Told you not to worry because everything would turn out alright.	1	2	3	4
33. Encouraged you to keep others from knowing how bad things were.	1	2	3	4
34. Encouraged you to go on as if nothing had happened.	1	2	3	4
35. Encouraged you not to think too much about problems you were encountering with breast cancer.	1	2	3	4
36. Encouraged you to keep your feelings from interfering too much with other things	1	2	3	4
37. Reassured you that you remained a competent and strong person.	1	2	3	4
38. Listened to you confide your worries or concerns about breast cancer.	1	2	3	4
39. Encouraged you to let your feelings out.	1	2	3	4
40. Encouraged you to express anger towards someone who caused a problem (eg: insurance company).	1	2	3	4
41. Encouraged you to take a chance on something risky (eg: try a new treatment).	1	2	3	4
42. Encouraged you to look on the bright side of things.	1	2	3	4
43. Was right there with you in the stressful times with your breast cancer.	1	2	3	4
44. Expressed interest or concern for your well- being.	1	2	3	4
Couples Coping with Breast Cance	r 2006		10	

	Frequently	Occasionally	Rarely	Never
45. Did a favor for you.	1	2	3	4

Relationship Discussion Questionnaire

Please rate <u>each item</u> on a scale of 1 (=Strongly Agree) to 9 (Strongly Disagree).

11) When I want to talk about a relationship problem, my partner usually tries to get out of the discussion.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9
12) My partner usually expresses any feelings about our relationship to me.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9
13) My partner is the kind of person who generally feels comfortable discussing relationship problems.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9
14) When my partner becomes aware of a problem in our relationship, my partner usually tries to start a discussion of the problem.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9
15) When discussing a relationship problem, my partner usually tries to keep the discussion going until we settle the issue.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9
16) If my partner and I are discussing an important relationship issue, my partner usually tries to keep discussing it even if it seems we are beginning to become emotional.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9
17) My partner usually keeps feelings about our relationship private and does not share them with me.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9
18) My partner is the kind of person who generally does not feel comfortable discussing relationship problems.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9
19) When my partner becomes aware of a problem in our relationship, my partner usually does not say anything about it.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9
20) When I want to talk about a relationship problem, my partner is usually ready to do so as well.	Strongly Agree 1 2 3 4	5	6	Strongly Disagree 7 8 9



	DO NOT WRITE IN THIS BLOCK 132
RESPONDENT'S NAME: MEDICAL INSTITUTION: TREATING DOCTOR'S NAME: DATE FORM WAS COMPLETED: AGE: SEX: EDUCATION:	1. PT. ID. NO. 2. STD. NO. 3. Dx 4. Dx Cd. 5. Rx 6. Rx Cd. 7. Med. Dept. 9. Soc. Stat. 8. Visit Cd. 9. Soc. Stat.
MARITAL STATUS:	

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 (\checkmark) 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.

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-] 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
 - 1 d) Illness has totally prevented me from doing my job
- (2) How well do you physically perform your job (studies) now?
 -] a) Poorly

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-] 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
- 1 c) Slightly less important
-] d) Equal or greater importance than before

(5) Have you had to change you 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
- 1 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

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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
 - 1 c) Communication has decreased, and I feel somewhat withdrawn from them
 - 1 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

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- 1 a) Severe financial hardship
- b) Moderate financial problems

meeting the financial demands of your illness?

-) c) A slight financial drain
- 1 d) No money problems

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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)?

- 1 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?
 - 1 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?
 - 1 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?
 - 1 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
 - 1 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

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-] 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
 - 1 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

- (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

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-] 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	I]	b)	A little bit	ן י]	c)	Quite a bit	[]	d)	Extremely
(2)	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?															
.,	ſ] a	1)	Not at all	I]	b)	A little bit	ſ]	c)	Quite a bit	I,]	d)	Extremely
(4)	4) Recently, have you blamed yourself for things, felt guilty, or felt like you have let people down?															
(-7	ſ	1 8	a)	Extremely	ſ]	b)	Quite a bit	[]	c)	A little bit	[]	d)	Not at all
(5)	Becently, have you worried much about your illness or other matters?															
(•)	[1 4	a)	Not at all	ſ]	b)	A little bit	[J	C)	Quite a bit	Į]	d)	Extremely
(6)	Becently, have you been feeling down on yourself or less valuable as a person?															
(0)	ſ	1	-,, a)	Extremely	1	1	b)	Quite a bit	ſ	1	c) A little bit	[]	d)	Not at all
(7)	l D	n oont	ay tay	bave you be	een c	- on	cerr	ned that your illne	ss h	as	ca	used changes	in th	e w	ay	you look that make you
(7)	le	ss at	tra	ctive?		•										
	[]	a)	Not at all	[]	b)	A little bit	[] c) Quite a bit	[]	d)	Extremely
									- 6	-						

	Date:
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Name:	Marital Status:	Age: Sex:	-
Occupation:	Education:		_

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness

- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- 3 I am so sad or unhappy that I can't stand it.

2. Pessimism

- 0 I am not discouraged about my future.
- 1 I feel more discouraged about my future than I used to be.
- 2 I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

3. Past Failure

- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back, I see a lot of failures.
- 3 I feel I am a total failure as a person.

4. Loss of Pleasure

- 0 I get as much pleasure as I ever did from the things I enjoy.
- 1 I don't enjoy things as much as I used to.
- 2 I get very little pleasure from the things I used to enjoy.
- 3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings

- 0 I don't feel particularly guilty.
- 1 I feel guilty over many things I have done or should have done.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

6. Punishment Feelings

- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

7. Self-Dislike

- 0 I feel the same about myself as ever.
- 1 I have lost confidence in myself.
- 2 I am disappointed in myself.
- 3 I dislike myself.

8. Self-Criticalness

- 0 I don't criticize or blame myself more than usual.
- 1 I am more critical of myself than I used to be.
- 2 I criticize myself for all of my faults.
- 3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes

- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

10. Crying

- 0 I don't cry anymore than I used to.
- 1 I cry more than I used to.
- 2 I cry over every little thing.
- 3 I feel like crying, but I can't.
 - Subtotal Page 1



11. Agitation

- 0 I am no more restless or wound up than usual.
- 1 I feel more restless or wound up than usual.
- 2 I am so restless or agitated that it's hard to stay still.
- 3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

- 0 I have not lost interest in other people or activities.
- 1 I am less interested in other people or things than before.
- 2 I have lost most of my interest in other people or things.
- 3 It's hard to get interested in anything.

13. Indecisiveness

- 0 I make decisions about as well as ever.
- 1 I find it more difficult to make decisions than usual.
- 2 I have much greater difficulty in making decisions than I used to.
- 3 I have trouble making any decisions.

14. Worthlessness

- 0 I do not feel I am worthless.
- 1 I don't consider myself as worthwhile and useful as I used to.
- 2 I feel more worthless as compared to other people.
- 3 I feel utterly worthless.

15. Loss of Energy

- 0 I have as much energy as ever.
- 1 I have less energy than I used to have.
- 2 I don't have enough energy to do very much.
- 3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

- 0 I have not experienced any change in my sleeping pattern.
- 1a I sleep somewhat more than usual.
- 1b I sleep somewhat less than usual.
- 2a I sleep a lot more than usual.
- 2b I sleep a lot less than usual.
- 3a I sleep most of the day.
- 3b I wake up 1–2 hours early and can't get back to sleep.

17. Irritability

- 0 I am no more irritable than usual. 140
- 1 I am more irritable than usual.
- 2 I am much more irritable than usual.
- 3 I am irritable all the time.

18. Changes in Appetite

- 0 I have not experienced any change in my appetite.
- 1a My appetite is somewhat less than usual.
- 1b My appetite is somewhat greater than usual.
- 2a My appetite is much less than before.
- 2b My appetite is much greater than usual.
- 3a I have no appetite at all.
- 3b I crave food all the time.

19. Concentration Difficulty

- 0 I can concentrate as well as ever.
- 1 I can't concentrate as well as usual.
- 2 It's hard to keep my mind on anything for very long.
- 3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

- 0 I am no more tired or fatigued than usual.
- 1 I get more tired or fatigued more easily than usual.
- 2 I am too tired or fatigued to do a lot of the things I used to do.
- 3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

- 0 I have not noticed any recent change in my interest in sex.
- 1 I am less interested in sex than I used to be.
- 2 I am much less interested in sex now.
- 3 I have lost interest in sex completely.

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_____ Subtotal Page 2

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