THE INITIATION OF COUPLE RELATIONSHIP DISCUSSIONS AMONG YOUNG WOMEN WITH BREAST CANCER

By:

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(Under the Direction of Stephanie Burwell)

ABSTRACT

Literature has shown that the quality of the couple relationship plays an integral role in a woman's adjustment to diagnosis and treatment of breast cancer. Decreased emotional support and demand/withdraw communication is associated with lower dyadic satisfaction and higher psychological distress. However, less is known specifically about how couple communication patterns affect young women, who face different life cycle stressors than older women. This study examined the association between initiator tendency and dyadic satisfaction, medical, and demographic variables. Results indicate that patient initiation was negatively associated with pain with sexual intercourse. Perceived partner initiation was positively correlated with patient quality of life and negatively correlated with patient age and full time work. Both patient and perceived partner initiation were associated with higher dyadic satisfaction.

INDEX WORDS: Breast cancer, medical family therapy, couples, young women, initiation, communication patterns

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CHAPTER 1

INTRODUCTION

Purpose of the Study

This study sought to understand how women aged 50 and younger with breast cancer perceive relationship discussion roles. Rolland's Family Systems-Illness Model (1994a;b), served as framework for understanding this phenomenon. The Family Systems-Illness Model utilizes a biopsychosocial lens within a family systems framework to conceptualize illness. The model addresses three dimensions of illness and disability: 1) psychosocial types (psychosocial and biological demands of the illness); 2) major developmental life phases, and 3) key family systems variables (Rolland, 1999). This study examined patients' degree of relationship discussion initiation and perceived-partner initiation. Initiator tendency is a term which refers to prosocial, neutral or negative requests from one's partner. The tendency to not initiate is termed avoidance (Denton & Burleson, 2007). The demand/withdraw pattern is most closely linked with initiate/avoid. However, demanding is negatively conceptualized and refers to harsh demands, complaining, or nagging. Withdrawal refers to defensiveness or passive inaction (Christensen & Heavey, 1990).

The demand/withdraw literature among non-medical samples generally indicates that women are more likely to initiate intimate relationship conversations (Christensen, Eldridge, Catta-Preta, Lim & Santagata, 2006; Christensen & Heavey, 1990). However, in heterosexual relationships when male-chosen topics are discussed, there appear to be no differences in occurrence between wife-demand/husband-withdraw and husband-demand/wife-withdraw patterns (Eldridge, Sevier, & Jones, 2007). In relationships with high levels of demand/withdraw communication, marital satisfaction decreases for both partners (Weger, 2005; Caughlin, 2002; Markma, & Hahlweg, 1993; Christensen & Shenk, 1991). Specifically, when the woman demands and the man withdraws, dyadic satisfaction decreases for the woman (Heavey, Christensen, & Malamuth, 1995).

Decreased emotional support and certain partner responses to breast cancer are related to higher psychological distress and lower dyadic satisfaction in breast cancer patients (Manne, Ostroff, Norton, Fox, Goldstein, & Grana, 2006; Manne, Ostroff, Winkel, Grana, & Fox, 2005; Manne, Taylor & Doughterty, 1997). Some of the partner responses that are associated with lower dyadic satisfaction include criticism, avoidance, demand/withdraw. Over time, women who view their partners as unsupportive tend to engage in more avoidant coping mechanisms (Manne et al., 2005). The demand/withdraw and mutual withdrawal patterns are associated with higher patient psychological distress and lower dyadic satisfaction (Manne et al., 2006; Hodgson, Shields, & Rousseau, 2003).

With regard to communication patterns, partner self-disclosure of breast cancer related feelings and fears is both directly and indirectly associated with patient feelings of intimacy. Intimacy is mediated by partner acceptance of illness, understanding, and caring (Manne, Ostroff, Rini, Fox, Goldstein, & Grana, 2004). Therefore, if a partner is withdrawn and non-disclosing, the patient is likely to experience greater psychological distress. In terms of dyadic satisfaction, Hodgson, Shields, & Rousseau (2003) found that disengagement is strongly related to lower patient and partner dyadic satisfaction. When women withdraw it does not affect dyadic satisfaction, but when their partners withdraw, it does (Hodgson, et al., 2003). Similar to non-medical couples, communication problems in women with breast cancer also impact dyadic satisfaction (Shands, Lewis, Sinsheimer, & Cochrane, 2006). In women with breast cancer

regardless of age, dyadic satisfaction and communication are important because they impact quality of life and treatment response (Manne et al., 2006; Walsh et al., 2005; Manne et al., 1997). However, less is known about young women who face different life-course related stressors than older women (e.g. raising young children, early in career development, fewer years partnered). These stressors may uniquely impact their partnered relationship and illness adjustment. Research suggests that young women have more psychological and quality of life problems (Kroenke, Rosner, Chen, Kawachi, Colditz, & Holmes, 2004). Therefore, it is important to examine communication patterns and dyadic satisfaction in young women with breast cancer.

How This Study is Original

Little research targets young women with breast cancer, or focuses on specific communication patterns and their implications for dyadic satisfaction. Some studies have included a dyadic component and examine couple adjustment to breast cancer diagnosis and treatment regardless of age (e.g. Hagedoon, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Kayser, Watson & Andade, 2007; Feldman & Broussard, 2006; Walsh, Manuel, & Avis, 2005; Lethborg, Kissane, & Burns, 2003; Holmberg, Scott, Alexy, & Fife, 2001; Northouse, Templin, & Mood, 1997; Pistrang & Barker, 1995; Zahlis & Shands, 1991; Northouse & Swain, 1987). The majority of studies have focused on the impact of breast cancer on only the patient and include social support (e.g. Weihs, Enright, & Simmens, 2008; Friedman, Kalidas, Elledge, Chang, Romero, Husain, Dulay et al., 2006; Sollner, Maislinger, Konig, Devries, & Lukas, 2004; Bloom, Stewart, Johnson, Banks, & Fobair, 2001; Kornblith, Herndon, Zuckerman, Viscoli, Horwitz, Cooper, Harris et al., 2001; Helgerson & Cohen, 1996), psychological well-being (e.g. Mehnert & Koch, 2007; Manne, Ostroff, Norton, Fox, Grana, & Goldstein, 2006; Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Kroenke et al., 2004; Mor, Malin & Alien, 1994; Scott, 1983), and sexual function following breast cancer treatment (e.g. Burwell, Case, Kaelin, & Avis, 2006; Fobair, Stewart, Chang, D'Onofrio, Banks, & Bloom, 2006; Bakewell & Volken, 2005; Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005; Kroenke, et al., 2004; Wilmoth, Coleman, Smith & Davis, 2004; Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Vinokur, Threatt, Caplan, & Zimmerman, 1989).

A smaller body of literature has studied communication, partner support and dyadic satisfaction of patients with various types of cancer (e.g. Manne et al., 2006, Manne et al., 2005, Manne, Ostroff, Rini, Fox, Goldstein, & Grana, 2004; Kagawa-Singer & Wellish, 2003; Hodgson et al., 2003; Manne & Schnoll, 2001; Manne, Alferi, Taylor, & Doughterty, 1999; Manne et al., 1997). These studies have helped our understanding of issues surrounding cancerrelated communication, dyadic coping, and dyadic satisfaction in cancer patients and their partners. However, these studies do not explicitly focus on young women, nor do they all focus on women with breast cancer. Therefore more information is needed to understand the specific communication processes (e.g., initiate/avoid) that contribute to dyadic satisfaction in this population so that appropriate communication intervention strategies can eventually be developed. Using Rolland's model to conceptualize the systemic impact of illness on couples, the current study adds to the literature by specifically focusing on the initiator tendency in young women with breast cancer and its association to dyadic satisfaction.

This study is also unique because the Initiator Style Questionnaire, a measure of communication initiation and avoidance (ISQ; Denton & Burleson, 2007), is used. Unlike the Communication Patterns Questionnaire (CPQ; Christensen & Sullaway, 1984), the ISQ has two separate scales that measure the degree of self-initiation and avoidance of relationship

discussions and perceptions of partner initiation and avoidance. The ISQ provides a self and partner subscale to determine differences in perceived levels of initiation. The CPQ cannot answer these questions because the demand/withdraw components are not separate constructs and cannot attend to individual differences in initiation.

The ISQ also differs from the CPQ in its conceptualization and operationalization of initiation versus demand. In the demand/withdraw literature, demanding is described as criticizing, nagging, or complaining. Withdrawal is often described as passive inaction, avoidance, or defensiveness (Christensen & Heavey, 1990). Both of these terms carry negative connotations. In Denton and Burleson's (2007) conceptualization of initiation, the term refers to both positive, prosocial requests and negative, harsh demands. Like withdrawal, avoidance can also refer to attempts to avoid a partner's request through negative disengagement. However, it can also mean that partners are simply not voicing their concerns.

Research Questions

Do young women with breast cancer initiate relationship discussions with their partners?

In accordance with the demand/withdraw and breast cancer communication literature, it was expected that patients would initiate conversations with their partners (e.g. Denton & Burleson, 2007; Manne, Taylor, & Dougherty, 1997; Christensen & Heavey, 1990). *Do young women with breast cancer perceive their partners as initiators of relationship discussions?*

Furthermore, it was anticipated that partners will also initiate discussions, but not as frequently as patients, as husbands of breast cancer patients tend to show more disengagement and avoidance than their wives (Hodgson et al., 2003).

Is the degree of both patient and perceived partner initiation associated with dyadic satisfaction?

It was anticipated that the tendency to initiate relationship discussions would be associated with dyadic satisfaction. Specifically, low perceived-partner initiation would be negatively associated with dyadic satisfaction. In breast cancer patients, higher levels of avoidance (e.g. low levels of initiation) are linked with greater dyadic distress, but constructive communication is associated with greater dyadic satisfaction (Manne et al., 2006). Additionally, in non-medical samples, both partner and patient initiation is associated with greater dyadic satisfaction (Denton & Burleson, 2007). Therefore it was predicted that mutually constructive communication (both partners initiating) will be positively associated with dyadic satisfaction. *Which psychosocial types (medical/biological), major developmental life phases, and demographic variables are associated with patient and perceived partner initiation?*

The Family-Systems Illness model (Rolland 1994a;b) suggests that the psychosocial demands of breast cancer and the couple's developmental life phase are important in understanding communication patterns. For this study, psychosocial types referred to the medical variables (e.g. length of time since diagnosis, treatment type, quality of life, and symptom severity). Developmental life phases included variables such as number of children, patient and partner age, and number of years in relationship. Accordingly, it was anticipated that certain psychosocial types and developmental phases will be correlated with initiation, such as overall quality of life, length of relationship, patient age, whether the couple has children, type of treatment, and degree of symptom severity.

CHAPTER 2

LITERATURE REVIEW

The following literature review focuses on young women with breast cancer and their communication patterns with their partners and degree of dyadic satisfaction. The review is organized by the following sections: 1) the demand/withdraw communication pattern; 2) the association between demand/withdraw and dyadic satisfaction; 3) the impact of breast cancer on the marital/partner relationship; 4) communication patterns in breast cancer patients; and 5) theoretical framework.

The Demand/Withdraw Communication Pattern

For the past three decades a variety of labels have been used to identify the pattern of interaction wherein one partner pressures to create change in the relationship by demanding, nagging, and criticizing, while the other partner pulls away through avoidance and withdrawal. According to Fogarty (1976), one partner *pursues* the *distancer*, who pulls away. Napier (1978) describes this as the *rejection-intrusion pattern* where typically the female partner, the intruder, seeks closeness while the male partner, the rejecter, fears intrusion and retreats. In 1993, Wile coined the term *demanding-withdrawn* where one partner pressures for contact by criticizing, complaining, and demanding, while the other partner withdraws. Currently, the term *demand/withdraw* is used to describe this pattern (e.g. Eldridge, et al. 2007; Caughlin, 2002; Gottman & Levenson, 2002; Klinetob & Smith, 1996; Heavey, Christensen, & Malamuth, 1995; Christensen & Heavey, 1990). The demand/withdraw (D/W) pattern is understood much in the same way Wile (1981) described it. One partner pressures the other through criticizing,

complaining, nagging, and demanding, while the other withdraws through avoidance, defensiveness, and inaction.

Demand/Withdraw Pattern

The majority of research on demand/withdraw is on heterosexual, generally married couples. Implications for gay or lesbian couples or straight cohabiting couples remain unclear. Nevertheless, within married couples, studies have discovered relatively similar patterns of demand/withdraw based on gender, type of discussion (e.g. problematic, neutral, relationship-centered, an argument), and which partner chooses the topic of discussion. More often than not, the wife-demand/husband-withdraw interaction occurs (Christensen & Shenk, 1991; Christensen & Heavey, 1990). This does not always mean that women are more demanding than men, but that this type of interaction occurs more often than husband-demand/wife-withdraw (Christensen & Heavey, 1990), as some studies have shown men to withdraw more than women (Eldridge, et al., 2007; Gottman & Driver, 2005; Christensen & Heavey, 1990).

The demand/withdraw pattern is usually specific to the nature of the discussion. More demand/withdraw interaction occurs during relationship discussions as opposed to discussions about problems unrelated to the relationship (Eldridge, et al., 2007). In a cross-sectional study of 50 newlywed couples without children, Gottman and Driver (2005) asked couples to argue for 15 minutes in the laboratory about a current relationship problem. They found that the amount of times the husband turned away from his wife was positively associated with her withdrawal, which was significantly related to his later withdrawal. The husband's turning away was also significantly related to his wife's use of an attack/defend interaction (Gottman & Driver, 2005).

There are usually differences in demand/withdraw patterns based on who chooses the discussion topic. If the woman chooses the topic of discussion, there is significantly more wife-

demand/husband-withdraw than husband-demand/wife-withdraw interaction (Eldridge, et al., 2007; Caughlin & Vangelisti, 1999; Heavey, et al., 1995; Christensen & Heavey, 1990). However, when the discussion topic is husband-chosen, there are no significant differences in how often the wife-demand/husband-withdraw and husband-demand/wife-withdraw patterns occur (Eldridge, et al., 2007; Caughlin & Vangelisti, 1999; Klinetob & Smith, 1996; Christensen & Heavey, 1990). This suggests that men are just as likely to engage in demanding and withdrawing as their wives are if men choose the topic.

Reconceptualizing Demand/Withdraw

More recently, Denton and Burleson have begun to re-label demand/withdraw as *initiator* tendency (Denton & Burleson, 2007). Avoidance is defined as relatively low levels of initiation (Denton & Burleson, 2007). Demanding is often pathologized as a negative behavior(s) that one partner uses to get the other's attention. Based on the demand/withdraw literature, women's behavior has been pathologized as abrasive and demanding, offering her partner no other alternative than to retreat and escape from the discussion. Men's withdrawal has also been negatively connoted as cold, distant, and uninvolved. Heavey, Christensen, & Malamuth (1995) suggest that the act of demanding involves negative interaction, and that the CPQ targets these negative behaviors. In contrast, in the ISQ initiation is a more neutral term that may include positive behaviors, such as making a polite request. It also captures negative behaviors, such as yelling (Denton & Burleson, 2007). Withdrawal is not always an act of avoidance or defensiveness in response to initiation of relationship discussions. Avoidance may also suggest that individuals have relationship concerns, but choose to not discuss them. Overall, the term initiator tendency offers a broader, less pathologizing description of communication related behaviors.

Assessments of demand/withdraw, such as the CPQ (Christensen & Sullaway, 1984), attend to the interaction as a dyadic variable. In contrast, initiator tendency is an individual internal process which may not always manifest in observable behaviors in different contexts. Initiator tendency is a stable individual difference that occurs within the context of a specific intimate relationship. Whereas in one relationship a person may be more likely to initiate, in another relationship, that person may be more of an avoider. The tendency to initiate or avoid is partially determined by the partner's communication style. For example, in a relationship with a critical partner, the individual will likely avoid. However, with a passive, quiet partner, the individual will be more likely to initiate relationship discussions. Within that specific relationship, initiator tendency will remain relatively stable (Denton & Burleson, 2007).

In order to attend to these individual differences, the Initiator Style Questionnaire (ISQ; Denton & Burleson, 2007) has two separate scales. One measures degree of participant initiation of relationship discussions and the other measures degree of perceived partner initiation. The use of two scales offers a more interactional picture of the patterns of initiation within the relationship. When analyzing just one partner, the researcher can understand the partner's level of initiation and the perceived partner initiation. However, when analyzing dyadic data, the researcher has an understanding of each partner's own level of initiation and perceived partner initiation. This type of data creates a more descriptive view of the dyadic interaction.

The Association Between Demand/Withdraw and Dyadic Satisfaction Relationship quality is influenced by the demand/withdraw communication pattern (Weger, 2005). Numerous studies have associated and predicted relationship distress in the presence of demand/withdraw (e.g. Eldridge, et al., 2007; Weger, 2005; Guay, Boisvert, & Freeston, 2003; Caughlin, 2002; Caughlin & Huston, 2002; Heavey, et al., 1995; Christensen & Shenk, 1991; Gottman & Krokof, 1989). Clinically distressed and divorcing couples evidence more demand/withdraw and avoidance during problem discussions than non-distressed couples (Christensen & Shenk, 1991). The demand/withdraw pattern is associated with both the husband and wife feeling less understood and validated by their spouses (Weger, 2005). Couples destined for distress or divorce evidence significantly higher levels of invalidation during premarital interaction than couples that remain non-distressed (Markman & Hahlweg, 1993). Once married, both partner's perceptions' of feeling validated by their spouse affects their dyadic satisfaction (Weger, 2005).

The demand/withdraw pattern has also been linked to partner discrepancies in desires for closeness and independence. The greater the discrepancy between partners, the greater the likelihood of demand/withdraw and less constructive communication (Christensen & Shenk, 1991). This may explain why even when husbands are more affectionate, there is an inverse association between their wives' dyadic satisfaction and reports of husband/demand-wife/withdraw (Caughlin & Huston, 2002). It appears demand/withdraw is associated with dyadic satisfaction above and beyond the correlations between satisfaction and affectional expression. Demand/withdraw patterns may account for variation in dyadic satisfaction that is not explained by affectional expression and negativity (Caughlin & Huston, 2002).

There also are certain relationship satisfaction findings that are gender-specific. In regard to wives' satisfaction, the demand/withdraw pattern has a direct effect on relationship quality (Weger, 2005). The wife-demand/husband-withdraw and husband-withdraw patterns predict significant declines in women's dyadic satisfaction, even if the discussion topic is chosen by the woman (Caughlin & Huston, 2002; Heavey, et al., 1995). Additionally, husband-demand/wifewithdraw is associated with a decrease in women's dyadic satisfaction (Caughlin & Huston, 2002). Both men and women who demand tend to exhibit higher levels of negative behaviors toward their spouses (Caughlin & Huston, 2002). Demand/withdraw does not appear to have a direct effect on men's dyadic satisfaction (Weger, 2005).

Preliminary Findings of Associations between Initiator Tendency and Relationship Satisfaction

Because Denton and Burleson (2007) conceptualize initiator tendency differently than demand/withdraw, they believed that their construct would not be negatively associated with dyadic satisfaction. Instead, they reasoned that discussion of relationship concerns is healthy and productive. Consistent with their hypotheses, in two of their studies they found that the ISQ measurement of initiator tendency was positively associated with dyadic satisfaction (Denton & Burleson, 2007). On the other hand, if initiation was closely related to demanding, the initiator tendency would be positively related to verbal aggression. However, there was negative association between these variables as avoiders reported higher levels of verbal aggressiveness. This may be because avoiders actually refrain from relationship discussions because they fear their contributions will be destructive to the relationship. For instance, when avoiders are pressured to engage, they might yell or scream, thus using avoidance as a way to maintain control of their response (Roberts, 2000).

The Impact of Breast Cancer on the Marital/Partner Relationship

The American Cancer Society estimates that 178,480 women in the United States will be diagnosed with invasive breast cancer in 2007 (American Cancer Society, 2007b). Approximately one third of these cases are expected to occur in women younger than age 55 (American Cancer Society, 2007a). Compared to older women, women younger than 50 experience higher levels of psychological distress, undergo more invasive and aggressive treatments, and have greater problems adjusting to breast cancer (Avis, Crawford, & Manuel, 2004; Ganz, Greendale, Petersen, Kahn, & Bower, 2003; Mor, Malin, & Alien, 1994). Additionally, this population experiences more 'off-time' life course events which can cause great strain on the woman and her partner. Off-time events refer to events that occur out of the biological and socially accepted timeline of life cycle (Rolland, 1999). Some of these events include premature menopause and infertility, both of which have important implications for sexual activity and family planning (Bakewell & Volken, 2005; Ganz et al., 2003).

The breast cancer experience also impacts the families, especially partners, who often have difficulty adjusting to and renegotiating roles throughout diagnosis and treatment. Partners may find themselves in caretaking roles, working longer hours to pay for medical bills, or more actively parenting children (Walsh, Manuel, Avis, 2005; Lethborg, Kissane, & Burns, 2003; Pistrang & Barker, 1995). The majority of the literature on partnered women with breast cancer focuses on marital relationships and less on partnered women. Therefore, implications for cohabiting heterosexual women and lesbians are unclear.

Studies indicate that during diagnosis and treatment, women and their husbands experience high levels of psychological distress (Northouse et al., 1997; Northouse, Jeffs, Cracchiolo-Caraway, Lampman, & Dorris, 1995; Northouse, 1989; Northouse & Swain, 1987). In a cross-sectional study of 300 women and 265 husbands one week prior to breast biopsy, 38% of women reported the highest level of distress, regardless of the manner in which their physicians discussed breast cancer prior to biopsy (Northouse, et al., 1997). Husbands have discussed feeling inadequate in their ability to help their wives cope with the diagnosis (Sabo, 1990). Both women's and men's baseline adjustment to cancer and general psychological wellbeing is related to their adjustment at one year following diagnosis. Couples with more initial adjustment problems and higher levels of depression report more difficulty adjusting to illness demands over time (Feldman & Broussard, 2006; Northouse, Templin, & Mood, 2001; Northouse et al., 1998). Furthermore, each partners' adjustment is significantly directly affected by their partner's level of adjustment (Northouse et al., 2001).

Strain placed on couples as a result of breast cancer diagnosis has been shown to have a lasting effect on the relationship. Researchers have found that the presence of tension and distress in the couple relationship remained throughout the first year following diagnosis (Shands et al., 2006). Women diagnosed with malignant breast cancer as opposed to benign breast disease report greater decreases in relationship satisfaction and family functioning (Northouse et al., 1998). In this longitudinal study comparing 58 couples with malignant breast cancer to 73 couples with benign breast disease one year post-diagnosis, Northouse et al. (1997) found that 56% of couples who were classified in the highest distress group at the beginning of the study remained in the same group 60 days post-diagnosis. Fifty percent remained in that group one year post-diagnosis (Northouse et al., 1997). Interestingly, studies indicate that longer relationship length and marital history are correlated with both men's and women's psychological adjustment and physical well-being (Feldman & Broussard, 2006; Northouse & Swain, 1987).

There are common themes couples describe as creating more stress on their relationship adjustment and satisfaction. For instance, couples often report difficulty in the renegotiation of roles such as becoming a caregiver, patient dependency on partner as caregiver, and increases or changes in patient and partner workload inside and out of the home (e.g., childcare) (Burwell, Templeton, Stidham, & Zak-Hunter, 2008; Lethborg et al., 2003; Northouse et al., 1998; Zahlis & Shands, 1991; Sabo 1990). Illness severity has also been positively associated with increases in role adjustment problems (Northouse et al., 2001; Northouse et al., 1998). Northouse et al. (2001) found that marital satisfaction has both a direct and indirect effect on the husband's role adjustment, which is mediated by his own level of uncertainty surrounding the breast cancer experience. In a qualitative study of 67 partners of women with breast cancer, Zahlis and Shands (1991) identified seven conceptual domains of demands breast cancer placed on husbands: 1) reacting to the illness; 2) negotiating the illness experience; 3) adapting his lifestyle to meet the demands of the illness; 4) being sensitive to her needs; 5) thinking about the future; 6) attempting to minimize the effects of the illness; and 7) feeling the impact on the relationship. Similar conceptual domains have been described in other studies as well (Shands et al., 2006; Walsh et al., 2005; Lethborg et al., 2003).

Communication Patterns in Breast Cancer Patients

The Impact of Breast Cancer on Communication

After breast cancer diagnosis, communication between patients and partners may strengthen or become more challenging. Some couples are able to maintain or increase their communication, which is related to feelings of greater intimacy, closeness, and understanding (Burwell, Brucker, & Shields, 2006; Manne, & Sherma et al., 2004; Manne et al., 2006). Constructive communication is negatively associated with distress and positively associated with relationship satisfaction in both partners (Manne et al., 2006). According to Pistrang & Barker (1995), good communication is characterized by high empathy and low withdrawal. Reciprocal self-disclosure during discussions about the cancer is associated with lower levels of both general patient distress and cancer-specific distress (Manne, Sherma et al., 2004). Perceived partner disclosure has a direct positive association with intimacy as well (Manne, Ostroff, Rini et al., 2004). Other couples communicate well overall, but struggle with specific cancer-related topics such as death, fears about cancer, and how to best support the woman (Shands et al., 2006; Walsh et al., 2005; Manne, Sherma, et al. 2004; Holmberg et al., 2001). The perceived quality of partner support is positively correlated with patient psychological well-being (Manne et al., 2005; Manne, Sherma, et al., 2004; Pistrang & Barker, 1995). Manne et al. (1999) conducted a 3-month follow-up survey of 151 male and female cancer patients. They found that as female cancer patients experienced greater disease and treatment-related impairment, they endorsed a greater degree of emotional support from their current husbands. Studies have also shown that instrumental support is important (Holmberg et al., 2001; Manne et al., 1999). Women's perceptions of their partners' behavior determine whether unsupportive behavior has detrimental effects on women's psychological well-being and adjustment (Manne et al., 2005). Overall, what appears to be most important is that partner support needs to meet patient expectations in order to be beneficial (Manne, Sherma et al., 2004).

Communication Avoidance

Young women report that communication avoidance causes strain on their intimate partner relationship and can negatively impact illness adjustment (Walsh et al., 2005; Manne et al., 1997). Both women and their well partners appear to avoid discussions (Manne et al., 2005; Hodgson et al., 2003; Holmberg et al., 2001). In their longitudinal study of disengaging communication in later-life couples with breast cancer, Hodgson et al. (2003) found that approximately 86% of husbands and 76% of wives used disengagement. Interestingly, wives' use of disengagement was not significantly correlated with their own marital satisfaction. Other studies have found that women's use of avoidant coping and distress was largely accounted for by her perception of her partner's behavior (e.g. avoidance) as being unsupportive. Over time, there is an association between unsupportive partner behaviors and avoidant coping and distress (Manne et al., 2005). With regard to women's psychological well-being, it appears that the quality of the helping relationship (poor helping is characterized by partner withdrawal) is more strongly associated than general relationship satisfaction (Pistrang & Barker, 1995).

Currently, I was only able to find one study which addressed demand/withdraw communication in breast cancer patients and their partners. Manne and colleagues (2006) examined cancer-related relationship communication, relationship satisfaction, and psychological health in 147 patients with early stage breast cancer and 127 of their partners. They adapted the Communication Patterns Questionnaire (CPQ; Christensen & Sullaway; 1984) by asking participants how they dealt with rate cancer-specific stressors (Manne et al., 2006). They found that demand-withdraw and mutual withdrawal was associated with greater distress and lowered relationship satisfaction for both patients and their partners. However, constructive communication was associated with lowered distress and greater relationship satisfaction in couples.

Some studies suggest that partners tend to use more avoidance and hostile coping when the illness demands are less (Feldman & Broussard, 2006; Manne et al., 1997). They hide negative feelings and avoid conflict more often than patients (Manne et al., 2008). However, not all partners may be avoiding in order to cause their partner increased strain. Instead, partners may worry that communicating their fears will be burdensome, and so they internalize their concerns as a way of protecting the patients (Manne et al., 2008; Lethborg et al., 2003). They may also feel her needs are more important. Others fear that stress contributed to the breast cancer occurrence, and went out of their way to avoid disagreement and conflict (Holmberg et al., 2001). Coyne and Smith (1991) have identified this relationship-focused coping strategy as "protective buffering". Protective buffering refers to concealing worries, concerns, and yielding to the partner to avoid disagreements in an effort to protect the partner from burden. In their 1991 study, Coyne and Smith found that among wives of myocardial infarction patients, protective buffering on the part of both wife and husband was positively associated with increases in wife's distress. This dynamic has also been described among cancer patients and their spouses (Manne et al., 2008; Manne, Dougherty, Veach, & Kless, 1999).

A recent longitudinal study measured protective buffering, relationship satisfaction, and psychological distress in 235 women with breast cancer and their partners (Manne et al., 2008). The authors found that protective buffering decreases over time among both partners. Furthermore, protective buffering significantly predicted greater psychological distress over time for the person providing the buffering. However, it was only associated with distress among those patients and partners who rated their relationships as more satisfactory. Protective buffering was not associated with distress in patients and partners with less satisfying relationships.

Theoretical Framework

The Family Systems-Illness Model (Rolland, 1999; 1994a; 1994b) provides a useful framework for understanding communication patterns among young women with breast cancer and their partners. In this model, Rolland proposes a biopsychosocial perspective imbedded within a family systems framework to conceptualize chronic illness and disorders (Rolland, 1999; Rolland, 1994a). This strength-based approach views family relationships as resources for resiliency and growth, not just sources of risk and problems in the midst of medical issues. Accordingly, families are not healthy or unhealthy. Rather, they display behaviors during the course of the illness which are either optimal or suboptimal for their particular family system

(Rolland, 1994a). Within this framework, three spheres of influence affect the family and patient experience of illness: 1) the type of illness; 2) individual, family, and illness life cycles; and 3) the overarching cultural and ethnic belief systems (Rolland, 1994a).

The model addresses three dimensions of illness and disability: 1) psychosocial types, 2) major developmental life phases, and 3) key family systems variables (Rolland, 1999). Psychosocial types of illness and disability refers to examining the psychosocial demands of illness and their biological similarities and differences. This dimension takes into consideration the onset, course, outcome, incapacitation, and level of uncertainty of the illness pattern (Rolland, 1999). Many times, illness is described as a static condition, without appreciation for the changes of illness over time. This model identifies three phases of illness (crisis, chronic, and terminal) and examines the psychosocial implications during and between each stage (Rolland, 1999).

The Family-Systems Illness model has a life cycle emphasis that examines natural life cycle processes which illness interrupts. During different times in the life cycle, family cohesion is relatively higher or lower to meet developmental needs. Therefore, when the illness interrupts these periods of higher bonding, the family typically experiences more strain (Rolland, 1999; Rolland, 1994a). For example, a young woman with breast cancer may find the crisis of a breast cancer diagnosis more challenging than a woman in a later stage of the life cycle because of her plans to find a partner and/or become a parent. As this example illustrates, the illness occurs at an 'off-time', which can be problematic when one attempts to meet developmental expectations and life course goals (Rolland, 1999; 1994b). Hence, it is important to distinguish the following when examining the effect of illness in the family: 1) the degree of cohesion needed at different life cycle phases; 2) the degree of psychosocial demands during different phases over the course

of the illness; and 3) the fluctuation of transition periods within the family and each individual's life cycle (Rolland, 1999). In addition, transgenerational family and cultural beliefs about health and illness affect how individuals and families illness experience.

In accordance with this model, I will be examining the psychosocial types, major developmental phases, and key family systems variables which affect and are affected by breast cancer in young women and their partners. I will investigate how specific variables which can be categorized into these components (e.g. patient age, treatment symptom severity, overall quality of life, relationship satisfaction, length of relationship) are associated with degree of initiation of relationship discussions in patients and patients' perceptions of their partners' degree of initiation.

Summary

It is important to study communication patterns and its association with relationship satisfaction in young women with breast cancer because these factors have been shown to impact patient's response to treatment and illness adjustment. For example, women and their partners experience high levels of psychological distress and decreases in relationship satisfaction during treatment (Shands et al., 2006; Northouse et al., 1998; Northouse et al., 1997; Northouse et al., 1995; Northouse, 1989). Communication avoidance and demand/withdraw communication patterns can cause strain on the partner relationship and negatively impacts illness adjustment (Manne et al., 2006; Walsh et al., 2005; Manne et al., 1997). However, constructive communication patterns are associated with lower levels of psychological distress and higher relationship satisfaction (Manne et al., 2006; Manne, Sherma et al., 2004). Women who experience lower psychological distress respond more favorably to treatment and make better treatment choices (Friedman et al., 2006). Furthermore, recent research suggests that when women perceive they can confide in their partners for emotional processing and support, it serves as a protective factor against breast cancer progression (Weihs et al, 2008). These new findings support the need for research examining communication patterns in breast cancer patients. This research can guide the creation of intervention strategies which aim to increase constructive communication.

The Family Systems-Illness Model (Rolland, 1994a) is a useful framework for examining communication patterns among young women with breast cancer and their partners. It addresses three major dimensions of illness and disability, 1) psychosocial types, 2) major developmental phases, and 3) key family systems variables. The model allows researchers to address variables which are unique to young women. For example, diagnosis and treatment will likely impact young women differently than older women because of their distinct positions in the life cycle. Additionally, the impact of family systems variables, such as partner communication patterns, can be more explicitly examined through this model.

Specifically, I will investigate 1) whether or not young women with breast cancer initiate relationship discussions with their partners; 2) whether or not young women with breast cancer perceive their partners as initiators of relationship discussions; 3) the degree of both patient and perceived partner initiation and its association with dyadic satisfaction; and 4) which psychosocial types (medical/biological), major developmental life phases, and demographic variables are associated with patient and perceived partner initiation.

CHAPTER 3

METHODS

Background

This study is part of a larger study that assesses the psychosocial impact of breast cancer on young women and their partners. Women completed a survey with measures designed to assess dyadic satisfaction and communication patterns, quality of life, breast cancer information, demographics, and general health. The data presented here focus on the cancer patient's perception of the couple's communication style and her marital satisfaction.

Sample

The sample consisted of 109 women who met the following criteria: 1) had their first breast cancer diagnosis (e.g., no recurrence); 2) were partnered and in a relationship with the same partner since diagnosis; 3) were no more than three years post-diagnosis; 4) had no other cancer diagnosis or major health problem; 5) were between the ages of 18-50; and 6) had completed initial surgery.

Procedure

The majority (96%) of study participants was recruited online through cancer support websites and other forums, such as the American Cancer Society and Young Cancer Survivors Coalition. Participants followed a link that connected them to an introduction about the study, an informed consent form, and survey. The principal investigator's (SRB) name and contact information were provided in case participants had questions or wanted more information about the study. Women who completed a written survey were recruited by healthcare providers from breast clinics, a local cancer patient support center, support groups for breast cancer patients, and through two newspaper advertisements.

Measures

Variables

The independent variables in this study were representative of the three dimensions of illness and disability that Rolland (1994) identifies in the Family Systems-Illness model: 1) psychosocial types; 2) major developmental life phases; and 3) key family systems variables. As described in the literature review, psychosocial types refers to an examination of the psychosocial demands of the illness which includes the onset, course, outcome, level of incapacitation or disability, and uncertainty about the illness (Rolland, 1999). In this study, the medical variables were most reflective of psychosocial types and included: cancer treatment type, severity of symptoms, general quality of life (QoL) and health status. The next dimension of Rolland's model is the major developmental life phases dimension that addresses factors related to the patient's and her partner's stages in their individual and relationship life cycle. Study variables related to this dimension included patient and partner age, length of relationship, relationship history (e.g. number of times married and divorced), and number and ages of children. In addition to these, other demographic variables were also included in the analyses. These variables include income, education level, ethnicity, employment and health insurance status. Lastly, key family systems variables are those that affect family dynamics. The study variables that reflected family systems variables were a relational assessment of dyadic satisfaction (as measured by the Revised-Dyadic Adjustment Scale) and an assessment of initiation of relationship discussions (as measured by the Initiator Style Questionnaire).

Independent Variables

Revised Dyadic Adjustment Scale (RDAS; Busby, Christensen, Crane, & Larson, 1995)

The Revised Dyadic Adjustment Scale (Busby et al., 1995) is a measure of relationship satisfaction and adjustment. It contains 14 items divided into three subscales; Consensus (items 1-6), Satisfaction (items 7-10), and Cohesion (items 11-14). The Consensus Subscale is rated on a 6-point Likert scale (0=always disagree to 5=always agree). The Satisfaction Subscale is also rated on a 6-point Likert scale (0=all the time to 5=never). Lastly, the Cohesion Subscale has two different scales. Item 11 is worth 0-4 points (0=never to 4=every day). Items 12-14 are rated on a 6-point Likert scale (0=never to 5=more often). Higher scores on the RDAS indicate a higher level of distress. A cut-off score of 48 is recommended to dichotomize participants into two groups, non-distressed (scores 0-47) and distressed (scores 48-69) (Busby et al., 1995). The RDAS has been reported to have good psychometric properties, and has strong convergent and criterion validity. The scale has been compared to other measures of dyadic satisfaction such as the Locke-Wallace Marital Adjustment Test. The overall internal consistency for the RDAS is .92 (Busby et al., 1995; Crane, Middleton, & Bean, 2000). For the present study, Chronbach's alphas were .92 overall, .83 for the Consensus Subscale, .90 for the Satisfaction Subscale, and .86 for the Cohesion Subscale.

Medical Variables

Medical variables were assessed using a breast cancer history questionnaire, a severity of symptoms scale, a general quality of life (QoL) measure, and a health status measure. On the breast cancer history items the patient indicates whether or not she has undergone different types of breast cancer surgeries and/or adjuvant treatments (e.g., chemotherapy, radiation, etc.). The symptoms questionnaire contains 14 items rated on a 5-point Likert scale (1=not at all to 5=very)

much). The patient rates how much symptoms have bothered her, such as nausea or hair loss, over the past four weeks. For the present study, Chronbach's alpha was .71. The general QoL measure is a one item question that asks the patient to rate her present QoL on a10-point Likert scale (1=worst *life possible* to 10=best *life possible*). The health status measure was designed specifically for this study to gauge whether young women with breast cancer perceive themselves in poor health, and whether breast cancer has affected their perceptions of their health. The measure contains two items. The first asks the patient to rate her overall health on a 5-point Likert scale (1=excellent to 5=poor) and the second item asks the patient to compare her current health to that prior to cancer on a 5-point Likert scale (1=much better now than before cancer).

Demographic Variables

This study examined seventeen demographic variables. They included: length of time since diagnosis, whether patients are currently in treatment, patient age, partner age, whether patients are married, whether patients are cohabiting, number of times married, number of times divorced, number of times widowed, length of current relationship (in years), whether patients have children, number of children, income, education level, ethnicity, and employment and insurance status.

Dependent Variable

Initiator Style Questionnaire (ISQ; Denton & Burleson, 2007)

The Initiator Style Questionnaire assesses the degree of initiator tendency which refers to the inclination to initiate a discussion of relationship problems with one's partner. What Denton and Burleson (2007) term initiation tendency is similar to demand/withdrawal communication (Christensen & Heavey, 1990), with a few important distinctions. Demand/withdraw focuses on a specific behavioral communication pattern between couples. This pattern is treated as a property or trait of the couple. Demanding is often termed as negative behaviors used to get a partner's attention (e.g., nagging, yelling). On the other hand, initiator tendency refers to an individual internal process that may or may not behaviorally manifest in every context. Therefore, initiator tendency is "a relationship-specific individual difference" (Denton & Burleson, 2007, p. 246). Initiator tendency may manifest as positive, prosocial behaviors such as a polite request or gentle teasing. Or, they may be more negative behaviors, such as an abrasive expression of concern or angrily yelling and demanding (Denton & Burleson, 2007).

This scale contains 20 items rated on a 9-point Likert scale (1=*strongly disagree* to 9=*strongly agree*). For the first ten items, patients rated how they typically respond to problems in their relationship. Then, patients rated how they perceive their partner as s/he responds to problems in their relationship on the last ten items. Items on the self subscale correspond numerically to the items on the partner subscale (e.g., items 1/15, 2/12, 3/17, 4/19, 5/13, 6/20, 7/16, 8/11, 9/14, and 10/18 assess the same relationship discussion behavior in each partner). Higher scores indicate a greater tendency to initiate. The ISQ has been shown to have face and construct validity and high internal consistency. Additionally, the ISQ has been compared to the CPQ, and shown to have convergent validity. The self-items have a coefficient alpha of .96 (Denton & Burleson, 2007). Additionally, test-retest reliability indicates Chronbach's alpha .91 for self-items and .77 for partner-items. In the present study, Chronbach's alphas were .95 for the overall ISQ, .91 for self-items and .96 for partner-items.

Statistical Analyses

The following research questions are guided by the Family Systems-Illness model (Rolland, 1994). The first three questions target key family systems variables. The last question attends to both the psychosocial demands of the illness and the major developmental life phases. *Research Question 1: Do young women with breast cancer initiate relationship discussions with their partners?*

Univariate descriptive statistics (frequencies, means, and standard deviations) were gathered on the ISQ Patient Subscale and compared with the means and standard deviations found by Denton and Burleson (2007) on the ISQself Subscale scores of women without cancer. *Research Question 2: Do young women with breast cancer perceive their partners as initiators of relationship discussions?*

Univariate descriptive statistics were conducted on the ISQ Partner Subscale and compared with the descriptive norms set forth by Denton and Burleson (2007). Paired samples t-tests compared mean scores of the two ISQ subscales to determine if there were differences in patient initiation versus perceived partner initiation. Additional paired samples t-tests were conducted on the corresponding Patient and Partner subscale items (items 1/15, 2/12, 3/17, 4/19, 5/13, 6/20, 7/16, 8/11, 9/14, and 10/18) to determine if specific items differ between patient initiation and her perception of partner initiation.

Research Question 3: Is the degree of both patient and perceived partner initiation associated with dyadic satisfaction?

Univariate descriptive statistics were conducted on the RDAS scores to determine the prevalence of relationship distress and satisfaction among the sample. Per Busby et al. (1995), a cut-off score of 48 was used to dichotomize women into non-distressed and distressed groups.
RDAS scores 48 and under indicate relationship distress. In order to determine if the relationship satisfaction score was associated with self or perceived partner initiation, Pearson correlations were conducted between the sample mean RDAS score and sample mean ISQ Patient Subscale and sample mean ISQ Partner Subscale. Furthermore, to determine if there was an association between relationship satisfaction and self or perceived partner initiation in non-distressed women, Pearson correlations were run between their RDAS and ISQ Patient Subscale and ISQ Partner Subscale scores. The procedure was repeated with the distressed group to determine if there was a similar association.

Research Question 4: Which psychosocial types (medical/biological), major developmental life phases, and demographic variables are associated with patient and perceived partner initiation?

For all continuous variables (months since diagnosis, symptom severity, general QoL, health status, patient and partner age, length of relationship (in years), number of times married, number of times divorced, number of children, and children's ages), Pearson correlations were conducted to compare the breast cancer and other health related variables, QoL, and demographic variables with the ISQ Patient Subscale and the ISQ Partner Subscale. All categorical variables (treatment type, health insurance status, whether patients have children, income, education level, ethnicity, and work status), were collapsed into smaller, representative categories based on their descriptive statistics. Next, dichotomized variables were created from the categorical variables, which indicated whether participants were in one category versus another (1=yes, 0=no). Point biserial correlations were conducted on these variables with the ISQ Patient Subscale to determine any associations.

CHAPTER 4

RESULTS

Research Question 1

Do young women with breast cancer initiate relationship discussions with their partners?

Univariate descriptive statistics were conducted on the ISQ Self Subscale. The mean and standard deviations were compared with the mean and standard deviations of the ISQ Self Subscale scores of women without cancer as found by Denton and Burleson (2007). The current study found that young women with breast cancer rate their own level of initiation similarly to the non-medical population Denton and Burleson studied (Denton & Burleson, 2007). Table 1 reports these results.

Table 1. Comparison of Current Study's Mean ISQ Scores to Denton & Burleson's (2007) Mean ISQ Scores (study 3)

Variable	Μ	SD
Current Study		
ISQ Self	6.75	1.75
ISQ Partner	5.56	2.36
Denton & Burleson (2007)		
ISQ Self	6.39	1.60
ISQ Partner	5.86	1.87

Research Question 2

Do young women with breast cancer perceive their partners as initiators of relationship

discussions?

Univariate descriptive statistics were conducted on the ISQ Partner Subscale. The mean and standard deviations were compared to the descriptive norms (mean and standard deviations) set forth by Denton and Burleson (2007) in a non-medical population. Participants in this study rated their partner's levels of initiation similarly to the participants in Denton and Burleson's (2007) sample (see Table 1). A paired samples t-test was conducted on the mean scores of the two ISQ subscales, ISQ Partner Subscale (M=5.56, SD=2.36) and ISQ Self Subscale (M=6.75, SD=1.75) to determine if there were significant differences in patient initiation versus perceived partner initiation. There was a significant difference (t(108) = -5.08, p<.001, d = -.49) and the 95% confidence interval for the mean difference between the two subscales was .72 to 1.65. This indicates that women with breast cancer perceive themselves to initiate relationship discussions more often than they perceive their partners as initiators.

Univariate descriptive statistics were also conducted on each item of the ISQ (Table 2). Additionally, paired samples t-tests were conducted on the corresponding ISQ Self and ISQ Partner subscale items (items 1/15, 2/12, 3/17, 4/19, 5/13, 6/20, 7/16, 8/11, 9/14, and 10/18) to determine if specific items differ in patient initiation and her perception of her partner's initiation (Table 2). For all items it was found that women tend to significantly initiate discussion more than their partners.

Self Item/ Partner	Self Mean/ Partner	Mean Difference	SD	df	t	Sig (2-tailed)
Item	Mean	Difference				(2-taneu)
1/15	6.78/5.40	1.38	3.17	107	4.53	.000*
2/12	6.79/5.67	1.12	2.73	107	4.26	.000*
3/17	6.71/6.01	.70	2.74	107	2.67	.009*
4/19	6.64/5.74	.91	2.63	106	3.57	.001*
5/13	6.33/5.62	.71	3.07	104	2.39	.019*
6/20	7.02/5.82	1.20	2.88	104	4.26	.000*
7/16	6.53/4.88	1.64	4.21	103	3.98	.000*
8/11	7.50/5.99	1.51	3.30	108	4.79	.000*
9/14	6.57/5.47	1.10	3.13	106	3.65	.000*

Table 2. Patterns of Initiate/Avoid of Matched Items on ISQ Self and ISQ Partner Subscale Paired Samples t-tests

10/18	6.80/5.87	.93	3.09	105	3.11	.002*

*=p<.05 significance level Note: On all items, patients had significantly higher initiation rates.

Research Question 3

Is the degree of both patient and perceived partner initiation associated with dyadic

satisfaction?

Univariate descriptive statistics were conducted on the RDAS scores to determine the prevalence of relationship distress and satisfaction among young women with breast cancer. As provided by Busby et al. (1995), a cut-off score of 48 was used to dichotomize women into distressed and non-distressed groups. Scores 0-47 indicated relationship distress and 48-69 indicated relationship satisfaction. As a whole, the sample was non-distressed, M = 48.51, SD = 10.93. There were 36 women in the distressed group, M = 35.67, SD = 7.88, and 73 women in the non-distressed group, M = 54.85, SD = 5.09.

To determine if the RDAS score was associated with patient or perceived partner initiation, Pearson correlations were conducted between the RDAS score and the ISQ Self and ISQ Partner Subscales. Results indicate that both patient and perceived partner initiation scores were positively associated with relationship satisfaction: RDAS and ISQ Self Subscale, r=.47, p=.00; RDAS and ISQ Partner Subscale, r=.51, p=.00. Patients' perception of themselves and their partners as initiators of relationship discussions was associated with an increase in patients' dyadic satisfaction.

Pearson correlations were also conducted between the RDAS and ISQ Self and ISQ Partner Subscales of distressed women to determine an association between initiation and relationship satisfaction. For the distressed group, perceived partner initiation was significantly positively associated with relationship satisfaction, r = .38, p < .05. However, patient initiation was not significantly associated with relationship satisfaction, r = .13, p = .436. This indicates that for distressed women, when their partners initiate relationship discussions, it was associated with increases in their own dyadic satisfaction, but their own initiation levels were not related to their dyadic satisfaction.

The same procedure was conducted on the RDAS and ISQ Self and ISQ Partner Subscales of non-distressed women. In the non-distressed group both patient initiation, r = .29, p<.05, and perceived partner initiation, r = .29, p<.05 were positively associated with relationship satisfaction. For non-distressed women, increases in relationship discussions by both themselves and their partners were associated with increases in patients' dyadic satisfaction.

Research Question 4

Which psychosocial types (medical/biological), major developmental life phases, and demographic variables are associated with patient and perceived partner initiation?

Univariate descriptive statistics were conducted on all psychosocial types (medical/biological), major developmental phases, and demographic variables. This study's participants were similar to the non-medical sample in terms of sample size, age, years married, number of marriages, education level, and ethnicity to those of Denton and Burleson's study (Denton & Burleson, 2007). The current sample had a higher mean number of children (4.01 vs. 1.2). Furthermore, a more detailed version of this sample's psychosocial types (medical/biological), major developmental life phases and demographic variables can be found in Table 3.

Table 3. Participants' Psychosocial Types, Major Developmental Phases, and Demographic Variables

Variable	N% or Mean (SD) (<i>n</i> = 109)		
Participant Age	40.38 (6.91)		

Partner Age	42.32 (7.83)
Relationship Status	
Married	86.3%
Partnered	13.7%
Years in Relationship	12.9 (8.45)
Relationship History	
Number of Times Married	1.19 (.52)
Number of Times Divorced	.36 (.58)
Number of Times Widowed	.01 (.10)
Children	
Yes	79.0%
No	21.0%
Number of Children	4.01 (1.51)
Ethnicity	
White	97.0%
Non-White	3.0%
Education Level	
High School Graduate/GED	11.7%
Some College/Associate's Degree	32.0%
College Graduate	25.2%
Above College	31.1%
Work Status	
Full Time	51.7%
Part Time	27.6%
Stopped Working Due To Ill Health	12.6%
Not Working	8.0%
Yearly Income	
\$10,000-39,999	7.8%
\$40,000-59,999	17.5%
\$60,000-74,999	15.5%
\$75,000 or Above	59.2%
Months Since Diagnosis	12.21 (9.56)
Type of Surgical Treatment	
Lumpectomy	70.3%
Axillary Node Dissection	83.3%

Mastectomy	57.6%
Breast Reconstruction	41.4%
Adjuvant Treatment	
Chemotherapy	74.3%
Radiation Therapy	62.0%
Hormone Therapy	58.3%
Currently In Treatment	74.8%
Currently In Treatment	/ 110/0
Patients with Health Insurance	99.0%

Pearson correlations were run on all continuous variables (months since diagnosis, symptom severity, general QoL, health status, patient and partner age, length of relationship in years, number of times married, number of times divorced, number of times widowed, number of children, and children's ages). Regarding the psychosocial types variables, two had significant associations. Pain with sexual intercourse (r= -.22, p<.05) was negatively correlated with patient initiation. Women's initiation of relationship discussions was associated with less pain with intercourse. Also, general quality of life (r= .22, p<.05) was positively associated with perceived partner initiation. This indicates that partner's initiation levels were associated with increases in patient quality of life. One major developmental life phase variable also had a significant correlation. Patient age was negatively associated with a decrease in perceived partner initiation. No other continuous demographic variables were significantly associated with initiation. Table 4 includes the correlations of the psychosocial types, major developmental phases, and demographic variables with the ISQ Self and ISQ Partner Subscales mean scores.

In order to compare ISQ Partner and ISQ Self Subscale scores with the categorical variables, these variables were collapsed into smaller, more representative categories based on their descriptive statistics and frequencies. Then, new dichotomized variables were created,

indicating whether participants fell into a certain category (1=yes, 0=no). Point biserial correlations were conducted between these variables and the ISQ subscales. Using this method, working full time was negatively associated with perceived partner initiation, r=-.213, p<.05 (see Table 4). Patient full time work was associated with a decrease in perceived partner initiation.

Table 4. Correlations of All Psychosocial Types, Major Developmental Phases, and Demographic Variables with ISQ Self and ISQ Partner Subscales

Variable	ISQ Self Subscale Mean Score	ISQ Partner Subscale Mean Score	
Psychosocial Types			
Months Since Diagnosis	06	03	
Symptom Severity			
Hot Flashes	.01	01	
Nausea	03	.14	
Vomiting	12	.01	
Diarrhea	00	02	
Difficulty with Bladder Control when Laughing or Crying	00	.00	
Difficulty with Bladder Control at Other Times	04	.06	
Vaginal Discharge	.01	.02	
Vaginal Dryness	12	02	
Pain with Sexual Intercourse	22*	09	
General Aches and Pains	.04	07	
Swelling of Hands and Feet	.06	03	
Weight Gain	.04	.02	
Weight Loss	04	01	
Unhappiness with the Appearance of Your Body	.04	03	
Health			
Quality of Life	.11	.22*	
General Health	17	05	
Health Now Compared to Before Breast Cancer	16	10	
Surgery Type			
Lumpectomy	08	02	
Axillary Node Dissection	.09	.14	
Mastectomy	.01	01	
Breast Reconstruction	.03	08	
Treatment Type			

Chemotherapy	.10	.03
Radiation Therapy	18	10
Hormone Therapy	14	12
In Current Treatment	.03	13
Major Developmental Life Phases		
Participant Age	11	21*
Partner Age	11	18
Relationship Status		
Married	.02	.07
Years in Relationship	11	16
Relationship History		
Number of Times Married	.06	.12
Number of Times Divorced	.08	.00
Number of Times Widowed	.03	17
Children		
Yes	03	19
Number of Children	.03	.01
Demographics		
Ethnicity		
White	.12	12
Non-White	12	.12
Education Level		
High School Graduate/GED	05	.01
Some College/Associate's Degree	.19	.17
College Graduate	12	04
Above College	03	13
Work Status		
Full Time	06	21*
Part Time	.11	.18
Stopped Working Due To Ill Health	08	.07
Not Working	.02	.02
Yearly Income		
\$10,000-39,999	00	.14
\$40,000-59,999	.09	.18
\$60,000-74,999	.02	04

\$75,000 or Above	08	18
Patients with Health Insurance	.11	.10

*= *p*<.05 significance level (2-tailed)

CHAPTER 5

DISCUSSION

Initiation of Communication among Young Women with Breast Cancer

Results of this study indicate that young women with breast cancer initiate discussions and perceive their partners' levels of discussion initiation similarly to Denton & Burleson's nonmedical sample (Denton & Burleson, 2007). Young women with breast cancer perceive themselves as initiators of relationship discussions more often than they perceive their partners as initiators of relationship discussions. These findings lend support to the general demand/withdraw literature which indicates that women tend to demand more often than their husbands and husbands tend to avoid more often than their wives (Eldridge et al, 2007; Christensen et al., 2006; Gottman & Driver, 2005; Heavey et al., 1995; Christensen & Heavey, 1990). However, the present study findings differ from other studies on breast cancer patients and their partners that have indicated that both are avoiders of relationship discussions (Manne et al., 2005; Hodgson et al., 2003; Holmberg et al., 2001). For example in a study comparing patients with breast cancer to patients without a life threatening illness, Hodgson and colleagues (2003) found that over 75% of women in their sample disengaged from communication with their partners and over time, they used avoidant coping strategies (Hodgson et al., 2003). Patient avoidance may also result when women perceive their partners to be unsupportive and, over time, this leads to higher patient distress (Manne et al., 2005).

Other studies show that partners of cancer patients avoid conflict and communication more often than patients, sometimes in attempt to protect the patient and this has been referred to as protective buffering (Manne et al., 2008; Manne et al., 1999). Protective buffering occurs when the partner tries to protect the patient from psychological discomfort by concealing his own worries and cancer-related concerns. Partners may also give into the patient in an attempt to avoid disagreements that may negatively impact the patient's mental well-being, consistent with Coyne's interactional theory (Benazon & Coyne, 1999). This theory proposes that the negative reactions from others can play a role in perpetuating depression. According to Coyne, there is considerable evidence that partners will attempt to hide negative feelings (Coyne, 1985; Coyne, 1976). The research on protect buffering indicates that this process decreases with time (Manne et al., 2008; Coyne & Smith, 1991). These findings are similar to the findings that avoiders may refrain from relationship discussions because they fear it will harm the relationship (Roberts, 2000). According to a qualitative study, partners of breast cancer patients thought that stress was a large contributor to breast cancer development (Holmberg et al, 2001). Consequently, these partners went out of their way to avoid conflict with the patient, even though they recognized that the avoidance resulted in more severe conflict (Holmberg, 2001). However, the current study did not directly assess the degree to which partners concealed worries or concerns and acquiesced to patient requests. It is difficult to ascertain whether that was the intent with this population. The results simply indicate that the participants perceived their partners to initiate relationship discussions less often than themselves.

Additional literature on marital conflict indicates that the wife-demand/husbandwithdraw pattern does not remain consistent when researchers consider which partner generated the discussion topic. In an observational study where participants filled out the Dyadic Adjustment Scale (DAS; Spanier 1976) and Communication Patterns Questionnaire-Short Form (CPQ-SF; Christensen & Heavey, 1993), couples were video-taped twice in ten-minute segments. During each segment, one spouse generated an important discussion topic, finding that the partner who chose the topic demanded, and the other partner withdrew (Klinetob & Smith, 1996). Other studies have indicated that when the wife chooses the discussion topic or seeks change in her husband, there is greater likelihood of the woman-demand/man-withdraw pattern (Eldridge et al., 2007; Christensen & Heavey, 1990). These studies also demonstrated that when the husband chooses the topic, there appear to be no significant differences in their interaction patterns (Eldridge et al., 2007; Christensen & Heavey, 1990). Certain items in the ISQ address which partner chooses the discussion topic (e.g. "When my partner becomes aware of a problem in our relationship, my partner usually tires to start a discussion of that problem", "When I become aware of a problem in our relationship, I usually try to start a discussion of that problem"). However, this study did not include partner data, which makes it difficult to ascertain whether the partners would view the initiation pattern differently and support previous findings.

Dyadic Satisfaction and Initiator Tendency

Inconsistent with studies on the demand/withdraw interaction, both patient and partner levels of initiation were positively associated with dyadic satisfaction. These studies indicate the wife-demand/husband-withdraw and husband-demand/wife-withdraw patterns are associated with significant declines in women's dyadic satisfaction (Caughlin & Huston, 2002; Heavey, et al., 1995). The inconsistencies with the demand/withdraw literature may be explained by the difference in conceptualization of initiate/avoid versus demand/withdraw. Initiation can refer to neutral of positive processes in addition to negative ones, whereas demanding is negatively conceptualized. As further support for this idea, this study's results duplicate the preliminary findings that higher levels of initiation are associated with higher dyadic satisfaction (Denton & Burleson, 2007). In this sample, participants and their perceived partner's levels of initiation were positively associated with dyadic satisfaction. This finding offers support to Denton and Burleson's (2007) assertion that increases in levels of initiation would be associated with higher dyadic satisfaction. The ability of partners to discuss relationship issues is an indicator of healthier relationships (Denton & Burleson, 2007).

When participants' scores on the RDAS were dichotomized into distressed versus nondistressed (Busby, et al., 1995), approximately one third of the sample exhibited dyadic distress. Participants in the non-distressed group exhibited the same association between dyadic satisfaction and initiation as the overall sample. Both patient and perceived partner initiation was positively associated with dyadic satisfaction. In the demand/withdraw and initiate/avoid literature, this interaction is described as constructive communication (e.g. Denton & Burleson, 2007; Manne et al., 2006). Constructive communication refers to both partners engaging in relationship discussions and not avoiding them. Within both medical and non-medical samples, constructive communication is associated with higher dyadic satisfaction (Denton & Burleson, 2007; Manne et al., 2006)

However, in the distressed group, only perceived partner initiation was positively associated with patient dyadic satisfaction. Research has demonstrated that low levels of partner initiation (e.g. avoidance or withdrawal) can negatively impact relationships. Gottman and colleagues have conducted a series of studies focusing on factors that predict marital satisfaction and stability (e.g. Gottman & Driver, 2005; Gottman & Levenson, 2002; Carrére, Buehlman, & Gottman, 2000; Gottman & Levenson, 1992; Gottman & Krokof, 1989; Levenson & Gottman, 1985,1983). Gottman identified four processes he saw occurring in high frequency among distressed couples. He termed these the four horsemen of the apocalypse: defensiveness, contempt, criticism, and stonewalling (Gottman, 1993). Stonewalling is a form of withdrawal. When husbands stonewall, it is predictive of divorce (Gottman, 1993). Similarly here, low levels of perceived partner initiation were associated with low dyadic satisfaction.

It is conceivable that distressed patients' increase in dyadic satisfaction is associated with partner initiation because it is an indication that partners are still engaged in the relationship. Avoidance on the part of both partners is evidenced in clinically distressed couples (Christensen & Shenk, 1991). However, for distressed patients in this sample, their own initiation levels were not associated with their dyadic satisfaction. Research indicates that this type of interaction is also present in clinically distressed couples (Christensen & Shenk, 1991). In particular, distressed wives perceive that their husbands feel negatively toward them, and feel negatively about how their husbands speak with them (Denton et al., 1994). Additionally, in a medical sample of Hodgson and colleagues (2003), women's disengagement was not related to her own dyadic satisfaction. This study's results appear to offer support for their findings.

Other Factors Associated With Initiator Tendency

Two psychosocial factors were associated with initiation. Women's initiation of relationship discussions was related to a decrease in pain with sexual intercourse. One explanation for this finding may be that young women are more likely to undergo reconstructive surgery following mastectomy (Rowland, Desmond, Meyerwitz, Belin, Wyatt, & Ganz, 2000). At one to three months post-surgery, these women exhibit lower sexual responsiveness, sexual embarrassment, situational distress, and diminished sexual arousal (Yurek, Farrar, & Anderson, 2000). Pain with sexual intercourse may be a response to feelings of sexual embarrassment or insecurity due in part to what the surgery symbolizes. In Western cultures, femininity is often associated with a woman's breasts. After surgical alteration of their breast/s women may struggle to redefine their femininity and sense of sexual attractiveness (Burwell et al., 2008). For

example, women who place more importance on the appearance and sensation of their breasts are more likely to have post-operative sexual problems (Northouse, 1994; Schain, d'Angelo, Dunn, Lichter, & Pierce, 1994; Vess, Moreland, Schwebel, & Kraut, 1988). Women who are able to discuss these feelings with their spouses may adjust better sexually and experience less pain. The ISQ does not specifically measure cancer-related relationship discussions. The study did not address whether patients were specifically thinking of cancer-related discussions when completing the ISQ. Most importantly, this is only speculation and future research is needed to determine causality and potential mediator or moderator effects on these variables.

Secondly, increase in patient general quality of life is associated with increases of perceived partner initiation. This echoes similar research which indicates that women who perceive their partners' behaviors as supportive (e.g. not withdrawing) display increased psychological well-being (Pistrang & Barker, 1995). When patients perceive their partners are willing to initiate and maintain relationship discussions, patients experience higher levels of their general quality of life.

Interestingly, the current study found no relationship between levels of initiation and treatment side effects. Some research indicates that communication patterns and physical side effects of treatment are related. For example, in a nine-month longitudinal study of patients with early stage breast cancer, Manne and colleagues (2006) discovered that constructive communication (e.g. both partners initiating discussions) was negatively associated with distress and positively associated with dyadic satisfaction. This association was stronger when patients were dealing with greater treatment side effects (Manne et al., 2006). Indeed, an earlier study of preferences for spousal support among cancer patients indicated that as women experienced higher levels of impairment due to treatment side effects, they endorsed higher levels of

emotional support from their partners (Manne et al., 2006). However, this study found no association between level of initiation and treatment side effects. This may be because this study focused specifically on young women with breast cancer, whereas other studies included women over 50 years old. Additionally, these studies utilized different measures (e.g. Inventory of Socially Supportive Behaviors, Dyadic Coping Scale, Illness Intrusiveness Rating Scale, Interpersonal Orientation Scales) from this study (e.g. breast cancer health questionnaire, RDAS, ISQ) (Manne et al., 2006; Manne et al, 1999). Furthermore, this sample's average time since diagnosis was 12.21 months, which is longer than other studies' (e.g 6-9 months). Research indicates that although it is still present, stress related to adjustment to diagnosis and treatment appears to decrease over time (Shands et al., 2006; Northouse et al., 1998). It is possible that women experience the need for more emotional support and constructive communication earlier as they are first adjusting to diagnosis and treatment side effects. Because of the greater time since diagnosis, the current study's sample may be better adjusted to treatment side effects and have a lower need for communication surrounding this topic.

One major developmental life phase variable was also associated with initiation. Patient age was negatively associated with perceived partner initiation. Research measuring demand/withdraw indicates that this communication pattern is consistent and can worsen over time in medical and non-medical populations (Manne et al., 2006; Manne et all., 2005; Caughlin, 2002; Caughlin & Huston, 2002; Gottman & Levenson, 2002; Christensen et al., 1995). Couples who evidence demand/withdraw communication at the beginning of their relationship are likely to continue with this pattern and eventually divorce (Gottman & Driver, 2005; Gottman & Levenson 2002; Gottman, 1993; Levenson & Gottman, 1985, 1983). Because of the negative impact that low partner initiation can have on the relationship, it is important to consider appropriate intervention strategies.

Lastly, when patients work full time, it is associated with decreased perceived partner initiation. A possible explanation for this finding relates to the concept of protective buffering discussed earlier (e.g. Coyne, 1985; Coyne & Smith, 1991). Partners may believe that full time work contributes to the patient's stress levels. In an effort to cause less stress for the patient, the partner initiates relationship discussions less often. This is only one possible explanation, and more research is needed in this area.

Implications for Medical Family Therapists

Over the past two decades, there has been an increased need for collaboration among mental health and medical providers to offer the most complete and comprehensive patient treatment (Doherty & Baird, 1983; McDaniel, Hepworth, & Doherty, 1992; Rolland 1994a, 1994b, 1999). Medical family therapy (MedFT) was introduced as a therapeutic framework to bridge the gap between medical and mental health providers. Medical family therapists follow the biopsychosocial model proposed by Engel (1977). This model takes into consideration the biological, psychological and social aspects of illness and disability. Medical family therapists acknowledge that no medical problem occurs without implications at the psychological and social systems levels. This framework is especially helpful and appropriate for working with young women and their partners facing breast cancer (Burwell et al, 2008).

The two main goals of medical family therapy are to promote agency and create communion (McDaniel et al., 1992). Promoting agency refers to helping the patient (and later, her family) gain a sense of control and competency with regard to her illness. Creating communion means helping the family system come together with each other and other support systems. In the case of a young woman with breast cancer and her partner, the medical family therapist would work with the couple to help both partners understand and learn ways in which they can feel in control of the illness and competent in understanding its ramifications, implications, and consequences. Additionally, the MedFT would aid the couple in understanding each other's wants/needs and how to be most supportive of each other during the course of the illness.

When working with patients of different ethnic or lower SES backgrounds, it is even more imperative to begin by offering psychoeducation regarding how the medical system functions and how to interact with members of the treatment team in order to create agency and communion. These patients likely have had fewer interactions with medical facilities and are unfamiliar with how to navigate this culture (Press, Carrasquillo, Sciacca, & Giardina, 2008). MedFTs can help guide patients and their partners in understanding medical customs and serve as a mediator between them and other treatment team members.

The current study offers some insights into particular findings MedFTs should take into consideration when working with young women with breast cancer. Because perceived partner initiation is associated with patient quality of life and dyadic satisfaction, it is imperative to include couple therapy in the treatment plan. Specifically, MedFTs should focus on the levels of initiation between both partners if the couple is non-distressed. According to the results of this study, their dyadic satisfaction is high when patient and perceived partner initiation is elevated. In distressed couples, it may be even more necessary to focus on increasing the partner's level of initiation and engagement of relationship discussions.

Emotionally Focused Therapy (EFT) (Johnson, 2004) could serve as an appropriate intervention strategy. Others have suggested the use of EFT for chronic illness and cancer

populations (Burwell et al., 2006; Kowal, Johnson, & Lee, 2003). EFT is recommended because of its attention to primary emotions, affect regulation, and its focus on eliminating the demand/withdraw pattern. The therapist addresses underlying emotions, and encourages open communication and empathic responses in both partners (Kowal et al., 2003). In this manner, EFT can help breast cancer patients and their partners initiate relationship discussions more often in order to feel more understood and secure in their relationship.

Another fitting intervention strategy could involve restorying the patient and her partner's relationship with breast cancer, specifically attending to communication patterns and dyadic satisfaction. One of the first techniques of MedFT is to solicit the illness story (McDaniel et al., 1992). Illness stories are dynamic; they are continually created and shared with others (Frank, 1997). It is important to pay attention to the social and psychological dimensions that affect how the partners story the illness individually and as a couple (Kleinman, 1988). All experiences are valid and important in coping with breast cancer. The couple should hear each other's stories to elicit understanding and compassion for their unique experiences (Burwell et al., 2008). It is also imperative to ask the couple about communication and dyadic satisfaction prior to breast cancer, to understand the degree to which breast cancer has infiltrated their lives. Through reconceptualizing their interactions with breast cancer, the couple can further learn to be a united front against its negative impact in their lives.

This study also suggests that it is important to intervene as early as possible. As patients age, they perceive their partners as less willing to engage in relationship discussions. Because quality of life and dyadic satisfaction are associated with perceived partner initiation and this type of initiation decreases with age, it is imperative to start intervening with couples when they are young or first diagnosed with breast cancer in order to work on communication patterns.

Younger women and their partners may be more amenable to communication interventions, as they may be less entrenched in a specific, dysfunctional pattern.

Furthermore, it is important to establish the couple's pattern of communication and dyadic satisfaction prior to breast cancer diagnosis. This study did not address these factors directly, however, other research has shown that some previously well-functioning couples have difficulty communicating with and supporting one another after diagnosis and during treatment (Shands et al., 2006; Walsh et al., 2005; Manne, Sherma et al., 2004; Manne et al., 1997). Breast cancer diagnosis is also related to decreased dyadic satisfaction and higher psychological distress (Manne et al., 2006; Manne et al., 2005; Manne et al., 1997). Breast cancer diagnosis can change the couple's communication patterns and dyadic satisfaction (Holmberg et al., 2001). The MedFT should assess and explore these areas with the couple in order to provide the most appropriate interventions.

This study also emphasizes the importance of including the partner in all aspects of treatment, not just couple therapy. Conceivably, if partners attended medical visits with the patient, they would have more information about diagnosis and treatment, and therefore, be better able to communicate about it. Indeed, patients find it very important and supportive when their partners attend medical visits, have questions prepared, take notes, and discuss this information at home after the appointment (Holmberg et al., 2001). By doing this, partners may be in a better position to initiate and participate in relationship discussions, reciprocate self-disclosure, be more empathic, meet patient's expectations for support. These factors have been associated with increased couple closeness and intimacy as well as patient psychological well-being and illness adjustment (Manne et al., 2005; Manne, Sherma et al., 2004; Manne et al., 1997; Pistrang & Barker, 1995).

Limitations

One of the limitations of this study is that the sample is relatively homogeneous. The majority of the sample was Caucasian, well-educated, employed, and had a high yearly family income. The homogeneity of the sample makes it difficult to generalize these results to other young women with breast cancer. As cited by Press et al.(2008), African American women are diagnosed at later stages, experience delays in treatment starting and completing treatment, are not always given the most aggressive medical treatments, but may have more aggressive forms of breast cancer. The experience of initiation patterns and dyadic satisfaction for a young, partnered African American woman with breast cancer may be very different from the experiences of this largely Caucasian sample.

Because this is a cross-sectional study, it is difficult to determine participants' levels of initiation or dyadic satisfaction prior to breast cancer. Research indicates that those who are dissatisfied in their relationships from the beginning are more likely to be dissatisfied throughout their relationship, especially if they engage in demand/withdraw patterns (Caughlin, 2002; Gottman & Levenson, 2002; Carrére et al., 2000; Gottman & Krokof, 1989). Moreover, communication patterns tend to remain stable throughout relationships, if the couple does not seek counseling. For example, couples who engage in demand/withdraw communication at the beginning of their relationship are more likely to continue in this pattern throughout their relationship, and for many, this will lead to divorce (Gottman & Driver, 2005; Caughlin, 2002; Caughlin & Huston, 2002; Gottman & Levenson, 2002; Gottman, 1993; Christensen et al., 1995). Therefore, in order to gain a more complete picture of this population's struggles and to more appropriately intervene, it would be important to conduct more longitudinal research with this population.

Another limitation is that this study does not include partner data. The researchers attempted to gather partner data by targeting male-centered advocacy websites, online coalitions, and support groups, and encouraging patients to have their partners fill out the survey. Qualitative reports from the patients and those men who completed face-to-face interviews indicated that discussing their partner's breast cancer was a tremendously emotional and difficult task. Other studies which gathered partner data generally had older sample sizes and recruited directly from research hospitals or medical treatment centers (e.g. Manne et al., 2007; Manne et al., 2006; Hodgson et al., 2003; Northouse et al., 2001, Northouse et al., 1998; Northouse, 1989; Northouse & Swain, 1987). Future research attempts in this area should be made to make this process less threatening and more supportive. It would be important to see how well the partners' perceptions of initiation and dyadic satisfaction correlated with the patients' and is also recommended for future research. Without partner data, only half the picture of relationship interaction is available. Oftentimes, couples have different views on their communication patterns and its implications for dyadic satisfaction. This data would help guide MedFTs regarding assessment and appropriate intervention.

The study design was to focus specifically on associations among variables. However, associations do not give much insight into causality or other mediating or moderating variables. Two measures of dyadic interaction were chosen, the ISQ and the RDAS. Other variables which may affect initiation and dyadic satisfaction were not examined or controlled for, such as patient depression, patient's perceptions of social and family support, or patient's sense of sexuality. In the larger study, measures were included to address these areas. However, for the purposes of this paper, they were not examined.

Finally, the majority of participants completed the survey online. Only recently have researchers begun conducting online psychological surveys. There are advantages and disadvantages to conducting online research. The main advantages include: access to a large population, less cost, 24-hour access, increased participant anonymity, participants can provide information at their own pace, and increased willingness to participate because it is a novel research approach (Ahern, 2005; Riva, Teruzzi & Anolli, 2003). This may be an ideal way to access young breast cancer patients, as research indicates that the Internet is an empowering tool for them to find support and share their stories (Pitts, 2004). The main disadvantages consist of: difficulties controlling the study environment, participants are generally unmonitored, selfselection biases, and the potential difficulties of creating a Web-based survey and storing the data (Riva et al., 2003). Cantrell & Lupinacci (2007) found it difficult to recruit members online and had problems with missing data. However, in their study comparing the Internet attitudes and behaviors of 203 online participants with 202 offline participants, Riva et al (2003) found that few differences between participant groups and suggested that Internet-based assessments can be a viable alternative for paper and pencil-based tests. Kornblith et al (2006) also reported no difficulties conducting research on cancer-related communication online.

Conclusion

Overall, the results of this study lend support to previous research in the areas of demand/withdraw and initiate/avoid in both medical and non-medical populations. Patients perceived themselves to initiate relationship discussions more often than their partners. Additionally, higher levels of perceived partner initiation were associated with greater dyadic satisfaction and patient quality of life. It appears as though the ISQ is an appropriate measure to assess levels of initiation among both partners in a medical population. Some findings are difficult to easily explain or understand based on the fact that this study solely focused on associative data (e.g. pain with sexual intercourse decreases as perceived partner initiation increases). It appears as though young women who have breast cancer could benefit from having therapeutic interventions targeted at increasing initiation between both partners, beginning soon after initial diagnosis. Future research should focus more on causality and predictability among these variables as well as focus more extensively on incorporating partner data. With a clearer understanding of the communication patterns of young women with breast cancer and their implications for dyadic well-being, interventionists will be better positioned to provide appropriate treatment.

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APPENDIX A

COVER LETTER/CONSENT FORM

Dear Spouse or Partner:

I am Dr. Stephanie Burwell in the Department of Child and Family Development at The University of Georgia. I invite you to participate in a research study entitled "The Psychosocial Needs of Women Aged 50 and Younger with Breast Cancer and their Partners".

The purpose of this study is to understand more about the psychosocial needs of younger women with breast cancer and those of their spouse or partner.

Please do not participate if you are not 18 years old or over.

If you agree to be in this study, you will complete a web-based survey that asks about your experiences related to coping with breast cancer. It should take approximately 45 minutes to complete. You can skip any questions that you do not wish to answer. As you complete the survey, your answers can be sent over the Internet by clicking on the NEXT button at the end of each page. If you do not wish to submit a response, please do not respond to the question. If you do not click NEXT, your responses will not be recorded or submitted to the researchers. In addition, with your permission, we may contact you 2-3 weeks after you participate to seek clarification or more information regarding your responses.

Please note that Internet communications can be insecure. We cannot guarantee your privacy and confidentiality while the data is transmitted to us over the Internet. However, once we receive the completed surveys, any information that is obtained in connection with this study and that can be identified with you will remain confidential except as required by law. All records pertaining to your participation will be kept in a password protected computer. When all of the data have been collected and analyzed, any individual identifying information pertaining to you will be removed or changed from our research records. If you are not comfortable with the level of confidentiality provided by the Internet, please feel free to print out a copy of the survey, fill it out by hand, and mail it to me at the address given below, with no return address on the envelope.

There are no direct benefits to you but the findings from this project may provide information on the psychosocial needs of younger women with breast cancer and their spouse or partner so that resources targeting these needs may be developed.

There are some minimal risks or discomforts associated with this research. They include psychological discomfort as you think about breast cancer and how it has affected you and your

relationship with your spouse or partner. The risk of harm or discomfort that may happen as a result of taking part in this research study is not expected to be more than in daily life or from routine psychological examinations or tests.

As compensation, you will be entered into a raffle for a \$60 gift card to Wal-Mart. Your participation is voluntary. Your may refuse to participate or discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled.

The researcher can be contacted for any further questions about the research, now or during the course of the project. Please see contact information for the researcher at the bottom of the page. Additional questions regarding your rights as a research participant or in the event of a research related injury should be addressed to The IRB Chairperson, University of Georgia, 612 Boyd Graduate Studies Research Center, Athens, Georgia 30602-7411; Telephone (706) 542-3199; E-Mail Address: IRB@uga.edu

By clicking on the link below, you are agreeing to participate in the above described research project.

Thank you for your consideration and important participation! Please keep this letter for your records.

Sincerely,

Dr. Stephanie Burwell The University of Georgia Department of Child and Family Development Family Science Center I Athens, GA 30602-2622 Phone: (706) 542-4897 Email: sburwell@uga.edu

1. SIGNATURES

I agree to take part in this study. My signature below will be indicated by checking the "I agree" box that the researchers have answered all of my questions to my satisfaction and that I consent to volunteer for this study.

SIGNATURES I agree to take part in this study. My signature below will be indicated by checking the "I agree" box that the researchers have answered all of my questions to my satisfaction and that I consent to volunteer for this study. I agree.

I do not agree.

APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE

Background Information

1.a PATIENT Date	of Birth:		PARTNER Date of Birth:
1.b Gender:	Age: Female		Age:
1.c Marital Status:	Married	Not Marrie	d
1.d Length of relation	onship or marria	ge: (years/month	s)
1.e Does your spou	se or partner liv	e with you? Y	Tes No
2. Number of times	-		
0	2	4	_
1	3	5 or more	_
3. Number of times	you have been	divorced:	
0	2	4	
1	3	5 or more	

4. Number of times you have been widowed:

0 ____ 2 ___ 4 ___

70

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: _____

APPENDIX C

ADDITIONAL DEMOGRAPHIC QUESTIONNAIRE

Additional Questions Patient/Partner

- 1. Do you have health insurance?
 - a. Yes
 - b. No
- 2. Is your spouse or partner covered on your health insurance?
 - a. Yes
 - b. No

3. What state do you live in? _____

4. What city do you live in? _____

- 5. Has anyone else in your family had breast cancer? If so, please list by their relation to you.
- 6. I am satisfied with my sex life.
 - a. Not at all
 - b. A little bit
 - c. Somewhat
 - d. Quite a bit
 - e. Very Much

APPENDIX D

BREAST CANCER HISTORY QUESTIONNAIRE

BREAST CANCER HISTORY

A.1 When w	as your breast cancer first diagnosed?	MONTH	YEAR
	e time of diagnosis have you had any of the follo circle "yes" or "no" for each type of treatmen	-	
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 you developed any other type of cancer? If yes, what type and when was this diagnosed?	1. NO	2. YES
A.4.	Have you had a recurrence of breast cancer? If yes, when was this?	1. NO	2. YES
A.5.	Are you currently undergoing any treatment for cancer? If yes, please describe your treatment:	1. NO	2. YES

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

APPENDIX E

SYMPTOM SEVERITY CHECKLIST

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

APPENDIX F

QUALITY OF LIFE AND HEALTH STATUS QUESTIONNAIRE

General Quality of Life

The next set of questions are about your current quality of life.

Here is a picture of a stepladder. The top of the ladder represents the best possible life for you. The bottom of the ladder represents the worst possible life for you. One which of these 10 steps of the ladder do you feel you personally stand at the present time? (Circle one number from 1 to 10.)

Health Status

Below are some questions about your current health status.

In general would you say your health is: (Please circle one number.)

I. Excellent2. Very Good	3. Good	4. Fair	5. Poor
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Compared to before you had cancer, how would you rate your health in general now? (Circle one number.)

- 1. Much better now than before cancer
- 2. Somewhat better now than before cancer
- 3. About the same
- 4. Somewhat worse now than before cancer
- 5. Much worse now than before cancer

APPENDIX G

REVISED DYADIC ADJUSTMENT SCALE

The Revised Dyadic Adjustment Scale

Most people have disagreements in their relationships. Please indicate below the approximate

extent of agreement or disagreement between you and your partner for each item on the

following list.

		A	lways A	Almost (Occasionally	Frequentl	y Almo	ost Always
		А	gree A	Always	Agree	Disagree	Alwa	ys Disagree
				Agre	ee			Disagree
1.	Religious matters							
2.	Demonstrations of affection							
3.	Making major decision	s 🗆						
4.	Sex relations							
5.	Conventionality							
	(Correct or proper behav	vior) 🗖						
6.	Career decisions							
		All	Most of	f More	Often			
	ť	he Time	the Tim	e than	Not Occa	sionally R	larely	Never

 How often do you discuss or have you considered divorce, separation, or 	8					
terminating your relationship?						
8. How often do you and your partner quarrel?						
9. Do you ever regret that you married (or lived together?)						
10. How often do you and your mate "get on each other's nerves"?						
		Every Day	Almost	Occasionally	Rarely	Never
Every Day						
11. Do you and your partner outside interests togethe	00	ein □				
How often would you	say the	e following e	events oc	cur between y	you and yo	ur partner?

		Less than	Once or	Once or			
		Once a	Twice a	Twice a	Once a	More	
	Never	Month	Month	Week	Day	Often	
12. Have a stimulating exchange of ideas							
13. Work together on a project							

14. Calmly discuss				
something				

APPENDIX H

RELATIONSHIP DISCUSSION QUESTIONNAIRE (FORMER NAME OF ISQ)

Relationship Discussion Questionnaire

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

1) When discussing a relationship problem I usually try to keep the discussion going until we settle the issue.	Strongly Agree 1 2 3 4 5	Strongly Disagree 6 7 8 9
 I usually express my feelings about our relationship to my partner. 	Strongly Agree 1 2 3 4 5	Disagree
3) I usually keep my feelings about our relationship private and do not share them with my partner.	Strongly Agree 1 2 3 4 5	Disagree
4) When I become aware of a problem in our relationship usually do not say anything about it.	Strongly Agree 1 2 3 4 5	Strongly Disagree 6 7 8 9
5) I am the kind of person who generally feels comfortable discussing relationship problems.	Strongly Agree 1 2 3 4 5	Disagree
6) When my partner wants to talk about a relationship problem, I am usually ready to do so as well.	Strongly Agree 1 2 3 4 5	Disagree
 I usually become silent or refuse to discuss a relationship problem further if my partner pressures or demands that I do so. 	Strongly Agree 1 2 3 4 5	Strongly Disagree 6 7 8 9
8) When my partner wants to talk about a relationship problem, I usually try to get out of the discussion.	Strongly Agree 1 2 3 4 5	Disagree
9) When I become aware of a problem in our relationship usually try to start a discussion of that problem.	Strongly Agree 1 2 3 4 5	Disagree

comfortable discussing relationship problems. As	rongly Strongly gree Disagree 2 3 4 5 6 7 8 9
11) When I want to talk about a relationship problem, my partner usually tries to get out of the discussion.	XStronglyStronglyAgreeDisagree123456789
12) My partner usually expresses any feelings about our relationship to me.	StronglyStronglyAgreeDisagree123456789
13) My partner is the kind of person who generally feels comfortable discussing relationship problems.	StronglyStronglyAgreeDisagree123456789
14) When my partner becomes aware of a problem in our relationship, my partner usually tries to start a discussion of the problem.	StronglyStronglyAgreeDisagree123456789
15) When discussing a relationship problem, my partner usually tries to keep the discussion going until we settle the issue.	StronglyStronglyAgreeDisagree123456789
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.	y Strongly Strongly Agree Disagree 1 2 3 4 5 6 7 8 9
17) My partner usually keeps feelings about our relationship private and does not share them with me.	StronglyStronglyAgreeDisagree123456789
18) My partner is the kind of person who generally does not feel comfortable discussing relationship problems.	StronglyStronglyAgreeDisagree123456789
19) When my partner becomes aware of a problem in our relationship, my partner usually does not say anything about it.	StronglyStronglyAgreeDisagree123456789
20) When I want to talk about a relationship problem, my partner is usually ready to do so as well.	StronglyStronglyAgreeDisagree123456789