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# The Effects of Uncertainty for Couples in Cancer Survivorship

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#### FLORIDA STATE UNIVERSITY

#### COLLEGE OF HUMAN SCIENCES

#### THE EFFECTS OF UNCERTAINTY FOR COUPLES IN CANCER SURVIVORSHIP

By

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A Dissertation submitted to the Department of Family and Child Sciences in partial fulfillment of the requirements for the degree of Doctor of Philosophy

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Natalie Senatore defended this dissertation on November 1, 2013. The members of the supervisory committee were:

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For my Grandpa John and Aunt Bobbie. I know if you had made it to survivorship you would have been the first people lining up to help me with this endeavor. Miss you always.

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#### ABSTRACT

The purpose of this study was to investigate the experience of uncertainty in illness for couples in the post-treatment phase of a cancer diagnosis. More specifically, the study sought to determine if lower levels of cancer uncertainty could lead to higher satisfaction with life, lower depression, and lower anxiety for both members of the couple. The additional influence of coping skill usage and marital quality was also examined in the context of the couple relationship. Symbolic interactionism was the theoretical framework guiding this study. An online survey was created that asked questions regarding sample demographics, uncertainty in illness, anxiety, depression, life satisfaction, marital quality and coping skills. Participants were contacted through letter mailings and in person recruiting through the Midwestern Site of the Cancer Treatment Centers of America as well as through Facebook recruitment and obtained a total sample of 84 couples. Data analyses involved using the Actor-Partner Interdependence Model (APIM) as well as path analysis using AMOS (Arbuckle, 2006) software to examine the hypotheses. Results indicated that a partner's higher level of uncertainty was significantly associated with their own higher levels of depression, anxiety, and lower level of satisfaction with life. Survivors' results indicated that their uncertainty was significantly connected to having higher anxiety. Finally, a partner's higher level of uncertainty was significantly related to higher survivor depression and anxiety. These findings suggest that a partner's level of uncertainty during the survivorship stage can function as an influential aspect of the adjustment to posttreatment life. Implications for researchers and practitioners are discussed.

#### **CHAPTER ONE**

#### **INTRODUCTION**

#### Background

The American Cancer Society predicted that in 2013 there would be 1,660,290 new cancer cases diagnosed, adding to the overwhelming total of 13.7 million Americans who have reported a history of cancer since 2008 (American Cancer Society, 2013). Increasing numbers of individuals have undergone successful cancer treatment and are now being declared "diseasefree" and living in remission, without active treatment. Although there will be 1.6 million new cancer diagnoses predicted for 2013, approximately 1.07 million of these people will survive the diagnosis and move out of treatment and into remission. Many of those being diagnosed with cancer will survive due to advances in detection and treatment, therefore it is widely accepted that increasing numbers of patients will find themselves living with cancer yet also being considered "disease free" (Schroevers, Ranchor, & Sanderman, 2006). A cancer survivor is an individual who has been diagnosed with cancer, regardless of when that diagnosis was received, who is still living (Centers for Disease Control and Prevention, 2008). Survivorship can be defined as a three-stage process: acute, extended, and permanent. No specific timeframes exist for the stages, nor do all patients go through every stage (Decker, Haase, & Bell, 2007; Mullan, 1985). The acute stage of survivorship is at the time of initial diagnosis when decisions are made about staging and treatments are initiated. The extended stage comes after completion of treatment and into possible remission. Survivors may have periodic examinations at this stage but treatment is over. Cancer survivors may have ambiguous feelings while dealing with the uncertainty of treatment outcomes and fear of recurrence. The permanent stage is defined as the achievement of cure long-term survival and is presumed to be permanent, although each type of cancer has its own criteria for long-term survival. Cancer survivors have reported feeling like warriors without a war when treatment ended and they were no longer in frequent contact with healthcare providers (Hewitt, Greenfield, & Stovall, 2006; McKinley, 2000).

This leads to a growing need to understand the experience of the survivor. Many survivors face emotional distress caused by the long-term symptoms of treatment and uncertainty about the possible recurrence of cancer, including lingering anxiety and depression (Shields & Rousseau, 2004). Uncertainty about recurrence can reduce resourcefulness and a sense of control

over life, as well as diminish coping skills (Garofalo, Choppala, Haman, & Gjerde, 2009). With the increasing trend towards survivorship comes a need to explore the illness experience beyond diagnosis and treatment and to consider all phases of the cancer trajectory. There is a need for insight into the long-term effects of cancer that this large and growing population of survivors may face when they are no longer treating their disease and are living in remission (Bowman, Deimling, Smerglia, Sage, & Kahana, 2003).

#### **Statement of the Problem**

Although there is literature written and research being conducted regarding partner studies in the context of a cancer diagnosis, the majority of these studies also focus on the diagnosis and/or treatment phase. To a much lesser extent, partner studies are being conducted in the context of cancer survivorship. Although there are some studies that include both survivors and their family caregiver/partner, many of these focus their application to a few limited areas. Typically, the research looks at social support, appraisal, and quality of life. There is a need to broaden the literature to look at both survivors and partners in terms of mental health issues such as depression and anxiety. Taking it a step further, there is a need to explore the impact of coping skill usage and marital quality for both the survivor and their partner in the survivorship stage.

In order to expand the literature, research needs to be conducted that includes partners as well as survivors in part of an effort to reduce suffering and promote long-term health for all who are impacted by the experience of cancer (Kim & Given, 2008; Manne & Badr, 2008). This lack of attention emphasizes the need for research with both parties, which holds the promise not only of improving survivors' health outcomes, but also those of their significant others. Targeting both survivors and partners will provide information for a fuller understanding of the experience of survivorship.

#### **Purpose of the Study**

The purpose of this study was to examine the bidirectional effect that uncertainty in illness has on both survivors and their partners when in the extended survivorship stage of a cancer diagnosis. By looking at uncertainty as the independent variable and seeing its impact on both partners in terms of their anxiety, depression, and overall life satisfaction, it can provide new information on a unique factor influencing adjustment to survivorship. This study differs from other studies available in the cancer research literature as it examined three unique contextual factors. The first factor is that the stage of cancer studied was long-term survivorship,

not adjustment to the illness/diagnosis or while in treatment. The second factor is that the survivor and partner data were paired and measured jointly, allowing the examination of mutual influence. Finally, the psychological dimension of uncertainty in illness has yet to be explored for couples in survivorship.

#### **Theoretical Framework**

#### Symbolic Interactionism

From a theoretical standpoint, the concepts and ideas of symbolic interactionism best apply to the study of uncertainty in cancer survivorship. As a theory, symbolic interactionism calls attention to the importance of how experiences are interpreted by those living the experience (White & Klein, 2008). A focal point is that the manner in which individuals interpret their environment will impact how they behave in their environment. People work to create meaning in order to make sense of their world and allow them to live within it (Blumer, 1969). A basic concept of the theory is that everyone has and recognizes symbols or signs that are societally agreed upon. A symbol creates a shared meaning for an object, whether it is a person, thing, or behavior. Communication and interpersonal interaction is based on knowledge of, creation of, and understanding of symbols (Chibucos, & Leite, 2005). The creation of symbols allows for meaning to be made and shared.

Each person has a "self," a combination of how one sees themselves as well as how others perceive him or her. This is important in symbolic interactionism, as no behavior or individual exists in isolation, therefore the process of socialization allows people to interact and co-create themselves. The theory explains that perception informs behavior. How individuals view themselves or the world around them will then alter their behavior in response to these interactions. This emphasizes the interdependent nature of society and the influence of interactions by the various people and relationships within a social setting.

Although there is one "self" for each person, the "self" will take on many different ways of existing and acting depending on the situation. Each of these different ways of existing is called a "role." A role is a prescribed set of attitudes, beliefs, and behaviors that determine cognitions and behaviors necessary to function in any given situation. Roles can differ from person to person and place to place. There are rules associated with roles and these rules dictate the expectations of how individuals should be conducting themselves in any given role. Although there are rules about roles, there is not always "clarity of role." This means that the rules may not be clear, may not be easily accessible, or may not be congruent with the person taking on the role. This can lead to role strain, where the person trying to take on the role does not have enough resources (personal or tangible) to complete their role effectively.

Symbolic interactionism provides a framework for understanding uncertainty in cancer survivorship as couples are working to create meaning and understanding of the survivorship phase of the cancer. The level of uncertainty one experiences may also be expressed as the extent to which one cannot make a coherent meaning for a situation or experience. Symbolic interactionism sees the creation of meaning as a central and defining process of the human life. A basic definition of uncertainty in illness is that it is the inability to make meaning from one's current situation. Because most of the medical attention and support is provided during the active phase of cancer treatment, the transition to the survivorship phase receives much less definition and thought. There may be little available to couples that are trying to piece together the meaning of this new phase. This is further compounded by the fact that, because of the nature of the disease, there is no guarantee that the disease will not return. Although cured for now, they can only consider themselves in remission as no cure has yet been found, therefore the uncertainty may persist as survivors are unable to give a permanent meaning to their disease state. Additionally, the influence of each partner's attempts to create meaning out of the uncertain survivorship stage may have a bidirectional impact, as each partner feeds off the other's level of uncertainty or ability to create meaning.

For couples who were in the midst of a cancer diagnosis, the cancer became a symbol for them. When the couples received the original diagnosis of cancer, it became a symbol and was influenced by each individual's appraisal of the diagnosis and prognosis. Both the survivor's and the partner's perceptions and meanings, as well as any socially constructed perceptions the couple held regarding what cancer means, were brought into the picture. The original symbol that cancer held may have been a positive one, where both partners rallied around a common goal or it may have been a negative one, interpreted as a threat to be eliminated. Regardless of the specifics, the cancer took on a symbolic meaning for the couple and served a function in their interactions. To move into the phase of survivorship means that the cancer no longer symbolizes what it did during diagnosis and treatment. A new meaning must be created and applied to survivorship; it must become symbolic in its own right.

Because symbolic interactionism sees meaning making an interactional process, it provides an important framework to explore how uncertainty is shared within the couple system. Because meaning is co-constructed, if either partner is unable to make an interpretation of the survivorship and create a shared symbol, there may be disconnect or struggle. Even if just one of the partners is struggling to make meaning around the symbol of survivorship, there will be a corresponding struggle for the other member of the couple system. This can be doubled when both partners are unable to make meaning from the situation and create agreed upon symbols.

Another important component of symbolic interactionism is the ability to take on roles. The previous roles enacted by the couple while dealing with an active cancer diagnosis no longer apply once they move into the survivorship phase. One is no longer a cancer patient but is now a survivor. The spouse is not necessarily a caretaker or support for a cancer patient any longer but has returned to the role of spouse. Typically, for those undergoing treatment, remission and living disease free is a goal to strive for and is typically viewed as an end point. Many cancer patients and spouses may not have thought about what it would mean to play the role of survivor and survivor's partner. There may be a lack of role clarity, as the new survivor is unsure how to behave or believe. Should they still be extremely health conscious, concerned about every ache and pain, and unsure about having hope that things are better or should they embrace their new freedom and live without major health or disease concerns? The partner may not know whether to continue in their caretaking and supportive role or wonder if they should embrace the freedom to stop worrying and fearing the worst that can become a reality with survivorship. When one partner is unable to find role clarity it may lead to the other partner being unsure about his or her own role expectations as well. So although only one person in the couple system may be struggling to find meaning, it can also have an affect on the partner.

Symbolic interactionism provides a framework for understanding the role of uncertainty in couples' adjustment to survivorship from cancer. Researchers may be able to predict outcomes such as depression, anxiety, and satisfaction with life by examining the influence that uncertainty has for both cancer survivors and their partners. By exploring how uncertainty is jointly constructed and experienced within cancer survivorship, research can examine how couple factors influence both the survivor and their partner (Brown, 1995). Based on the integration of symbolic interactionism and the variables, a conceptual model is presented in Figure 1.



Figure 1. Conceptual Model of Factors Influencing Anxiety, Depression, and Life Satisfaction.

#### **Research Questions**

1. To what extent does uncertainty in illness influence the experience of depression and/or anxiety, for both survivors and partners?

Hypothesis: Both survivor's and partner's experience of uncertainty will have a direct relationship to depression and anxiety.

2. To what extent does uncertainty in illness influence the experience of satisfaction with life, for both survivors and partners?

Hypothesis: Both survivor's and partner's experience of uncertainty will have a direct relationship to satisfaction with life.

3. To what extent does a partner's level of uncertainty influence the survivor's level of depression, anxiety, and satisfaction with life?

Hypothesis: A partner's level of uncertainty will have a direct relationship with depression, anxiety, and satisfaction with life.

4. To what extent do survivor's levels of uncertainty in illness influence the partner's level of depression, anxiety, and satisfaction with life?

Hypothesis: A survivor's level of uncertainty will have a direct relationship with depression, anxiety, and satisfaction with life.

#### **Interaction Effects**

A moderator model was used to examine the association between uncertainty and depression, anxiety, and satisfaction with life and how coping skill usage and marital quality

influences this relationship. Therefore, path analysis was used to investigate these possible interaction effects. The purpose of the moderator model was to examine:

1. The extent to which coping skill usage influences the relationship of uncertainty in illness on depression, for both survivors and partners.

Hypothesis: Coping skill usage will moderate the relationship between uncertainty and depression.

2. The extent to which coping skill usage influences the relationship of uncertainty in illness on anxiety, for both survivors and partners.

Hypothesis: Coping skill usage will moderate the relationship between uncertainty and anxiety.

3. The extent to which coping skill usage influences the relationship of uncertainty in illness on satisfaction with life, for both survivors and partners.

Hypothesis: Coping skill usage will moderate the relationship between uncertainty and satisfaction with life.

4. The extent to which marital quality influences the relationship of uncertainty in illness on depression, for both survivors and partners.

Hypothesis: Marital quality will moderate the relationship between uncertainty and depression.

5. The extent to which marital quality influences the relationship of uncertainty in illness on anxiety, for both survivors and partners.

Hypothesis: Marital quality will moderate the relationship between uncertainty and anxiety.

6. The extent to which marital quality influences the relationship of uncertainty in illness on satisfaction with life, for both survivors and partners.

Hypothesis: Marital quality will moderate the relationship between uncertainty and satisfaction with life.

#### **Conceptual Definitions**

For the purposes of this study, the following terms are defined:

*Survivor:* A man or woman who has been diagnosed with and completed treatment for a Stage I-IV cancer diagnosis and is currently in remission and considered disease free. *Partner:* The spouse or committed mate of the survivor who has been in a relationship with them for at least one year.

*Uncertainty*: is the meaning a person constructs for illness events, with uncertainty indicating an absence of meaning, as measured by the Mishel Uncertainty in Illness Scale-Survivor (MUIS-S; Mishel, 1997).

*Anxiety:* is defined by a psychological and physiological state that elicits feelings of uneasiness, apprehension, fear and/or worry, as measured by the Generalized Anxiety Disorder 7-item scale (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006).

*Depression:* is defined by a combination of symptoms that encompass low mood and a state of reduced ability to experience pleasure, as measured by The Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977).

*Coping Skills:* is defined by a behavioral or cognitive tool that may be used to offset or alleviate stress, as measured by the Brief COPE (Brief COPE; Carver, 1997).

*Marital Quality:* is defined by a global assessment of the perceived quality of a relationship, as measured by the Quality of Marriage Index (QMI; Norton, 1983).

*Satisfaction with Life:* is defined by looking at both the positive and negative emotional aspects of overall quality life and the cognitive judgment of overall quality life, as measured by the Satisfaction with Life Scale, a global measure of life satisfaction (SWLS; Diener, Emmons, Larsen, & Griffin, 1985).

#### Abbreviations

- 1. CTCA: Cancer Treatment Centers of America
- 2. SWLS: Satisfaction with Life Scale
- 3. MUIS-S: Mishel Uncertainty in Illness Scale-Survivor
- 4. CES-D: Center for Epidemiologic Studies Depression Scale
- 5. GAD-7: Generalized Anxiety Disorder 7-Item Scale
- 6. QMI: Quality of Marriage Index
- 7. APIM: Actor-Partner Interdependence Model

#### Assumptions

The nature of this study utilized self-report questionnaires. Therefore, the assumption underlying this procedure is that self-reported answers by survivors and partners were an accurate accounting of current thoughts, feelings, and behaviors. Furthermore, it indicates an assumption that the participants had the ability to accurately assess their personal information in a truthful manner, to the best of their ability.

#### Limitations

There are a few limitations inherent with survey research that is self-administered. The first limitation is that respondents might feel compelled to submit socially desirable responses to the various questions asking about their feelings and behaviors. Additionally, the number of respondents who completed the survey also limited the study in two ways. The first limitation of the study respondents is that their willingness to participate may introduce various biases that cannot be estimated or controlled for, such as a higher level of functioning, eagerness to do more regarding their disease, or a lack of support and a desire to connect. Secondly, respondents who skipped or missed questions will not have provided complete data that may be accounted for in the analysis. Finally, because the survey participants were contacted through a privatized cancer treatment hospital, the treatment they received may differ from the experience of other cancer survivors and therefore, the results may not be generalizable to all survivors and partners.

#### **Delimitations**

This study was delimited to survivors and partners that had an email account and Internet access in order to complete the online survey. Those who were able to participate because of their Internet access may have certain characteristics, both demographically and socially, that differ from those who do not have Internet access. Additionally, there were relationship and cancer characteristics (outlined in the methods section) that were necessary to require of participants in order that the sample would not be confounded by other variables of influence.

## CHAPTER TWO

The process of cancer survivorship may be likened to a journey, with changes over time in the experience for all family members (Anderson & Martin, 2003). Although one family member is given the diagnosis, each person who is in a close relationship with the cancer patient experiences the impact and effect. Patients and partners can create an especially close bond through the diagnosis and treatment phase, yet less is know about this bond in the post-treatment phase of a cancer diagnosis. This chapter presents a review of literature related to the experience of uncertainty in cancer illness. First, an overview of uncertainty in illness is examined for individuals and couples, as well as the experience of being in treatment or in survivorship. Next, the interaction effects of marital quality and coping skills are addressed. Finally, the impact and prevalence of depression and anxiety for cancer patients and partners is discussed as well as satisfaction with life.

#### **Uncertainty in Illness**

Survivors may face feelings of uncertainty for years after they have finished their treatment because of the long-term effects and the risk of recurrence of cancer (Shaha et al., 2008). In one study of 206 cancer survivors, all participants identified the possibility of cancer recurrence as a current worry. They reported being uncertain about the future development of the disease and what might occur, demonstrating that survivors are still uncertain and fear a recurrence of cancer (Schroevers et al., 2006). Moderate to high levels of fear of disease recurrence were found in 56% of breast cancer survivors from a study sample size of 136 participants and these levels were not determined by time since diagnosis, meaning that fear of disease recurrence was found independent of how long one had been dealing with cancer (van den Beuken-van Everdingen et al., 2008). Common concerns included fear of recurrence, uncertainty about the future, and coming to terms with losses (Cimprich et al., 2005). The studies that were conducted indicated that recurrence and uncertainty are commonly reported fears among cancer survivors that persist over time. Studies have shown moderate levels of fear of recurrence in breast cancer survivors and no change in their fear from 3 to 12 months postdiagnosis (Gil et al., 2004; Gil et al., 2006). Other investigators have reported persistent fear of recurrence in long-term cancer survivors even though they were no longer in the acute phase of

illness. This persistent fear can also be mutually influential for partners, as a survivor's fear of recurrence has been found to influence the partner's fear of recurrence, and has a degree of influence on the partner's general distress (Hodges & Humphris, 2009). Fear of recurrence is rapidly becoming a universal concern during survivorship, and has been linked to poorer psychological adjustment, increased emotional distress, and lower quality of life outcomes for survivors and their family members (Mellon, Kershaw, Northouse, & Freeman-Gibb, 2007; Mellon & Northouse, 2001). Psychological distress in cancer survivors can be detrimental to treatment adherence and self-care tasks and is associated with poor health behaviors and decreased overall quality of life (Lynch et al., 2008).

The concept of uncertainty in illness was developed as a theory and then translated into psychometric measures for research purposes. According to uncertainty in illness theory, uncertainty is generated when components of illness, treatment-related stimuli, and illness related events possess the characteristics of inconsistency, randomness, and/or unpredictability, in situations of importance to the individual (Mishel, 1981). In the first testing of the model, a small sample of 61 women with gynecological cancer were asked to assess what the antecedents to uncertainty were in their disease experience, or what thoughts or behaviors triggered their uncertainty (Mishel & Braden, 1988). In order to refine the theory and its scales, another survey of women with gynecological cancer was done, taking the antecedents previously found and the relationship they had with uncertainty. Results of the study indicated that mastery and coping were mediating functions of uncertainty (Mishel & Sorenson, 1991).

#### **Uncertainty for Individuals in Treatment**

Two studies specifically explore uncertainty for individuals who are currently undergoing cancer treatment. The first is a study by Galloway and Graydon (1996) that looked at uncertainty in the time after surgery for 40 colon cancer patients. The study used self-report to assess uncertainty and symptom distress in addition to a researcher-designed questionnaire to assess the information needs of the patients and whether the patients felt that these needs were being met. Higher levels of symptom distress and more unmet information needs were associated with higher levels of uncertainty for patients. In a more recent study, Shaha et al. (2008) conducted a 40 article review of the uncertainty literature for individuals who were diagnosed with breast, prostate, and colorectal cancer (the three most prevalent types). Overall, the literature review indicated that uncertainty was reflective of three domains. These domains included: uncertainty

due to lack of information, uncertainty concerning how the disease would progress, and uncertainty related to coping with the cancer.

#### Uncertainty for Individuals in Survivorship

The largest numbers of studies that exist on the topic of uncertainty were focused on individuals in survivorship. A small longitudinal study of 53 participants by Garofalo et al. (2009) found that uncertainty was able to predict a large percentage of variance in both functional wellbeing and physical wellbeing. A large intervention study was conducted to understand uncertainty and coping for female breast cancer survivors. The study had a sample size of over 200 women who were randomly stratified by race (African American and White) and were then stratified by treatment or control. The intervention consisted of a month of weekly telephone calls to survivors, during which, nurses guided participants through cognitive behavioral coping strategies to address their thoughts of uncertainty. Longitudinal findings for 10 months post-intervention and 20 months post-intervention indicate that for the intervention, uncertainty was significantly decreased at both time points, for both races. Significant increases in various coping strategies were also reported for the intervention group (Gil et al., 2005; Gil et al., 2006). In a small, convenience sample of 89 Latina breast cancer survivors, the overall scores for the Latina population was higher on level of uncertainty experienced when compared to other white samples (Sammarco & Konecny, 2008). In a 2009 study by Sammarco, a group comparison was conducted between older breast cancer survivors and younger breast cancer survivors. Each group had between 100-200 participants and was measured on domains of social support, uncertainty, and quality of life. The study found no significant difference between the age cohorts on level of uncertainty experienced, despite the fact that differences between the groups were found on other items like social support. Uncertainty was also the strongest predictor of quality of life (Sammarco, 2009).

#### **Uncertainty for Couples in Treatment**

In a study of 85 pairs of patients and their family members, the meaning of illness, coping, and quality of life was examined. Less negative social support (i.e. blaming, criticizing, distancing, belittling) and a less negative appraisal of the event were both associated with higher quality of life (Downe-Wamboldt, Bulter, & Coulter, 2006). Although, for both patient and spouse, early experiences of more symptoms and more initial concerns created a more negative appraisal of illness and increased uncertainty. Active coping was associated with better quality of

life while avoidant coping was associated with poorer outcomes (Kershaw et al., 2008). Fear of recurrence has been shown to be more of a burden for cancer survivor's partners than the survivors themselves and the research continues to show that there is a significant positive correlation between the survivor and partner levels of distress and fear of recurrence, even over time (Hodges & Humphris, 2009).

Northouse, Dorris, and Charron-Moore, (1995) found that both hopelessness and uncertainty were significantly related to both partner's levels of adjustment to the disease. Increased hopelessness and higher levels uncertainty were associated with poorer adjustment. There was no interdependence measure in the study, so it is unknown how these factors affected each other. In another study, Northouse et al., (1998) found that couples in the malignant breast cancer group reported higher uncertainty appraisal, more adjustment problems, and showed larger decreases in functioning. Additionally, the adjustment levels of the husband and wife correlated over time. Both uncertainty and hopelessness have been found to have a significant impact on adjustment for both members of the couple system. Also, the adjustment problems the couple experienced at the beginning of treatment were sustained over time (Northouse et al., 2001). Another study conducted by Northouse et al. (2007), examined the effects of a clinical intervention trial on uncertainty and coping skills that involved three 90-minute home visits and two 30-minute telephone sessions that targeted couples' communication, hope, coping, uncertainty, and symptom management. Those couples receiving the intervention reported less uncertainty and increased communication compared to the control group.

#### **Uncertainty for Couples in Survivorship**

The final piece of the puzzle is becoming the most relevant, as survivorship numbers continue to climb, yet is the most lacking area of research dealing with uncertainty. Shields and Rousseau (2004) conducted a pilot study to examine the impact of an intervention for breast cancer survivors and their spouses. They offered two different treatment options, one where couples attended two group therapy session and one where the couples only attended a one-time meeting, as well as a control group. More improvement in mental health was reported for the two-group meeting format.

The only true studies of couple and family survivorship experiences focus on quality of life and fear of recurrence. Both of the studies were conducted by Mellon and colleagues and were one-time cross-sectional data collections. Both studies used cancer registries to find their

population and used stratified random sampling to match the population on race (African American or Caucasian). Both studies had sample sizes between 100-200 dyads. The initial study found a mutual influence that when the survivor's quality of life was high the partner's quality of life was high. Additionally, survivors reported less fear or recurrence than their partners did (Mellon et al., 2006). The second study was based on the same sampling procedure and method, although the population was significantly older with most participants being 65 years or older. Hierarchical linear modeling was used to determine that the partner. Those who reported a more positive appraisal reported less fear of recurrence. The findings also showed that partners continue to report more fear of recurrence than cancer survivors do (Mellon et al., 2007).

#### Marital Quality

Examining the role of the marital or partner relationship is especially relevant when considering illness as a major factor in the life of the couple. Both of the partners involved in an intimate relationship can experience distress when even just one of them has been diagnosed with a serious illness (Northouse, Templin, Mood, & Oberst, 1998). Coyne and Fiske (1992) observed two unique aspects that influence marital adjustment in the midst of health challenges. The first thing that affects marital adjustment is each spouse's individual response to the illness. The second aspect is seen in the reciprocal nature of the relationship, which influences how each individual's response may reinforce or hinder their partner's adjustment. Partner adjustment may be considerably influenced by the adjustment of the patient (Coyne & Fiske, 1992).

Although being married is often a buffer that can be associated with lower mortality for people from a variety of illnesses, it is actually the quality of the marriage that most significantly influences one's health (Halford, Scott, & Smythe, 2000; Weighs, Enright, Howe, & Simmens, 1999). Chronic illness may burden the marital relationships in a distinctive way, with disparities seen between healthy couples and couples where one person has an illness (Badr & Acitelli, 2005). Within the general population, a couple's perception of insufficient intimacy and support during stressful times has been associated with a higher likelihood of mood issues (Prince & Jacobson, 1995). This may have an additional impact for a couple, in that a distant spouse may be creating a negative impact on their partner's wellbeing, which is also compounded by the disease experience (Pistrang & Barker, 1995).

Research has consistently found that a good marital relationship predicts better emotional adaptation to breast cancer (Coyne & Anderson, 1999; Skerrett, 1998). A chronic stressor, such as cancer, may undesirably affect marital wellbeing as the disease, and the stress associated with it, may introduce chances for conflict and strain that the couple may not have otherwise been faced with (Karney, Story, & Bradbury, 2005). Prince and Jacobson (1995) reported, for both husbands and wives, that a spouse in a distressed marriage was 25 times more likely to be depressed than a spouse in a nondistressed marriage. There is evidence that diagnosis and treatment of breast cancer can place pressures on a relationship, potentially leading to marital discord (Northouse, et al., 1998; Wai Ming, 2002). The interpersonal nature of the cancer experience requires a greater understanding of how couples maintain their relationships while coping with the disease (Ey et al., 1998).

Research on the quality of life of cancer patients has stressed the significance of social support from their marital relationship. Generally, marital satisfaction is shown to be an important moderating factor in the link between quality of life and level of psychological distress (Jenewein et al., 2008). A more positive marital relationship is associated with a higher quality of life among patients with cancer (Manne et al., 2004). Relationship quality can positively impact a cancer patient's quality of life, despite the added stress due to the disease. The quality of the relationship has shown a positive effect on the quality of life for both members of the dyad, despite pain and disease progression (Morgan, Small, Donovan, Overcash, & McMillan, 2011). There may also be gender differences in the experience of quality of life for married couples. In male patients, lower quality of life was associated with more physical complaints and higher levels of distress. For wives, lower quality of life was related to low marital quality and high levels of distress. Different experiences by role (patient versus partner) have also shown different impacts on quality of life. Having a positive relationship with their spouse had the highest correlation with the patients' quality of life, whereas being able to cope with problems had the highest correlation with the spouses' quality of life (Swensen & Fuller, 1993). The quality of the relationship has also been found to have an influence on level of pain and how patients rate it. Increases in quality of the relationship are associated with a decrease in patient pain, a significant total effect that has been equated to receiving a dose of morphine or lowering a pain rating from an 8 to a 7 for patients (Morgan et al., 2011).

There is an important correlation between marital quality and level of patient and partner distress. The level of marital satisfaction at the time of diagnosis is closely related to breast cancer patients' future distress (Ptacek, Ptacek, & Dodge, 1994). Repeated measures of marital quality across time show that the level of marital quality remains consistent over time. Higher levels of patient impairment are associated with greater patient psychological distress. Greater patient distress has, in turn, been related to poorer spouse marital quality over time (Fang, Manne, & Pape, 2001). The psychosocial experience of this disease typically includes emotional distress, sexual issues, and relationship difficulties (Henson, 2002; Tan, Waldman, & Bostick, 2002), as well as concerns for the future due to the possibility of relapse and the long-term impact of treatment (Moyer & Salovey, 1999). For patients and partners, psychological distress is predicted by dyadic adjustment and coping styles after a cancer diagnosis and if one partner becomes distressed, the other is likely to follow (Banthia et al., 2003; Ko et al., 2005; Morgan et al., 2011). Those who are married but who report low marital quality, particularly men, may be at higher risk for adjustment problems while actively receiving treatment for cancer (Rodrigue & Park, 1996).

In a study done by Yang and Schuler (2009) it was found that marital distress was associated with slower recovery trajectories and poorer outcomes. Stress declines more slowly for the maritally distressed patients (at baseline), and at five-year follow-up, these patients' marital distress levels remained significantly higher. The maritally distressed patient was also found to have a slower recovery in performance status and more symptoms/signs of illness and treatment side effects through three years. These findings are notable because the analyses controlled for baseline depressive symptoms, which were significantly higher for maritally distressed survivors. Therefore, marital distress is associated with poorer outcomes beyond those occurring when individuals have persistent depressive symptoms (Yang & Schuler, 2009).

Higher relationship quality was found to predict lower patient distress and the quality of the relationship buffered the effects of cancer avoidance or intrusion on distress. Specifically, avoidance and intrusions were not associated with distress for men in more satisfactory relationships, but they were associated with greater distress for men in less satisfactory relationships (Banthia et al., 2003). Relationships that demonstrate high marital quality are able to attribute negative behaviors to stress and frustration, as opposed to blaming or criticizing, thus reducing any destructive impact. However, when trust is low, undesirable behaviors are

attributed to characteristics and intentions of the partner and negative interactions may occur at high frequency and intensity (Morgan, 2009). Patients, who reported that their marriage was unsatisfactory, were at greater risk for elevated distress in the future than were those who were satisfied with their marriage (Weighs et al., 1999). Higher marital quality, as perceived by the patient was associated with fewer general and illness-specific adjustment problems. Those who reported greater satisfaction with their marriage reported fewer symptoms of depression, anxiety, and global distress (Rodrigue & Park, 1996).

A number and variety of factors influenced marital satisfaction for couples going through the experience of a cancer diagnosis and treatment. The method and amount of support that spouses provided for their partners was found to very important and linked to the patient's marital satisfaction, with more frequent and diverse ways of providing support being seen as most helpful and influential (Hagedoorn et al., 2000). Individuals who engaged in prorelationship behaviors adjusted to living with lung cancer better than those who did not: specifically, patients and spouses who reported greater use of positivity and engaging in more shared tasks reported less distress at baseline. Couples where both partners engaged in more frequent maintenance behaviors reported greater dyadic adjustment at baseline and over time (Badr & Carmack-Taylor, 2008). Patients have reported less distress when they also rated the relationship as high in cohesion-expression (we both express ourselves openly) and higher levels of conflict, as well as when their partners reported lower mood disturbance. This may indicate that partners can benefit from open engagement around problems and concerns throughout the disease. Furthermore, by focusing on the couple relationship (rather than the patient's coping), couples may be better able to lessen distress (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000). Active engagement is also positively associated with marital satisfaction. In contrast, protective buffering (keeping information or feelings to oneself in order to prevent distressing a partner) and overprotection were negatively correlated with satisfaction (Hagedoorn et al., 2000). Mutual support experienced by partners predicts wellbeing for patients and partners (Halford et al., 2000). Demonstrations of partners' support are most critical during times of stress when people feel vulnerable (Hinnen, Hagedoorn, Sanderman, & Ranchor, 2007; Manne et al., 2004); in a study of patients with breast cancer, those with higher marital satisfaction had lower hopelessness and fewer adjustment issues (Northouse, Templin, & Mood, 2001).

Two unconstructive strategies, mutual avoidance and patient demand-partner withdraw, were also associated with greater distress. This indicates that the degree to which one or both partners avoid talking about cancer-related concerns, can either facilitate or reduce relationship closeness and therefore impact psychological distress (Manne, Badr, Zaider, Nelson, & Kissane, 2010). Research has shown that relationships where the husband exhibits withdrawal behaviors and the couple reports a low level of marital satisfaction have been associated with more mood disturbance and depressive symptoms (Giese-Davis et al., 2000). Partner unsupportive behaviors, including distress-maintaining attributions, hostility, and depressed affect, were associated with less relationship satisfaction (Manne et al., 2004).

Communication is also another part of the cancer experience for couples. When patient and partner engage in communicating positivity and hopefulness to each other, as well as taking a more active role in their relationship by sharing tasks and seeking support, these activities have helped to enhance patient and spouse dyadic adjustment over time (Badr & Carmack-Taylor, 2008). Also, reciprocal self-disclosure during the cancer discussion was associated with lower levels of both cancer-specific and general distress. These results are consistent with the marital communication literature that suggests sharing one's thoughts and feelings to one's spouse improves intimacy and ultimately strengthens relationship quality (Manne et al., 2004)

Emotional support is another important aspect of the couple relationship during the disease experience. Seeking emotional support and using positive reappraisal are more effective (i.e., were significantly and positively correlated with marital satisfaction) for people low in spousal support (Ptacek & Pierce, 2007). It has been shown that women's impressions of their partners' emotional involvement after surgery for breast cancer predicts their adjustment in sexual, marital, and emotional arenas over the following year (Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005). Analyses revealed that the woman's perception of having a positively involved partner related positively to her own wellbeing. For men, the more emotional support they perceived from their partners, the more they are able to utilize effective coping skills. In turn, the more effective use of coping skills, the less illness intrusion they experience (Feldman & Broussard, 2005).

#### **Partner Concerns**

Entering into the survivorship stage is not an issue for the patient alone. This transition and phase is a relevant concern for the survivor's significant other or partner. To an important

extent, patients and partners are interdependent in that cancer impacts their shared lives, both emotionally and practically. Thus, the partner influences the adjustment of the patient, and conversely, the patient's diagnosis and treatment of cancer affects the adjustment and emotional wellbeing of the partner (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008). There is evidence that at times partners may be more distressed than patients themselves. Despite frequently being identified by patients as integral to their health and functioning, significant partners are often neglected in research and the clinical care setting (Northouse et al., 2007). Often, the patient's partner is also in the role of a caregiver to some extent. This additional role has been associated with increased physical, psychological and social morbidity. Partners typically assume a significant physical and emotional care burden and elevated rates of psychological and psychosomatic symptoms, equal to or higher than that experienced by patients (Hodgkinson et al., 2007).

In recent studies, partners' adjustment scores not only were correlated but also accounted for a significant amount of variance in one another's adjustment to colon and breast cancer (Hagedoorn et al., 2008; Shaha et al., 2008). Similarly, in a study of couples' adjustment to metastatic breast cancer, higher mood disturbance in survivors was related to higher mood disturbance in their partners. Additionally, the level of cancer worries reported by one member of a dyad was related to the amount of worries reported by the other (Mellon et al., 2008). For the most part, the mutual effect of survivors' and family partners' adjustments on one another has been examined primarily during the active phase of treatment, using measures of adjustment or emotional distress. It is not clear if this mutual effect extends beyond the treatment phase of illness into the survivor phase (Kershaw et al., 2008; Mellon, Northouse, & Weiss, 2006). Another study indicated that partners worry more about the survivors' future than survivors do, perceive less emotional support, report stronger concerns regarding family issues, and at times report more distress than the cancer survivors themselves report (Mellon et al., 2006).

#### **Coping Skills**

Patients need to find ways to cope and adjust to their survivorship of cancer as part of their everyday life, just as they had to adjust to their diagnosis. In order to manage uncertainty, a range of coping strategies is typically utilized (Shaha et al., 2008). Research exploring coping skills impact on adjustment suggests that coping through cognitive, emotional, or behavioral disengagement or avoidance is detrimental to long-term adjustment, whereas coping through

active acceptance, seeking social support, emotional expression, or other approach-oriented coping strategies predicts diminished distress over time (Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000). The coping strategy of protective buffering has been shown to influence both depression and self-care agency for cancer patients. Patients attempts to protect their close family members from the stressors associated with their illness has not shown to be an effective coping technique, as it leads to increased depression and a lower sense of personal empowerment (Kayser et al., 1999). Personal and social resources that were present at the beginning of treatment best distinguished the different trajectories of mental and physical functioning over time. Those with personal resources knew when to call upon social resources and were more likely to have social resources available. Patients who were able to utilize their resources had better adaptation to the experience of cancer (Helgeson, Snyder, & Seltman, 2004). Yet if not remediated, acute or chronic stress may contribute to emotional distress, life disruptions, and, in turn, to a stable, lower quality of life. Cancer survivors reported continuing problems with emotional distress, fatigue, reduced energy, and loss of stamina (Broeckel, Jacobsen, Balducci, Horton, & Lyman, 2000; Michael, Kagwachi, Berkman, Holmes, & Colditz, 2000). When left untreated, stress and lowered quality of life conspired to produce a difficult trajectory on the road to cancer survivorship (Green et al., 2000).

Some of the most frequently used coping strategies reported include: calming self-talk, distraction, and relaxation (Gil et al., 2005). Longitudinal research in breast cancer patients completing their course of medical treatments showed that coping by means of an emotional approach predicted better psychological adjustment over and above the influence of other coping strategies (Low, Stanton, Thompson, Kwan, & Ganz, 2006). For women in survivorship, treatment interventions have shown improvements in coping skills such as: cognitive reframing, cancer knowledge, and communication (Mishel et al., 2005). A large randomized, controlled trial for women in treatment studied coping strategies and their impact on the meaning that women make of their illness. Positive coping strategies predicted a strong sense of meaning, while the absence of positive strategies led to a loss of meaning for patients. Active coping and social support were important predictors of positive outcomes while avoidant coping was associated with poorer outcomes (Jim, Richardson, Golden-Kreutz, & Andersen, 2006). Regardless of role (i.e., patient or spouse), individuals who engaged in the strategies of positivity, networks, and shared tasks reported less distress at baseline than other participants. Couples where both

partners engaged in more frequent maintenance behaviors reported greater dyadic adjustment at baseline and over time. Over time, the effects of providing more assurances and experiencing a partner's increased reliance on social networks differed; patient distress was exacerbated, and spouse distress was alleviated (Badr & Carmack Taylor, 2008).

The type of coping style or behavior used was a significant contributor to the survivor's and their partner's cancer worries (Mellon et al., 2008). Research indicated that those who were more flexible in changing their daily tasks and who had preexisting resources for coping with stressors had more positive outcomes than did families who were rigid and typically coped with stressors poorly (Radina & Armer, 2009). Coping skills interventions showed a positive impact on both usage as well, as other psychological domains. Interventions incorporating coping skills have reported significant decreases in uncertainty as well as significant increases in the use of skills such as cognitive reframing, cancer knowledge, and information seeking (Gil et al., 2006).

In a qualitative study, Zunkel (2002) identified four relational behaviors by which each partner contributed to the coping with cancer. These behaviors included: sharing in the patient's recovery, helping the patient, normalizing the household, and moderating or minimizing the intrusion of the cancer. Zunkel (2002) defined two distinct types of processes: an acknowledging type and a moderating or minimizing type. The acknowledging process incorporated the illness into family life, with couples openly expressing their feelings and acknowledging their partners' responses to the cancer and recovery. In contrast, the moderating or minimizing process attempted to limit the cancer's impact on the family.

Two types of relational coping patterns have been identified (Kayser, Watson, & Andrade, 2007). The first pattern was termed "mutual responsiveness" and was defined by the way the couple would refer to the cancer experience as a mutual stressor that had an impact on both of them. The partners communicated their response to the stress to each other and they listened and supported each other's responses. Talking openly about their stress allowed them to approach managing the disease in a coordinated way that involved both emotion-focused and problem-focused types of coping strategies. Similarly, Manne et al., (2004) found that open communication positively affected the psychological adjustment for both cancer patients and their spouses. The second pattern of coping was called disengaged avoidance, and was defined by the way the members of the couple would refer to the cancer experience as an individual stress, affecting each of them individually, with no reference to their joint experience. These

couples avoided communication about the disease and their coping efforts were problem-focused coping behaviors that involved dealing with practical tasks of the cancer while ignoring the emotional experience. Previous research found that avoidant coping was also associated with unsupportive behaviors (Manne, Ostroff, Winkel, Grana, & Fox, 2005) and more distress for patients and partners (Manne, et al., 2006).

#### **Depression and Anxiety**

Closely tied in with the experience of survivorship is the intertwined relationship of anxiety, depression, and uncertainty. Typically, these major components of survivorship change and fluctuate across the disease trajectory (Shaha, Cox, Talman, & Kelly, 2008). Multiple studies have identified clinical levels of anxiety and depression for various types of cancer patients posttreatment and into survivorship (Lynch, Steginga, Hawkes, Pakenham, & Dunn, 2008). Psychological distress was prevalent in up to 35% of cancer survivors studied from a database with 9000 patients who had completed measures on psychological distress and symptoms (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Studies have shown that there are many late-effects that remain post treatment, including general anxiety, avoidance, and depression (Deimling, Kahana, Bowman, & Schaefer, 2002). Based on longitudinal and crosssectional evidence, cancer survivors can experience symptoms of depression and anxiety for more than 10 years after treatment. These symptoms were present in survivors of four types of cancers (breast, gynecological, prostate, and colorectal) who had undergone various different treatments (Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010).

Emotional distress is commonplace among those who have been diagnosed with cancer. Specifically looking at women who have been diagnosed with breast cancer, a number of studies have looked at the incidence of stress, anxiety, and depression among this population. Illness uncertainty, symptom distress, fear of recurrence, and additional illness problems have been positively related to emotional distress. These variables, along with positive reappraisal have been found to collectively explain 51% of the variance in emotional distress in a sample of 109 women one to sixe years post-treatment for cancer (Mast, 1998). One statistic is that about one half of all women with cancer experience a level of distress, anxiety, or depression such that it interferes with and impairs their daily lives (Hegel et al., 2006). In one study with a sample of 236 participants, clinical depression has been identified in 10% of those with breast cancer (Hegel et al., 2006), while another study with a sample of 72 showed a range of 15–25%

(Sephton et al., 2009). This indicates that clinical depression, which is marked by symptoms of hopelessness, worthlessness, and loss of interest in pleasurable activities, may be a common occurrence among women with breast cancer, as well as other cancer survivors. Even if clinical levels of depression are not present, cancer survivorship may be indirectly related to higher depressive symptomatology through the mediating role of health issues. Fatigue and pain symptoms are found to be positively related to higher levels of depression (Townsend, Ishler, Bownman, Hannum Rose, & Juszczak Peak, 2009).

It has been shown that women with breast cancer had enduring and modestly higher levels of distress than comparison-control women. Distress in their male partners was not elevated in comparison to their matched general population controls. Although the level of distress decreased over time, 15 months after diagnosis, patients were still more distressed than comparison-controls and also more distressed than their partners. Peak levels of distress followed by a decline thereafter were observed after the end of treatment. Ending treatment may be correlated with an increase in distress as survivors and partners may lose the security associated with being in treatment and in regular contact with healthcare professionals (Hinnen et al., 2008). Some studies have found that even with an intervention component, significant reductions in distress such as anxiety, depression, and confusion are not observed (Sandgren, McCaul, King, O'Donnell, & Foreman, 2000). Even after lengthy or intense treatments have concluded, individuals may still report disruptions in major life areas (Cordova et al., 1995). Permanent and unanticipated effects from cancer treatments have the potential to impact intimate relationships, social support, and even heighten emotional distress (Ey, Compas, Epping-Jordan, & Worsham, 1998; Hagedoorn et al., 2000; Mast, 1998; Stegina et al., 2001).

In terms of gender roles, different experiences of depression have been found for couples dealing with cancer. Six months post surgery has shown that female patients perceive more psychological distress, as evidenced by depression, than male patients. Also, at three and six months after surgery, female spouses perceive more psychological distress than male spouses. Finally, prior to surgery, role differences in distress were found for females as well as males, with females experiencing more distress in the role of patient and males perceiving more distress when they were the spouse (Tuinstra et al., 2004). Women who are experiencing high levels of stress and negative affect have been show to have a significant effect on their partner's depression (Segrin, Badger, Dorros, Meek, & Lopez, 2007).

Both survivors and partners have shown significant positive relationships between their own psychological distress and their partners, even over multiple time points (Hodges & Humphris, 2009). Partners who are supportive and better adjusted to the disease are a predictor of less depression and anxiety among patients in treatment (Maly, Umezawa, Leake, & Silliman, 2005). Women who perceive their partner relationships as highly mutual and interdependent rated lower on depression measures (Kayser, Sormanti, & Strainchamps, 1999). The role of the partner's experience of depression is not widely studied on its own. Research done by Feldman and Broussard (2006) looked at the experience of husbands whose wives had breast cancer and determined that depression was present and played an influential role in the men's functioning. Those who were depressed were predisposed to poorer adjustment to the illness, as well as issues with their coping patterns. A high level of depression was inversely correlated with a decreased use of positive coping skills. Higher levels of psychological distress have been found to be predictive of relative decreases in social support (Moyer & Salovey, 1999). Studies have shown that over a third of participants, both patients and spouses have reported psychological distress, and this distress was typically correlated. Distress predictors for patients included less positive social interaction support, more behavioral disengagement and self-distraction coping, and the spouse reporting less use of humor for coping. Predictors for spouses included more behavioral disengagement and substance use coping, more blaming the patient for causing the cancer, and the patient using more behavioral disengagement coping (Carmack Taylor et al., 2008).

#### Satisfaction with Life

Exploring the overall quality and satisfaction with life is import for cancer survivors and their significant partners (Ganz, 2005; Mellon, 2002). Surviving cancer had positive effects, such as greater appreciation of life, improved interpersonal relationships, enhanced spirituality, and healthier lifestyle choices. Negative influences of survivorship included fear of the future, fear of recurrence, and lingering long-term effects of cancer treatment from surgery, chemotherapy, and radiation (e.g., physical or psychological changes). In 2008, Kim and Given conducted an overarching review of the literature regarding quality of life for family caregivers of cancer survivors. They moved beyond the initial phase of survivorship where patients may still be receiving a good deal of attention and focused on long-term survivorship. They found that quality of life could fluctuate along the illness trajectory, depending on a variety of factors. Within the transition from patient to survivor, longitudinal research has shown that quality of life

can shift over time. In a study by Garofalo et al. (2009), it was found that there was a decrease in family and social wellbeing scores over time, while overall quality of life scores initially increased significantly, but at follow-up had then decreased significantly. Some studies have found a lower quality of life for cancer survivors that did not change across multiple years of survivorship, meaning that low quality of life scores remained low at 2-4 years into survivorship and continued to remain low after the 5 year mark of survivorship (Smith, Zimmerman, Williams, & Zebrack, 2009). While other studies did show a positive overall quality of life during the first year of survivorship, the overall trend of quality of life declined over time through survivorship (Loerzel, McNees, Powerl, Su, & Meneses, 2008). Typically, waitlist controls show decline in quality of life during the transition to survivorship, and although some studies have shown their quality of life may improve over time, the level it reached continues to be significantly lower than those who entered a treatment intervention (Meneses et al., 2007).

Overall quality of life for younger breast cancer survivors has been predicted by: current age, self-efficacy, death worries, anxiety, sleep quality, and symptom bother, which combine to explain 54% of the variance in quality of life in a sample of 195 women (Bell, Ziner, & Champion, 2009). On an individual level, a study of 89 Latina breast cancer survivors found that the amount of social support survivors perceived was able to predict 15% of the variance in quality of life scores, while their level of uncertainty was able to predict 10% of additional quality of life variance. The relationship between social support and quality of life was positive, while the relationship between uncertainty and quality of life was negative (Sammarco & Konecny, 2008). Additionally, another study found significant predictors of quality of life in breast cancer survivors included (in order of most variance explained): uncertainty, additional illnesses, social support, older age, and surgical treatment (Sammarco, 2009).

The adjustment process for cancer survivors may be burdensome and lengthy, and deteriorations in quality of life are often compounded when there are additional health concerns or struggles that surface during survivorship (Andersen, 2002). Health related quality of life was influenced by coping type (either adaptive or escapist coping). When respondents are reporting high levels of depression, negative affect, and overall impact of events, it may be that their heightened negative state is prompting them to start using more coping skills, more frequently. This may indicate that those who report more negative outcomes are those who continue to be affected by the disease even after treatment and therefore engage a range of coping strategies to
lessen the psychological affects (Blank & Bellizzi, 2006). Expressive coping also has been related to improved quality of life for those who perceived their social contexts as highly receptive. Although, coping through emotional processing has also been linked to experiencing distress over time (Stanton et al., 2000). Patients with a pessimistic explanatory style have shown significantly lower scores on all of the health-related quality of life measures, compared to those with a nonpessimistic style. Breast cancer survivors who exhibit a pessimistic explanatory style may report lower health-related quality of life for years after receiving a cancer diagnosis, compared to nonpessimistic women (Petersen et al., 2008).

Satisfaction and quality of life is another piece of survivorship that needs to explore both survivor and partner experiences. Women who perceive their partner relationships as highly mutual and interdependent rated higher on quality of life (Kayser et al., 1999). For a sample of 85 couples currently experiencing cancer, it has been found that how well a patient is able to manage their illness accounts for 31% of the variance in quality of life scores for patient and partner. Additionally for both patients and family members, the less negative social support and the lower need for social support also indicated higher quality of life scores (Downe-Wamboldt et al., 2006). Kershaw et al. (2008) found that there was a significant relationship between patient's and partner's mental quality of life, indicating a mutual influence of partners while in active treatment. While in the survivorship stage, there have been several significant predictors of quality of life for families. Some of these significant predictors included: concurrent family stressors, family member fear of recurrence, social support (as a resource), and the meaning made of the cancer by the family. It has also been found that family members' fear of recurrence has a direct effect on family quality of life (Mellon & Northouse, 2001).

There has also been research support for mutual influence between survivors and partners in terms of quality of life, meaning that when a survivor's quality of life was high, their partner's quality of life was high and vice versa. The emotional wellbeing of women who have had breast cancer has been shown to have an impact on their partner's wellbeing, where changes in wellbeing of the survivor (whether improved or deteriorated) were mirrored by similar changes in their partner (Segrin et al., 2007). Although mutual influence between partners may exist for quality of life, what predicts individual quality of life can differ by role of survivor or partner. For survivors, social support has been shown to account for the most variance in quality of life while for partners, fear of recurrence accounts for the most variance in quality of life. Additionally, those caregivers who were also married to the survivor reported higher quality of life, as compared to other dyad types (Mellon et al., 2006).

Although the areas of anxiety, depression, and uncertainty are not new ideas in cancer research, there remains a gap that needs to be addressed. Most of the dyadic research being conducted on the experience of cancer is conducted with a patient and partner who are currently undergoing treatment. This phase of the disease is well studied from an individual perspective and increasingly from a dyadic perspective, and is where most of the information about the cancer experience comes from. Yet the trend of the disease as a whole is moving towards greater and greater numbers of patients moving into survivorship, and this is where the major gap in the literature remains. Although there has been an increase in survivorship research over the last five years, the focus continues to remain on studying only the cancer survivor. The research seems to miss the fact that spouses have also transitioned from the treatment phase of the disease and are now active participants in the survivorship phase. This is most obviously seen in the section regarding uncertainty and couples in survivorship, as there are less than a handful of studies that have attempted to explore this area of cancer research. Assessing *both* the survivor and their significant other during the survivorship phase on these specific dimensions would help address this gap in the literature. Furthermore, the specific dimensions of anxiety, depression, satisfaction with life, marital quality, and uncertainty have yet to be combined and fully examined in one research study. By incorporating these various dimensions that are often studied separately into one study, the overall picture of cancer survivorship for couples will become clearer.

### **Summary and Conclusions**

The impact of uncertainty in illness for cancer has many far ranging effects, from increased levels of depression and anxiety for both patients and partners to decreased quality of life and increased need for positive emotional support. The tendency of researchers to study patients and partners during the active treatment phase of the cancer experience has created a gap of understanding for those who move past treatment. Little research has specifically focused on the impact each member of the couple system has on each other's post-treatment experiences of depression, anxiety, and life satisfaction. By further examining the impact of uncertainty, as influenced by coping skills and marital quality, on depression, anxiety, and life satisfaction there can be implications for cancer patients, their families, medical care providers, and therapists.

# **CHAPTER THREE**

# METHOD

The focus of this study was to investigate the influence of uncertainty in illness for cancer survivors and their partners on depression, anxiety, and life satisfaction. It also aimed to explore the relationship of uncertainty in illness to these variables, as moderated by coping skills and marital quality. Survey research methods were employed to obtain this information.

#### Sample

The sample size included 84 participating couples. The mean age of survivor participants was 56 years old (SD = 9.65) with 47 females and 37 males. Partner participants had a mean age of 55 years old (SD = 10.019) with 37 females and 47 males. 82 out of 84 participant couples identified as Caucasian, with the remaining two couples identifying as African American. The length of the couples' relationships ranged from 2 years to 48 years, with the average relationship length being 26.8 years (SD = 12.4). The vast majority of participants reported being legally married (96.4%), with only 3 couples reporting a cohabitating relationship. All participants reported being in their relationship while treatment was received.

The most frequently reported level of education for survivors was a Bachelors degree (30.9%), followed by a high school diploma (21.4%), and then an Associates degree (15.5%). The most frequently reported level of education for partners was a Bachelors degree (37.5%), followed by a high school diploma (23.8%), and then a Masters degree (16.7%). Survivors were employed full time (39.3%), retired (39.3%), and part time (13.1%). Partners were employed full time (44%), followed by retired (33.3%), and part time (15.4%). The average family income was between 75,001 and 90,000 dollars per year. This information is included in Table 1.

The type of cancer experienced by survivors covered a wide range of disease sites. The top cancer sites were as follows Breast (33.8%), Prostate (20.8%), Ovarian (10.4%), Skin (6.5%), Leukemia (3.9%), and Lymphoma (3.9%). In addition, there were two cases reported for each of the following cancers: Kidney, Colorectal, Thyroid, Lung, and Head/Neck. Finally, there was one case reported for each of the following cancers: Bladder, Brain, Abdomen, Anal, and Colon. The cancer site information listed here is reflective of the first cancer diagnosis. There were 11 participants (13.1% of the sample) who experienced a second cancer diagnosis and treatment, and two of those 11 (18.2% of the sample) who experienced a third cancer diagnosis.

### Table 1

	Survivor	Partner
Item	M SD	M SD
Age	56 (9.7)	55 (10.2)
Years in relationship	26.9 (12.6)	26.9 (12.6)
Years since end of treatment	6.8 (18.1)	N/A N/A
Item	0⁄0	%
Gender		
Male	44.1	55.9
Female	55.9	44.1
Employment Status		
Full-time	39.3	44.1
Part-time	13.1	15.4
Retired	39.3	33.3
Educational Level		
Masters Degree	15.5	16.7
Bachelors Degree	30.9	37.5
Associates Degree	15.5	10.7
High School	21.4	23.8

Sample Demographic Information (N = 84)

Eligibility criteria for this study consisted of various components in order to insure that the proper sample was obtained. Criteria included: (1) a prior diagnosis of Stage I–IV cancer in a primary episode; (2) to be currently receiving no active form of treatment for cancer (declared disease free, as opposed to refusing treatment); (3) have a partner willing to participate in the investigation; (4) the survivor and partner must have been in a relationship (married or cohabitating) for at least 1 year; (5) the partner must have at least 6 months experience with the patient in the active phase of the disease before going into remission; and (6) no partnerships where both members have been diagnosed with cancer.

Criteria one excluded stage V cancer, as that is typically a more severe experience, with the worst prognosis. Criteria four was implemented to establish a baseline amount of time that the patient and partner had been romantically committed to each other in order that mutual influence would have developed over the course of at least a 1-year relationship. Criteria five was used in order to make sure that the partner had exposure and experience with the cancer during diagnosis and treatment and had moved into the survivorship stage with the patient. This criterion attempted to screen out those partners who had met survivors when they had already moved into survivorship and would have limited understanding of the shift from active diagnosis and treatment to the current survivorship lifestyle. Criteria six was established to eliminate confusion in reporting the data in regards to which study participant was the patient and which was the partner, as well as for the additional challenges a couple would face where both had cancer, as it was not the focus of this study. Additionally, all participants must be over the age of 18 and able to read English.

### **Unit of Analysis**

To gain a comprehensive look at this area of couple studies, it is important that the unit of analysis was dyadic in nature. There is an inherent need for dyadic data to not just examine two people, with no regard to what the relationship between them truly is, but to focus on dyads in which partners are engaged in a significant and involved relationship with one another. Becker and Useem (1942) stated that two people might be considered a dyad when their interactions are intimate and face-to-face over a significant period of time, allowing them to develop an examinable pattern of interacting personalities. Thompson and Walker (1982) emphasized the interdependent nature that must be present in a dyad. This reciprocity characteristic is what becomes the focus of dyadic research, turning the relationship into a new unit of analysis. For the purposes of this study, the analysis of dyads was appropriate. The dyadic nature of the study was supported by the eligibility criteria that partners must have been in a relationship with each other for at least one year, as well as both had exposure to the cancer experience prior to entering into survivorship. Additionally, considering the unit of analysis to be a dyad supports the use of interdependence modeling.

## **Data Collection**

The sample for this study was obtained through the Cancer Treatment Centers of America (CTCA). There are four established CTCA branches located throughout the United States. The sample for this study was obtained through the Midwestern site, located in Illinois. In collaboration with the department of marketing and outcomes research it was identified that the most applicable area of services to draw a sample from was the CTCA Survivorship Support department. Survivorship Support was designed specifically for CTCA patients and their loved ones and works to help patients take care of important medical and non-medical aspects of posttreatment care and focuses on quality of life when treatment is complete. At the CTCA Midwestern site they maintain a database of survivors and their partners from which the study sample was collected.

In order to draw a sample from CTCA Midwestern it was necessary to obtain CTCA Institutional Review Board (IRB) approval. IRB approval was also obtained from Florida State University after CTCA IRB approval was granted. After IRB approvals were given, the investigator and the director of Survivorship Support created the patient contact letter that would be mailed to the individuals from the survivor database. The contact letter indicated that patients could opt out of participation at any time, but if they were interested in participating, to respond by email with their contact information. In order to encourage participation and show appreciation for their time, the cover letter informed potential participants of the opportunity to submit their name at the completion of survey (by both themselves and their partner) into a random drawing to win 1 out of 4 available \$25.00 visa gift cards. Additionally, CTCA also shared this information and the opportunity to participate in the study with survivors at their follow-up appointments with the survivorship department. Sample recruitment through CTCA lasted over a period of eight months, starting in April and lasting thru November. There were three separate waves of mailing out the contact letter to CTCA survivors during the course of recruitment and in person recruiting was used in an ongoing manner.

Couples who were interested in participating responded to the initial mail or in person contact and were then contacted by the researcher to initiate the consent process and to answer any questions the participants may have had. Once consent was received, the participants were emailed a link to the survey questionnaire. Each person within the couple received a separate email and within that email was the link for the web-based online survey that was used to complete the survey. Each participant was also be given a unique ID for himself or herself in the survey email and were instructed to enter that ID when they completed the online survey. The IDs for survivors consisted of the letter "A" (for patient) and a three digit marker (for example: A172), and the ID for partners consisted of the letter "Z" (for partner) and a three digit marker (for example: Z172), with the digits being the same for each couple so that the data would be correlated between partners. The first page of the survey served as the electronic consent form, restating information about the survey and its purposes. Participants were not able to proceed with the survey unless they agreed to the consent form. The survey took approximately 20-30 minutes for each individual to complete and contained demographic and illness characteristics, in

addition to scales, as part of the data collection. The only required questions of the survey are the consent form and the person's unique ID.

In addition to data collection through CTCA, participants were also recruited through Facebook in order to increase sample size. The Facebook recruiting was very basic and consisted of the researcher posting a few brief details regarding the study on their personal Facebook wall and inviting others on Facebook to share the information on their own pages if they were willing. The invitation to participate was posted as a status update and gave the basic details regarding eligibility and informed interested parties to email the researcher for further information. The researcher responded anyone who commented on a status update, answering their question or directing them to email the study for further guidance. Once an interested participant contacted the researcher, the procedure was identical to the CTCA procedures. They were emailed an informational letter and then contacted for consent after they indicated a willingness to continue. Survey procedures remained the same after this point. Facebook recruiting took place over a period of three months, from September thru the end of November. There was an initial posting at the beginning and then a reposting of the study information about a month and a half into the recruiting.

The CTCA recruitment gathered 67 total couples for participation in the study. It is difficult to tell the total number of people who were approached for the study because the inperson recruiters did not keep track of the number of couples they asked at their follow-up appointments. A total of 547 letters were mailed out, giving a very rough estimate of 12% for a response rate. Due to the very basic nature of the Facebook recruiting, there was no real way to track how many people viewed the opportunity to participate versus how many actually committed to the study. It is likely that many more people viewed the posting than participated as the Facebook recruiting only obtained 17 additional participants yet the researcher's friend list who would have seen the posting and shared it was over 800 people. Table 2 provides detailed information regarding the demographic information for the two respective samples. Because the Facebook sample is very small, it is hard to draw significant conclusions. Overall, the samples were very similar in terms of education, employment, and income (all averaged 60-75,000). The CTCA group was slightly older, in a relationship longer, and had completed treatment longer ago in comparison to the Facebook group, but the only one of these demographic items that was significantly different between the groups was the age of the survivors. Patients recruited from CTCA were significantly older (6 years for survivors and 5 years for partners) than those recruited from Facebook.

## Table 2

	Face Surv	book vivor	CT Surv	CA vivor	Facebook Partner		CTCA Partner		Survivors t-score	Partners t-score
Item	$\frac{(n = 1)}{M}$	= <u>17)</u>	<u>(n =</u> M	= <u>64)</u>	$\frac{(n = M)}{M}$	= <u>17)</u>	$\frac{(n = M)}{M}$	<u>• 64)</u>		
	<i>IVI</i>	12.2	57	<u>5D</u>	<i>IVI</i>	10.5	<i>IVI</i>	<u></u>	2.2(*	1.07
Age Voors In	51	12.2	57	85	51	10.5	50	9.6	2.30*	1.97
Relationshin	23.4	9.3	27.6	13.0	23.4	9.3	27.6	13.0	1.53	1.33
Years Since Treatment	4.8	5.2	6.5	9.4	N/A		N/A		-1.29	-1.27
Item	tem %			%						
Gender									1.04	807
Male	35	5.2	48	3.4	64	4.7	56	5.2		
Female	64	I.7	56	5.2	35.2		48.4			
Employment									1.49	.934
Full-time	64	1.7	32	2.8	52	52.9 41.8				
Part-time	5	.9	16	5.4	17.6 15					
Retired	29	9.4	41	1.8	23	3.5	35	5.8		
Education									.662	.474
Masters	11	.8	16	5.7	11	1.8	17	<i>'</i> .9		
Bachelors	25	5.3	19	9.4	29	9.4	28	3.4		
Associates	17	7.6	25	5.4	23	3.5	16	5.4		
HS Diploma	17	7.6	22	2.4	29	9.4	22	2.4		

\**p* < .05

## Instruments

After a thorough review of the literature on uncertainty and the experience of cancer, the researcher selected well-used and established instruments to measure each of the variables of interest to the study. The instruments selected for use in this research were chosen because of their frequency of use in the research as well as generally achieving psychometric properties that meet the standard for research within the social science field. The scales listed below examined each variable in the study.

#### **Demographic Questionnaire**

A researcher-designed demographic questionnaire was used to obtain survivors' and partners' reports of illness and relationship factors. Examples of personal demographic factors included age, gender, race, ethnicity, marital status and length of relationship, level of education, and occupation. In addition, there were illness demographic factors to be assessed, including: the stage of cancer when last in treatment, the time since diagnosis, time since being declared disease free, the type of treatments received, and number of recurrences.

#### **Uncertainty in Illness (Independent Variable)**

The Mishel Uncertainty in Illness Scale-Survivor (MUIS-S; Mishel, 1997) was used to measure the level of perceived uncertainty of the couples in the survivorship stage. Uncertainty in illness for survivorship is defined as the inability to determine the meaning of illness-related events, which is then related to fear of cancer recurrence. This scale has 22-items, each with a 5item Likert response scale that ranges from *strongly agree* to *strongly disagree*. The scale assesses uncertainty in the areas of symptomatology, treatment, relationship with caregivers, and planning for the future. The scores are summed, with higher scores on the MUIS-S indicating a higher level of uncertainty for the individual responding. Items 6, 8, 18, 19, 21, and 22 are reverse coded on the scale. The scale can be used to measure a two-factor model or a four-factor model. The two-factor model consists of the degree of ambiguity concerning the state of the illness and the degree of complexity/comprehension one has regarding their illness, while the four-factor model adds inconsistency and unpredictability. Mishel adapted statements from the original adult version of the scale to reflect concerns experienced by survivors, as opposed to those experiencing acute illness events. Items include: "I have been told different things about what my treatment side-effects mean," and "I don't know if my cancer will ever come back." (Clayton, Mishel, & Belyea, 2006; Gil et al., 2006).

Internal consistency reliability in research with the MUIS-S has found an alpha of .80 (Clayton et al., 2006). In a study comparing the effects of an uncertainty management intervention for African American women and White women survivors, the MUIS-S has shown alpha coefficients ranging from .78 for the African American women sample to .84 for White survivors sample (Mishel et al, 2005). Validity of the scale has been demonstrated by the findings that it discriminated between the two study treatment groups (one a control group, the other receiving an uncertainty management intervention program) with the treatment group

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showing continued reduction in uncertainty over time. Validity was also demonstrated by the scale being correlated significantly with items such as troublesome thoughts and symptom bother. It also shows convergent validity with scales that measure comprehension and understanding. For the current sample in this study, the alpha for survivors was .764 and the alpha for partners was .888. This measure is not in the public domain; therefore the scale was purchased from the original author and then the researcher was provided with the scale and accompanying manual for use in the current research study.

#### **Coping (Moderator Variable)**

In order to measure coping skill usage, the Brief COPE was used. The BriefCOPE is a revision of Carver's original COPE scale (Carver, 1997; Carver, Scheier, & Weintraub, 1989). The shorter item set was created, in part, because of patient reported fatigue in taking the longer version as well as redundancy in the questions. In the revised version, the brief COPE took out two scales of the full COPE (the scales removed included restraint coping and suppression of competing activities because these subscales had not shown statistical relevance or value in previous research), reduced the scales to only two items each, and added a new subscale. The criterion for retaining the two items was two-fold: the item must have had a high loading on the factor in the original analysis and the item must have clarity and ease of communication with various populations (as tested over time). Self-blame was the two-item scale that was added to the Brief COPE, as other research had shown that it can be a predictor of poor adjustment under stress.

The current Brief COPE scale contains 14 different subscales with two questions each, to measure each construct (no reverse coding necessary). The constructs measured include: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, and self-blame. The overall measure assesses coping responses that are problem focused coping responses as well as secondary aspects and behaviors that may be a result of the stressor. The scale also measures coping responses that are both potentially dysfunctional as well as adaptive responses. Responses range on a Likert scale from 0 (*I haven't been doing this a lot*). The reliability analysis of the Brief COPE indicates that all scales meet or exceed the value of .50, which is regarded as minimally acceptable (Nunnally, 1978). The alpha reliabilities for the scales indicate that all exceeded .60 except venting, denial, and

acceptance. Although .70 is a typically used cut-off, it is a misconception to assume that reliability coefficients lower than .70 are unacceptable. If the scale measures multiple or several attributes or dimensions rather than one, it lowers the alpha (Yu, 2001). This is especially the case for the Brief COPE as it assesses 14 domains; therefore, internal reliability is supported for the scale.

The Brief COPE has been studied in a population of women breast cancer patients who were undergoing radiation therapy (Fillion, Kovacs, Gagnon, & Endler, 2002). The test-retest mean correlation of the measure was .70 and the Cronbach alpha reliability coefficients of the shortened COPE were higher than those observed in the full-length version, ranging from .56 to .89. The instrument also correlated with existing measures of coping, such as the Coping with Health Injuries and Problems (CHIP), which demonstrates convergent construct validity. Criterion validity was examined by comparing the BriefCOPE and mood disturbance as measured by the Profile of Mood States (POMS), and found that disengagement had large positive correlations with anxiety, depression, anger, and confusion. For the current sample in this study, the alpha for survivors was .868 and for partners it was .830.

The measure is in the public domain; therefore, because the author has allowed free access for use, researchers can use this instrument without written permission. The author also grants freedom with language and allows for changes as the researcher sees necessary.

For the current study, the information needed pertaining to coping skills was going to be used to inform one comprehensive variable that would function as a moderator in the relationship between uncertainty and each of the study's outcome variables. The BriefCOPE is designed with multiple subscales but it is not designed to give an overall picture of coping and it is not suggested that the various scales be summed to give one score relative to how well an individual is coping.

In order to effectively use the data from the BriefCOPE in the current study, the researcher performed a factor analysis for all the data from the BriefCOPE for both survivors and partners. The results of the factor analysis provided 9 different loadings, but the results show a significant drop off after the top three factors. These top three factors accounted for 40.4% of the variance in survivors scores and 38.6% for partners scores. Therefore, the researcher took each of the scale items that loaded most strongly on the top three factors and summed these items

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together to create an overall, sample specific measure of positive coping unique to both survivors and partners based on the data collected.

The survivors' positive coping scale included BriefCOPE items 2, 5, 7, 10, 12, 14, 15, 17, 20, 23, 24, and 25. Items 5, 10, 15, and 23 loaded on factor one and were characterized by seeking support from others. Items 2, 7, 14, and 25 loaded on factor two and were characterized by taking some sort of action (active coping). Items 12, 17, 20, and 24 loaded on factor three and were associated with having a positive outlook and acceptance. The various items and their factor loadings are located within Table 3.

## Table 3

Summary of Factor Analysis Results for Positive Coping for Survivors (N = 84)

	Fa	actor Loadin	gs
Item	Seeking	Taking	Positive
	Support	Action	Outlook
I've been getting emotional support from others.	.731	.017	.103
I've been getting help and advice from other people.	.714	.236	.273
I've been getting comfort and understanding from someone.	.825	.112	.164
I've been trying to get advice or help from other people about what to do.	.619	.095	058
I've been concentrating my efforts on doing something about the situation I'm in.	.387	.542	.145
I've been taking action to try to make the situation better.	.271	.651	.250
I've been trying to come up with a strategy about what to do.	050	.722	.173
I've been thinking hard about what steps to take.	.120	.606	.043
I've been trying to see it in a different light, to make it seem more positive.	.092	.401	.638
I've been looking for something good in what is happening.	.114	.201	.717
I've been accepting the reality of the fact that it has happened	.276	051	.714
I've been learning to live with it.	016	.263	.634
Eigenvalues	2.9	2.3	1.8
% of variance	26.5	8.2	5.7

Note: Factor loadings over .50 appear in bold.

The partners' positive coping scale included BriefCOPE items 2, 5, 10, 14, 15, 17, 22, 23, 25, and 27. Items 5, 10, 15, and 23 loaded on factor one and were characterized by seeking support from others. Items 2, 14, 17, and 25 loaded on factor two and were characterized by reframing and planning to take action. Items 22 and 27 loaded on factor three and were associated with religious coping. The partner factor loadings had two less items incorporated into the overall factor. The various items and their factor loadings are located within Table 4.

Table 4

	F	Factor Loadir	ngs
Item	Seeking	Taking	Religious
	Support	Action	Coping
I've been getting emotional support from others.	.583	.127	.256
I've been getting help and advice from other people.	.751	.263	013
I've been getting comfort and understanding from someone.	.888	.157	.002
I've been trying to get advice or help from other people about what to do.	.834	.093	.178
I've been concentrating my efforts on doing something about the situation I'm in.	.124	.591	.027
I've been trying to come up with a strategy about what to do.	.157	.610	.002
I've been looking for something good in what is happening.	.164	.874	.120
I've been thinking hard about what steps to take.	.265	.691	.181
I've been trying to find comfort in my religion or spiritual beliefs.	.071	.107	.847
I've been praying or meditating	.080	088	.864
Eigenvalues	2.8	1.6	1.2
% of variance	26.3	8.2	4.1

Summary of Factor Analysis Results for Positive Coping for Partners (N = 84)

Note: Factor loadings over .50 appear in bold.

## Marital Quality (Moderator Variable)

To assess the state of the marital relationship for both partners, the Quality of Marriage Index (QMI; Norton, 1983) was administered. The QMI is a six-item, one-dimensional index of marital quality. The scale has been recommended as a global assessment of marital satisfaction by researchers (Bradbury, Fincham, & Beach, 2000). It is referred to as a global measure because the scale focuses on overall assessments that respondents have about their marriages. The scale avoids items that may serve as more typical predictors (communication and other behaviors) and focuses on statements and sentiments that are more indicative of overall marital quality and satisfaction. The six items in the scale ask the respondent to evaluate the overall state of his or her marriage. Examples of items include "we have a good marriage," "our marriage is strong," "my relationship with my partner is very stable," "my relationship with my partner makes me happy," and "I really feel like part of a team with my partner." Respondents then indicate the extent of their agreement with these statements on a Likert-scale from 1 (*very strong disagreement*) to 7 (*very strong agreement*) with no need for reverse coding on any of the items. The final item is on a 10-point scale ranging from very strong disagreement to very strong agreement to the prompt "On the scale below, indicate the point which best describes the degree of happiness, everything considered, in your marriage (relationship)."

Although Norton did not report the QMI's validity and reliability in his original article, it is supported by its correlations with other scales measuring the experience of the marital relationship, including the DAS (Spanier, 1976) and the Kansas Marital Satisfaction Scale (Schumm, Paff-Bergen, Hatch, Obiorah, Copeland, et al., 1986). The original scale did provide correlational estimates for each item, with results between .72 and .82. For the current sample in this study, the alpha for survivors was .974 and the alpha for partners was .874. The measure is in the public domain; therefore, because the author has allowed free access for use, researchers can use this instrument without written permission.

### **Depression (Dependent Variable)**

To obtain a measure of depression, the Center for Epidemiologic Studies Depression Scale (CES-D; Radloff, 1977) was the selected measure for both patients and partners. The scale is a 20-item measure that explores areas related to depressive symptomatology for the general population. This measure was specifically developed for use as a community survey where it was expected that most respondents would not have a depressive disorder, making it an appropriate measure to use for this research study as at least half the respondents (partners) were not expected to show clinical levels of depression. Patients report on both the severity and frequency of various feelings and behaviors they may have experienced within the past week such as crying spells, loneliness, self-esteem, sleep, and so forth. Responses are on a four point Likert

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scale and range from rarely or not at all (1 = experienced less than one day a week) to most or all of the time (4 = experienced five to seven days a week) with items 4, 8, 12, and 16 being reverse coded. Higher scores indicate more depressive symptoms present for the respondent, with a minimum score of zero and a maximum score of 60. Scores of 16 or greater on the CES-D are traditionally interpreted as suggestive of clinically significant depression (McDowell & Newell, 1996).

This is a well-used scale and has shown to be valid and reliable over time in various populations (Ensel, 1982; Weissman, Sholomskas, Pottenger, Prusoff, & Locke, 1977). In nonclinical samples the scale has average reliability coefficients at .85. In clinical or psychiatric populations, the scale has average reliability coefficients at .90 (Simmons, Huddleston-Casas, & Berrv, 2007). The CES-D discriminates well between psychiatric inpatient and general population samples and discriminates moderately among levels of severity within patient groups. The CES-D has been moderately to strongly correlated with other depression measures such as the Hamilton Anxiety Rating Scale (HAM-A) and the Raskin Rating scale (Hamilton, 1959; Raskin, Schulterbrandt, Reatig, & McKeon, 1969). The pattern of correlations of the CES-D with other scales gives reasonable indication of discriminant validity, with higher correlations with other depression measures and lower correlations with positive affect, cooperation, understanding, and aggression (Radloff, 1977).

The psychometric properties of the CES-D have been explored for a cancer specific population. The CES-D was assessed for both women undergoing treatment for breast cancer and women with no history of cancer. Both groups were measured on two occasions: for the group undergoing treatment they responded prior to treatment and midway through treatment. The CES-D was found to have good internal consistency, with alpha coefficients of .85 for both groups, as well as adequate test–retest reliability in both groups. Construct validity was demonstrated in two ways, via comparisons between the groups and by comparing the CES-D with measures of fatigue, anxiety, and global mental health functioning. The CES-D was established as a valid and reliable measure of depressive symptomatology in this sample of breast cancer patients (Hann, Winter, & Jacobsen, 1999). For the current sample in this study, the alpha for survivors was .906 and for partners it was .864. The measure is in the public domain; therefore, because the author has allowed free access for use, researchers can use this instrument without written permission.

### **Anxiety (Dependent Variable)**

To measure the level of anxiety that patients and partners were experiencing, they completed the Generalized Anxiety Disorder 7-item scale (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006). The scale has seven total items and uses a Likert-type scale that ranges from 0 to 3 (0 = not at all, 1 = several days, 2 = more than half the days, and 3 = nearly every day) with no items reverse coded. Scores range from 0 to 21, with a cut off score of 10 or greater on the GAD-7 used for identifying that significant anxiety is present, with scores over 15 indicating severe anxiety. The prompt for the scales instructs respondents to select how often they have been bothered by specific problems over the course of the last two weeks. Some of the prompts include: feeling nervous, anxious, or on edge, not being able to stop or control worrying, trouble relaxing, being restless, becoming easily annoyed or irritable, and feeling afraid.

The internal consistency of the GAD-7 in a patient population has found a Cronbach alpha reliability of .92. Test-retest scores also indicate strong reliability with an intraclass correlation of .83. In terms of construct validity, there is a strong association between increasing GAD-7 severity scores and worsening function, as measured by the Mental Health Outcome Study Short Form (MOS SF-20). Convergent validity was found for the GAD-7 by demonstrating correlation with the Beck Anxiety Inventory (r = .72) and the anxiety scale of the 90-Item Symptom Checklist (r = .74). Within the general population, the GAD-7 has been evaluated and internal consistency was identical across all subgroups with an alpha of .89. Correlations with other measures were also found, both for convergent and divergent validity. For convergent validity, the Patient Health Questionnaire (PHQ-2) was positively correlated with an r value of .64. For divergent validity, the Rosenberg Self-Esteem Scale was negatively correlated with an r of -.43 (Lowe et al., 2008). For the current sample in this study, the alpha for survivors was .917 and for partners it was .920. The measure is in the public domain; therefore, because the author has allowed free access for use, researchers can use this instrument without written permission.

### **Satisfaction With Life (Dependent Variable)**

To obtain a global measure of how satisfied both partners were with their life in general, they completed the Satisfaction With Life Scale (SWLS; Diener, Emmons, Larsen, & Griffin, 1985). This scale measures the dependent variable of life satisfaction by examining the extent to which the respondents agreed with five items relating to one's overall evaluation of life from both a cognitive and emotional perspective. The items on the SWLS are global, or more of a broad perspective, rather than specific to certain domains. This allows survivors and partners to evaluate the state of their lives in terms of their personal values (Pavot & Diener, 1993). Additionally, because this scale reflects a global measure of life satisfaction, it is appropriate to use with both survivors and partners in cancer survivorship, where cancer is no longer the defining feature of their livelihood. The instructions for the scale prompt respondents to indicate their level of agreement with the following statements: "in most ways my life is close to ideal," "the conditions of my life are excellent," "I am satisfied with my life," "so far I have gotten the most important things I want in life," and "if I could live my life over, I would change almost nothing."

The SWLS uses a Likert-type scale that ranges from 1 to 7 (1 = strongly disagree, 2 =disagree, 3 = slightly disagree, 4 = neither agree nor disagree, 5 = slightly agree, 6 = agree, and 7 = strongly agree) with no items being reverse coded. With each item being scored from 1 to 7, a total score can range from 5 to 35 with higher scores indicating a higher satisfaction with life and lower scores indicating dissatisfaction with life. In order to not bias respondents by the other measures in the study, these five questions appear first in the survey to give an overall impression of satisfaction with life before assessing depression, anxiety, and uncertainty. Initial and subsequent studies have examined the internal consistency of the SWLS and alpha reliability coefficients have repeatedly exceeded .80 (Pavot & Diener, 1993). The original scale study found an alpha coefficient equaling .87 and the two-month test-retest correlation coefficients were equal to .82 for the sample (Pavot & Diener, 1993). Other studies have produced similar results, including Pavot, Diener, Colvin, and Sandvik (1991), who found an alpha of .85, and retest correlation of .84. The original validation study correlated the SWLS with ten other measures of subjective wellbeing to determine adequate convergence validity. Most measures correlated with an alpha of .50 or higher for each of two independent samples indicating that the SWLS is accurately measuring satisfaction, in a similar manner as other satisfaction scales (Diener et al., 1985). For the current sample in this study, the alpha for survivors was .846 and the alpha for partners was .874. The measure is in the public domain; therefore, because the author has allowed free access for use, researchers can use this instrument without written permission. For an overall view of how study variables are associated, a correlation matrix is provided in Table 5.

# Table 5

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13
1. P MUIS	-												
2. P CES-D	.54**	_											
3. P GAD	.51**	.63**	_										
4. P SWLS	38**	39**	33**	-									
5. P QMI	37**	40**	31**	.39**	_								
6. P COPE	01	.01	.12	.04	14	_							
7. S MUIS	.44**	.19	.24**	16	.09	.07	-						
8. S CES-D	.36**	.28*	.27*	21	21	15	.28**	-					
9. S GAD	.38**	.16	.29**	26*	09	.12	.45**	.47**	-				
10. S SWLS	13	12	09	.23*	.06	.07	23*	48**	37**	_			
11. S QMI	06	11	13	.24*	.31**	.05.2	21	12	29**	.38**	_		
12. S COPE	.15	.03	.08	13	23*	.25*	.06	04	.14	.15	02	-	
13. Time Married	23*	07	14	.08	.09	.12	11	16	27*	.20	.28*	.14	_

Bivariate Pearson Correlations of Study Variables (N = 84)

*Note.* P = partner data, S = survivor data

MUIS = Mishel Uncertainty in Illness Scale; CES-D = Center for Epidemiological Studies-Depression; GAD = Generalized Anxiety Disorder; SWLS = Satisfaction with Life Scale; QMI = Quality of Marriage Index; COPE = Factor Analysis of BriefCOPE. \*p < .05. \*\*p < .01.

#### Analysis

The main objective of this study was to examine the mutual influence that committed partners' uncertainty in illness had on their own and each other's depression, anxiety, and life satisfaction. The secondary objective was to explore the extent to which marital quality and positive coping moderated the relationship between uncertainty and the outcome variables.

## **Data Entry**

Path analysis using AMOS software (Arbuckle, 2006) was used to test all hypotheses. One data set was created using SPSS version 21.0 that contained one entry for each dyad with each person's scores on the various measures listed on the same line. Each variable was given a distinguishable name so that it was clear which scores belonged to the survivor (indicated by the letter "s") and the partner (indicated by the letter "p").

#### **Missing Data**

Missing data were addressed using Full Information Maximum Likelihood (FIML) estimation in AMOS (Arbuckle, 2006). FIML assumes that the distribution of endogenous variables is normal (Kline, 2005). FIML allows for the use of all the available data from the sample by generating estimators that maximize the likelihood of the observed sample (Kline). In this collected data, there were 7 participants who had missing data. The data were missing at random, with some participants only missing one question while others skipped a few random questions with no discernible pattern. Therefore FIML estimated scores for these participants' missing information based on the data from the observed sample. This procedure allows researchers to obtain the maximum amount of data and the information that is created is done in a statistically sound manner.

## Power

When analyzing data that is dyadic in nature, power must be considered with two concepts in mind. The first thing that must be considered is the power of the test of nonindependence (addressed in the upcoming statistical issues section). The second consideration is the ability to discern meaningful results from the sample size and model proposed (Cohen, 1992). A typical power analysis sets the standard for sufficient statistical power at .80. Kline (2005) suggests that if statistical power is set at .80 in path analysis, the ratio of sample size to number of parameter must be between 10:1 and 20:1 for each parameter estimated. Each model for this study included 10 parameters but the sample size, due to the

dyadic nature of the data, must be considered 84. Therefore, the study does not meet recommended cutoffs for obtaining statistical power.

### **Statistical Issues**

One key piece of gathering and working with dyadic data becomes the ability to determine whether the dyad members can be distinguished from one another by some variable. This is an important issue in quantitative methods for relationship data because the analytic strategies, which are required and/or appropriate for distinguishable data, may not work as well or be appropriate for indistinguishable dyads. In this study, it was permissible to treat the dyad members as distinguishable because they differed on the factor of role in that one was a survivor and one was considered their significant partner. This was also buffered for in the eligibility criteria, specifically criteria six, which does not allow participation by couples where both members have had a cancer diagnosis.

Because the participant dyads were assumed to be mutually influential of each other and because the dyad members were determined to be distinguishable, the level of nonindependence scores between patients and partners on uncertainty was assessed using a Pearson product-moment correlation coefficient, a statistical test to determine the proportion of variance that is due to the couple (Kenny, Kashy, & Cook, 2006). This information is located in Table 6.

#### Table 6

Measure	Pearson Coefficient	<i>p</i> -value (2-tailed)
MUIS	.443	.000**
CES-D	.279	.010*
GAD-7	.294	.007**
SWLS	.231	.035*
QMI	.311	.004**
BriefCOPE	.251	.043*
QMI	.058	.598
BriefCOPE	023	.835

V	ariable	Correl	ations f	or	l'est of	ſΛ	on-1	nde	epend	ence	2
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\*\*\**p* < .001, \*\**p* < .01, \**p* < .05

In this instance, the correlation testing was based on the dyadic functioning as the unit of analysis. Considering Cohen's (1988) often used standards for correlations, which identifies .5 as a large correlation, .3 as medium strength correlation, and .1 as small correlation, there was a sufficient correlation between patients' and partners' outcome scores found for all variables in the model, except for the variables that were created to serve as interaction terms in the moderation equations.

## Data Analysis Plan

Actor-Partner Interdependence Model. The actor-partner interdependence model (APIM; Kenny & Cook, 1999; Kenny et al., 2006) was used to analyze the interaction and influence that each of the partners may have on each other's experiences of cancer survivorship. Use of the actor-partner interdependence model has been recommended in the study of families (Rayens & Svavardottir, 2003), close relationships (Campbell & Kashy, 2002), and outcomes for couple therapy (Cook, 1998). The use of this model for the data was important because it allowed participant data to be observed from two different standpoints. APIM integrates the interdependence in two-person dyads with the necessary statistical techniques for testing these types of data.

In the case of couples, the idea is that a person's score on an independent variable can influence his or her own score as well as the partner's score on any given outcome variable. APIM uses the term "actor effect" to denote when an individual's score on a predictor variable influences their own score on an outcome variable. Whereas a "partner effect" happens when an individual's score on a predictor variable influences the dyadic partner's outcome score (Kenny et al., 2006). Due to the nature of this study having distinguishable dyads, there were 6 actor effects present, 3 for the survivor (A) and 3 for the partner (B). There were also 6 partner effects potentially present, 3 from the survivor to the partner ( $P_1$ ) and 3 from the partner to the survivor ( $P_2$ ). Figure 2 depicts the APIM, with A and B representing actor effects and S and P representing partner effects for depression. Each outcome variable is the same model as Figure 2. The following equations represent the APIM for each outcome variable.

$$\begin{split} DEPRESSION_{(survivor)} &= a_{(survivor)}X_1 + P_2 X_2 + E_1 \\ DEPRESSION_{(partner)} &= b_{(partner)}X_2 + P_1X_1 + E_2 \\ ANXIETY_{(survivor)} &= a_{(survivor)}X_1 + P_2 X_2 + E_1 \\ ANXIETY_{(partner)} &= b_{(partner)}X_2 + P_1X_1 + E_2 \end{split}$$

SATISFACTION<sub>(survivor)</sub> =  $a_{(survivor)}X_1 + P_2 X_2 + E_1$ SATISFACTION<sub>(partner)</sub> =  $b_{(partner)}X_2 + P_1X_1 + E_2$ 



Figure 2. APIM Model

**Estimating the APIM and interaction effects.** Instructions and information for estimating the APIM with SEM can be found in the book Dyadic Data Analysis (Kenny, Kashy, & Cook, 2006) along with an explanatory webinar Kenny (2013) has provided detailing the process. Path analysis using AMOS software (Arbuckle, 2006) was used to test the first aim of the study regarding the APIM hypotheses. The study model from Figure 2 was constructed using AMOS software and the combined dyadic data set was used to associate the model to the study data. When estimating the APIM with path analysis, an important first step is to center the predictor (exogenous variable) of uncertainty in illness across both survivor's and partner's data. It is important that causal variables have a meaningful zero and if there is no inherently meaningful zero in the scale, then the variable should be centered across groups. Uncertainty in illness does not have a meaningful zero, therefore it was centered. Creation of the centered variable is done by taking the mean for each group (survivor mean and partner mean), adding those means together and diving by two, and then computing a new variable for each person's uncertainty score minus the grand mean. This process helps ensure that the data are meaningful.

According to Kenny, Kashy, and Cook (2006), when using structural equation modeling to estimate the APIM with distinguishable dyads, a saturated model is created which has zero degrees of freedom and no measures of fit can be computed. The use of SEM to estimate the APIM is to estimate two regression equations with correlated error terms. It is then not problematic that the base model is saturated and no measures of fit can be obtained. The typical fit indices, such as the chi-square, CFI, NFI, and RMSEA, cannot be estimated for this model, as there is no data left to base the estimation on. After the model has been built and analyzed, the output notes for model page were checked to make sure that the parameters were accurately estimated and that the model analyzed resulted in a saturated model.

**Interaction effects**. The second aim of the study was to examine the extent to which positive coping skills and marital quality moderated the relationship between uncertainty in illness and depression, anxiety, and satisfaction with life. The concept of moderation implies that the relationship between an independent and dependent variable is strengthened or weakened by the role of the moderating variable. Path analysis using AMOS software (Arbuckle, 2006) was used to test the interaction effect hypotheses. A structural model is shown in Figures 3 and 4. All the variables in the study were considered composite variables.



Figure 3. Structural Model for Coping Skills Interaction Effects

For both marital quality and positive coping, the structural models were tested in a series of steps in order to establish moderation. The first step was to identify the main predictor, the potential moderator, and the outcome variable. The second step was to prepare the data by centering all continuous variables other than the outcome variable. Next, a new variable must be created to serve as the interaction (moderator) term (the centered predictor multiplied by the centered moderator). The next step was to analyze the path analysis according to the structural model indicated in Figures 3 and 4. If the interaction term is significant, then there is a moderation effect. If it is not significant, there is no moderation occurring. Finally, to interpret the meaning of the moderator, the moderator itself should not contribute significantly to the model. A correlation test is run to determine whether there is a significant relationship between the workable is a moderator. However, if both independent variables are correlated with the outcome variable, then it is mathematically impossible to determine which variable is functioning as a moderator and which is the main predictor.



Figure 4. Structural Model for Marital Quality Interaction Effects

# **CHAPTER FOUR**

# RESULTS

In this chapter, information regarding the results from the preliminary analyses and parameter estimates for both the APIM and interaction effects path analysis are provided. First, a table detailing the means and standard deviations of the variables used within the models is presented. Second, the assumptions of path analysis are reviewed and then a summary is provided for each research question addressing whether the results supported the original hypotheses of the study.

## Table 7

		Survi	vor	Partner				
Measure	M	SD	Range	α	M	SD	Range	α
Uncertainty	47.51	9.95	31-65	.76	50.89	12.99	30-71	.88
Depression	14.32	10.83	7-27	.90	14.13	8.84	6-28	.86
Anxiety	4.05	4.41	0-15	.92	5.01	4.69	0-16	.92
Life Satisfaction	28.07	5.37	19-35	.85	27.54	5.34	18-35	.87
Marital Quality	31.87	5.27	22-36	.97	31.76	5.12	21-36	.87
Positive Coping	32.36	7.52	24-42	.86	30.04	7.61	21-44	.83

*Means and Standard Deviations for Study Variables* (N = 84)

## **Preliminary Analysis**

When conducting path analysis, several basic assumptions must be met in order to test the model and interpret the data. These assumptions include:

1. All relations are linear. The causal assumptions (what causes what) are shown in the path diagram.

This assumption is met in the model and data.

2. The residuals (error terms) are uncorrelated with the variables in the model.

This assumption is met in the model and data.

3. The variables are measured on dichotomous nominal, interval, or ratio levels.

This assumption is met in the model and data.

4. Low multicollinearity is assumed.

This assumption is met in the model and data because there is only one predictor (uncertainty in illness) and therefore it cannot correlate with any other predictors, which can cause multicollinearity.

5. The path model should not be under identified

This assumption is not met in the model. The model specified is a saturated model because the number of parameters to estimate is the same as the number of sample moments available to analyze, therefore leaving zero degrees of freedom.

6. The sample size should be 10 times (or ideally 20 times) as many cases as parameters. This assumption is not met in the data. Each model had ten parameters, totaling a need of at least 100 participating dyads. The study recruited 84 dyads.

## **Path Analysis Research Questions**

The first set of research questions were examined using path analysis. Although the model is saturated and does not provide meaningful model fit indices, AMOS software can still analyze the data and provide information regarding the significant and nonsignificant pathways within the model.



Figure 5. APIM Results for Depression



1. To what extent does uncertainty in illness influence the experience of depression and/or anxiety, for both survivors and partners?

Hypothesis #1: Both survivor's and partner's experience of uncertainty will have a direct relationship to depression and anxiety.

Results from the path analysis revealed that a survivor's experience of uncertainty does not have a significant direct relationship to their depression but it does have a significant direct relationship with their anxiety ( $\beta = .15$ , SE = .05, p = .001). A partner's experience of uncertainty had a significant direct relationship to their own depression ( $\beta = .38$ , SE = .07, p < .001) as well as a significant direct relationship to their own anxiety ( $\beta = .18$ , SE = .04, p < .001).

In other words, for every one unit increase in survivor uncertainty, a survivor's anxiety goes up by .15 units. For every one unit increase in the partner's uncertainty, their own depression goes up by .38 units and anxiety goes up by .18 units.



Figure 6. APIM Results for Anxiety

\*\*\**p* < .001, \*\**p* < .01, \**p* < .05

2. To what extent is uncertainty in illness influence the experience of satisfaction with life, for both survivors and partners?

Hypothesis #2: Both survivor's and partner's experience of uncertainty will have a direct relationship to satisfaction with life.

Results from the path analysis revealed that a survivor's experience of uncertainty does not have a significant direct relationship to their satisfaction with life. A partner's experience of uncertainty had a significant direct relationship to their satisfaction with life ( $\beta = -.16$ , SE = .05, p < .001).

This means that for every one unit increase in a partner's uncertainty, the partner's life satisfaction goes down by .16 units.



Figure 7. APIM Results for Satisfaction with Life

\*\*\**p* < .001, \*\**p* < .01, \**p* < .05

3. To what extent does a partner's level of uncertainty influence the survivor's level of depression, anxiety, and satisfaction with life?

Hypothesis #3: A partner's level of uncertainty will have a direct relationship with depression, anxiety, and satisfaction with life.

Results from the path analysis showed that a partner's experience of uncertainty does have a significant direct relationship to the survivor's depression ( $\beta = .24$ , SE = .09, p = .01) and a significant direct relationship to the survivor's anxiety ( $\beta = .08$ , SE = .04, p = .03). Results indicated that a partner's experience of uncertainty does not have a significant direct relationship to the survivor's satisfaction with life. In other words, for every one-unit increase in the partner's uncertainty, a survivor's anxiety increases by .08 units. And for every one unit increase in the partner's uncertainty, the survivor's depression increases by .24 units.

4. To what extent do survivor's levels of uncertainty in illness influence the partner's level of depression, anxiety, and satisfaction with life?

Hypothesis #4: A survivor's level of uncertainty will have a direct relationship with depression, anxiety, and satisfaction with life.

Results from the path analysis indicate that a survivor's level of uncertainty does not have a significant direct relationship on a partner's anxiety, depression, or life satisfaction. In other words, cancer survivor's levels of uncertainty were not related to any partner's outcome variables.

## **Moderation Research Questions**

The second set of research questions examined whether two different variables (marital quality and positive coping) functioned as moderators in the relationship between uncertainty and the outcome variables. If either moderator was found to be significant, it would mean that the variable was impacting uncertainty's effect on the outcome variables. Although there are three variables involved in the moderation equation, the interaction term must be significant for the possibility of moderation to occur.

1. The extent to which coping skill usage influences the relationship of uncertainty in illness on depression, for both survivors and partners.

Hypothesis #1: Coping skill usage will moderate the relationship between uncertainty and depression.

Results from the path analysis support hypothesis 1. Standardized estimates for the survivors model were: uncertainty ( $\beta = .25$ , p = .02), positive coping ( $\beta = -1.7$ , p = .34), and the interaction term ( $\beta = -.45$ , p = .01). Because the interaction term was significant, the next step to determine moderation is to explore the correlation of the moderator variable and the dependent variable. The moderator itself should not contribute significantly to the model. If there is no significant relationship between the moderator and the dependent variable, then the moderator is functioning properly. However, if both the independent variable and the moderator are correlated with the dependent variable, then it is mathematically impossible to determine which variable is actually the moderator, and which variable is the main predictor. The correlation of the moderator and the dependent variable is moderator and the dependent variable was not significant (r = .04, p = .69); therefore, positive coping can moderate the relationship between uncertainty and depression by lowering the effects

of uncertainty for cancer survivors. This means that a cancer survivor with a high level of uncertainty may be able to lower their level of depression by the use of positive coping skills which may help to negate the feelings of uncertainty.

Standardized estimates for the partners model were: uncertainty ( $\beta = .40, p = .01$ ), positive coping ( $\beta = .19, p = .01$ ), and the interaction term ( $\beta = -.19, p = .01$ ). Because the interaction term was significant, the next step to determine moderation is to explore the correlation of the moderator variable and the dependent variable. The correlation of the moderator and the dependent variable was not significant (r = .01, p = .93); therefore, positive coping moderates the relationship between uncertainty and depression for partners of cancer survivors. In the same manner as positive coping is useful for cancer survivors, partners who utilize positive coping skills may also lower their depression due to their experience of uncertainty.

2. The extent to which coping skill usage influences the relationship of uncertainty in illness on anxiety, for both survivors and partners.

Hypothesis #2: Coping skill usage will moderate the relationship between uncertainty and anxiety.

Results from the path analysis do not support hypothesis 2. Standardized estimates for the survivors model were: uncertainty ( $\beta = .20, p = .01$ ), positive coping ( $\beta = .83, p = .24$ ), and the interaction term ( $\beta = .02, p = .74$ ). Although uncertainty was significant, the interaction term was not. Therefore, positive coping did not moderate the effect of uncertainty on anxiety for survivors of cancer.

Standardized estimates for the partners model were: uncertainty ( $\beta = .18, p = .01$ ), positive coping ( $\beta = 1.0, p = .17$ ), and the interaction term ( $\beta = .01, p = .79$ ). Although uncertainty was significant, the interaction term was not. Therefore, positive coping did not moderate the effect of uncertainty on anxiety for partners of cancer survivors. For neither survivors nor partners did coping skills influence the association between their uncertainty in illness and the anxiety.

3. The extent to which coping skill usage influences the relationship of uncertainty in illness on satisfaction with life, for both survivors and partners.

Hypothesis #3: Coping skill usage will moderate the relationship between uncertainty and satisfaction with life.

Results from the path analysis partially support hypothesis 3. Standardized estimates for the survivors model were: uncertainty ( $\beta = -.13$ , p = .03), positive coping ( $\beta = 1.48$ , p = .11), and the interaction term ( $\beta = .02$ , p = .80). Although uncertainty was significant, the interaction term was not. Therefore, positive coping did not moderate the effects of uncertainty on satisfaction with life for survivors of cancer. Survivors utilizing positive coping skills did not decrease the influence of uncertainty on life satisfaction.

Standardized estimates for the partners model were: uncertainty ( $\beta = -.17$ , p = .01), positive coping ( $\beta = .33$ , p = .70), and the interaction term ( $\beta = .11$ , p = .03). Because the interaction term was significant, the next step to determine moderation is to explore the correlation of the moderator variable and the dependent variable. The correlation of the moderator and the dependent variable was not significant (r = .04, p = .72), therefore positive coping can moderate the relationship between uncertainty and satisfaction with life for partners of cancer survivors. Unlike the survivors' data, for partners utilizing more coping the influence of uncertainty in illness on life satisfaction was weaker, so they reported more satisfaction with their current life.

4. The extent to which marital quality influences the relationship of uncertainty in illness on depression, for both survivors and partners.

Hypothesis #4: Marital quality will moderate the relationship between uncertainty and depression.

Results from the path analysis do not support hypothesis 4. Standardized estimates for the survivors model were: uncertainty ( $\beta = -.22$ , p = .02), marital quality ( $\beta = .26$ , p = .31), and the interaction term ( $\beta = .02$ , p = .47). Although uncertainty was significant, the interaction term was not. Therefore, marital quality did not moderate the effect of uncertainty on depression for survivors of cancer.

Standardized estimates for the partners model were: uncertainty ( $\beta = -.51$ , p = .01), marital quality ( $\beta = .31$ , p = .01), and the interaction term ( $\beta = .01$ , p = .17). Although uncertainty and marital quality were significant, the interaction term was not. Therefore, marital quality did not moderate the effect of uncertainty on depression for partners of cancer survivors. For both cancer survivors and their partners, the impact of uncertainty in illness on their depression and the quality of their marriage did not affect these associations. 5. The extent to which marital quality influences the relationship of uncertainty in illness on anxiety, for both survivors and partners.

Hypothesis #5: Marital quality will moderate the relationship between uncertainty and anxiety.

Results from the path analysis do not support hypothesis 9. Standardized estimates for the survivors model were: uncertainty ( $\beta = .20$ , p = .01), marital quality ( $\beta = .13$ , p = .11), and the interaction term ( $\beta = .01$ , p = .21). Although uncertainty was significant, the interaction term was not. Therefore, marital quality did not moderate the effect of uncertainty on anxiety or depression for survivors of cancer.

Standardized estimates for the partners model were: uncertainty ( $\beta = -.17$ , p = .01), marital quality ( $\beta = .13$ , p = .15), and the interaction term ( $\beta = .00$ , p = 1.0). Although uncertainty was significant, the interaction term was not. Therefore, marital quality did not moderate the effect of uncertainty on anxiety for partners of cancer survivors. This means that the neither the survivor nor the partner experience of anxiety that may be due to uncertainty in illness may be lowered by the quality of their marriage.

6. The extent to which marital quality influences the relationship of uncertainty in illness on satisfaction with life, for both survivors and partners.

Hypothesis #6: Marital quality will moderate the relationship between uncertainty and satisfaction with life.

Results from the path analysis partially support hypothesis 10. Standardized estimates for the survivors model were: uncertainty ( $\beta = .09$ , p = .08), marital quality ( $\beta = .33$ , p = .00), and the interaction term ( $\beta = .01$ , p = .61). Although marital quality was significant, the interaction term was not. Therefore, marital quality did not moderate the effect of uncertainty on anxiety or life satisfaction for survivors of cancer.

Standardized estimates for the partners model were: uncertainty ( $\beta = .50$ , p = .01), marital quality ( $\beta = .13$ , p = .01), and the interaction term ( $\beta = .03$ , p = .01). Because the interaction term was significant, the next step to determine moderation is to explore the correlation of the moderator variable and the dependent variable. The moderator itself should not contribute significantly to the model. If there is no significant relationship between the moderator and the dependent variable, then the moderator is functioning properly. However, if both the independent variable and the dependent variable with the dependent variable, then it is mathematically

impossible to determine which variable is actually the moderator, and which variable is the main predictor. The correlation of the moderator and the dependent variable was significant (r = .38, p < .00); therefore, it cannot be determined whether uncertainty or marital quality functions as the moderating variable or the independent variable in affecting the outcome variable.

## Conclusion

Marital quality did not moderate the relationship between uncertainty and depression, anxiety, or life satisfaction for either survivors or for partners. This suggests that the quality of a marriage that a couple has did not affect the positive relationship between uncertainty and depression and anxiety (where increases in uncertainty lead to increases in depression and anxiety) and did not change the negative relationship between uncertainty and life satisfaction (where increases in uncertainty lead to decreases in life satisfaction).

Positive coping results indicate coping may moderate the relationship between uncertainty and depression for both cancer survivors and their significant others. When members of the couple system utilize positive coping skills, they may be able to decrease the impact that uncertainty in illness has on increasing levels of depression, lowering those overall scores. Positive coping was not shown to change the relationship between uncertainty and anxiety for either survivors or for partners. This means that partners who utilize positive coping skills may lower the impact of uncertainty in illness on their life satisfaction, but no such effect may be expected for cancer survivors.

# **CHAPTER FIVE**

## DISCUSSION

The purpose of this study was to examine the mutual influence that uncertainty in illness would have on both cancer survivors and their committed partners. There have been few studies that examine the experience of uncertainty for survivors as well as their partners who went through the disease treatment process together. This lack of research may be due to a number of factors such as the increased difficulty of finding willing couple participants or the perception that only those diagnosed with cancer will experience life-altering effects.

The most salient results from the study indicate that partners are the neglected piece of the uncertainty in illness experience. The results indicated that a partner's level of uncertainty in illness showed a statistically significant impact on their own depression, anxiety, and life satisfaction. In addition, partners' results showed that their uncertainty had statistically significant connections to the survivors' depression and anxiety. Previous researchers have reported that family members were found to be more distressed than cancer patients (e.g., Sarne et al., 2006) or survivors (e.g., Northouse, Mood, Templin, Mellon, & George, 2000).

Recent literature has left a gap in the research regarding the couple experience of uncertainty in illness during the survivorship phase of cancer diagnosis and treatment. The hypothesized model examined the impact of uncertainty on depression, anxiety, and satisfaction with life, as well as examined possible moderators in the relationship between uncertainty and the outcome variables. Summary results are reported according to each hypothesis and all findings should be taken in light of a sample size that was below suggested cutoffs.

## Methodology

One of the most complicated features of this study was the need for dyadic data for accurate statistical analysis. Despite using two different avenues of data collection, one a specifically targeted population for whom this study was applicable (CTCA), the target number of 100 couples was not met. This process was made more difficult by the researcher not having direct access to any of the potential participants and having to go through third party sources in order to contact potential study members. Additionally, having the majority of participant contact come through a mailed letter or an impersonal Facebook post did not provide a connection point to help invest couples in the study or allow for more personal recruitment. More specific details regarding how the target sample will be acquired should be discussed and planned for prior to starting data collection in order to have well thought out methods for making sure the sample population will be adequate for the study's planned statistics. Not obtaining a large enough sample for the required statistical analyses can have a noteworthy impact on the results of the study and is discussed further in the limitations section.

Upon reflection of the study data and analyses, there are a couple of measurement issues that should be addressed. First of all, although the MUIS is a valid and well-used scale, it would have been useful to include another scale that examines uncertainty or fear of reoccurrence. Because uncertainty was the only predictor in the study, it is important that this variable be valid and accurately measuring the construct. If another similar scale had been included, the two could have been compared to determine correlation and validity to help insure the data for the proposed model was sound. Additionally, the selection of the BriefCOPE may not have been the most effective scale for the moderation analyses planned for the study. Because the study conceptualized positive coping skills as an overall meta-skill that people may possess, it was ineffective to use a scale that was unable to be summed and consisted of multiple, specific subscales. A more useful coping scale would have focused on positive coping skills and been designed to produce an overall score of how well a person was coping.

Closely related to the selection of the coping scale was the decision to perform a factor analysis of the BriefCOPE results. Because the researcher desired to examine the moderation of an overall positive coping measure, the decision to combine the top three factors (as determined from the factor analysis) provided the most simple and clean approach to meeting the conceptual model of the study. On the other hand, the decision to combine the three factors may have aggregated the data in a way that nuanced differences were not discernible during the moderation analyses. If each of the three factors had been allowed to function separately as a potential moderator, more of the analyses may have had significant results as well as the fact that the significant specific items/coping skills would have been identified and could have provided useful information to inform the overall picture of the experience of uncertainty in illness.

## **Research Questions**

## **APIM Research Questions**

**Hypothesis one.** The hypothesis that both survivor and partner experiences of uncertainty in illness would have a direct relationship with depression and anxiety was partially supported. A

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survivor's level of uncertainty only directly impacted their own level of anxiety whereas the partner's level of uncertainty directly affected their own level of both anxiety and depression. This suggests that when survivors are uncertain, their levels of depression increase but their level of anxiety remains relatively stable. On the other hand, partners may be more influenced by their uncertainty, showing increases in both depression and anxiety when uncertainty is high. Previous literature indicates that both depression and anxiety are commonly occurring experiences, both during and post treatment, for various types of cancer and forms of treatment (Lynch, Steginga, Hawkes, Pakenham, & Dunn, 2008; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010). Although the concepts of anxiety and depression are often grouped and studied together, there is a marked difference in how each manifests itself in a person's life. Using a symbolic interactionism framework, it is possible that these cancer survivors had attached a positive meaning to moving into survivorship that did not include or allow for depressive symptoms or feelings. There may have been a shift in how they viewed their life post-treatment that was much more positive than the grueling process of surgery, chemotherapy, and radiation. This potential attitude shift in survivorship may have accounted for a lack of significant findings for survivor depression, while allowing for anxiety regarding their thoughts and worries about the disease to return. These survivors may have had anxious concerns but did not classify themselves as depressed. Additionally, Spiegel (1995) reports that cancer patients are no more likely to suffer from depression than other equally serious medical patients. Finally, the variety of cancer type diagnoses reported in the sample may have influenced this outcome, as the most reported types were also the most well researched and treated types of cancers.

**Hypothesis two.** The hypothesis that both survivor's and partner's experience of uncertainty will have a direct relationship to satisfaction with life was partially supported. There was no significant effect of uncertainty on a survivor's life satisfaction. On the other hand, a partner's experience of uncertainty negatively affected his or her own satisfaction with life, such that an increase in uncertainty was associated with a decrease in life satisfaction. Although not a great deal of research has been done regarding partner life satisfaction, previous literature has indicated that survivor quality of life remains relatively stable over time, perhaps resulting in uncertainty having less of a significant impact on survivors life satisfaction (Smith, Zimmerman, Williams, & Zebrack, 2009). As noted earlier, what predicts individual quality of life may differ by role of survivor or partner. Social support has been shown to account for the most variance in
quality of life for survivors whereas for partners, fear of recurrence accounts for the most variance in quality of life (Mellon et al., 2006). Because this sample showed positive coping skills such as seeking support and emotional coping, survivors may have used these sources of support and maintained higher life satisfaction whereas the high levels of uncertainty in illness partners reported may have more of an impact on their experience. Additionally, a study by Parker et al. (2002), found that men, individuals whose cancer had not reoccurred, and those not undergoing active treatment reported a better quality of life. This sample shared a number of similar characteristics with the Parker et al. study and, therefore, uncertainty might not have been as powerful a predictor for life satisfaction.

**Hypothesis three.** The hypothesis that a partner's level of uncertainty will directly relate to the survivor's depression, anxiety, and satisfaction with life was partially supported. Results indicated that a partner's uncertainty can influence the survivor's depression and anxiety, but this did not affect the survivor's satisfaction with life. The more uncertainty a partner experiences may lead to the survivor taking on more uncertainty than they originally felt. This finding is in line with the few previous research studies regarding couples in cancer survivorship done by Mellon et al. (2006, 2007). These studies found that partners continue to report more fear of recurrence than cancer survivors do and this may lead to higher levels of uncertainty for partners, thus allowing partners to more strongly influence the survivor's outcomes on depression and anxiety. Additionally, despite time since treatment, partners are never as intimately connected with the disease experience, treatment, and follow up, which may leave them with many more questions and unknowns to add to their uncertainty. Study data indicate that the survivors had similarly high level of anxiety and depression even though they did not reach significance in the model. The addition of the partner's uncertainty may have been the piece that activated their depression and anxiety to the point of being significant.

**Hypothesis four.** The hypothesis that a survivor's level of uncertainty will have a direct relationship to the partner's depression, anxiety and satisfaction with life was not supported. The results of the study indicate the survivor's experiences of uncertainty do not have a meaningful impact on their partners. This finding may be explained by the previous research conclusions that cancer patients (even in survivorship) receive much more attention and care and therefore have lower levels of illness uncertainty and because of this, they are less influential on their partner's experiences. Other studies have supported the observation that as survival extends, the reported

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quality of life is closer to that of healthy persons who have not had cancer (Dorval, Maunsell, & Deschenes, 1998; Olweny, Juttner, & Rolfe, 1993). Because there was such a wide range of time since treatment ended for these patients, as well as an older average age, many of them may have had more time to process and adjust to their post-treatment life, which decreased their uncertainty.

### **Moderation Research Questions**

**Hypothesis one.** The hypothesis that coping skills would moderate the relationship between uncertainty and depression for both survivors and partners was supported. The impact of uncertainty on depression for both survivors and partners was lessened by positive coping skill usage, meaning that the strength of the relationship between uncertainty and depression was able to be influenced (lessened in this case) by positive coping. Several reports document positive coping strategies leading to enhanced quality of life in long-term survivors of cancer (Ganz, 2001; Ganz, Rowland, & Desmond, 1998). When couples engage in positive coping behaviors it may serve to negate the direct influences of uncertainty. For example, researching to find information or clarifying symptoms with a doctor are all positive coping strategies that would alleviate the impact of uncertainty.

**Hypothesis two.** The hypothesis that coping skills would moderate the relationship between uncertainty and anxiety for both survivors and their partners was not supported. Positive coping did not have an effect on anxiety as predicted. This may be due to the fact that the highest loading BriefCOPE questions that were incorporated into the overall coping factor were related to taking action, seeking support, and having a positive outlook. These types of behaviors seem to have worked to moderate depression, but perhaps the behavior and attitudes needed to moderate the influence of anxiety are of a different variety that were not utilized by this group of couples (Mellon et al., 2008).

**Hypothesis three.** The hypothesis that coping skills would moderate the relationship between uncertainty and life satisfaction for both survivors and partners was partially supported. The use of positive coping skills was found to lessen the impact of uncertainty on life satisfaction for partners only, not for survivors. This may be a unique aspect of this study sample, as results from the APIM indicated that uncertainty had a direct effect only for the partner's satisfaction with life, but not for survivors. Therefore, because in the initial APIM results uncertainty was not shown to have a direct effect on a survivor's life satisfaction, life satisfaction may have been less

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of a concern for survivors and therefore positive coping would have less of a moderating impact on the variables relationship.

Hypothesis four, five and six. The hypotheses stating that marital quality would moderate the relationship between uncertainty and depression, anxiety, and life satisfaction for both survivors and partners were not supported. This is not surprising for survivor depression or satisfaction with life, as there was no significant direct relationship to begin with. Yet, the fact that marital quality did not play a role in influencing any of the outcome variables may be another instance where conceptualizing a different model may be useful. Marital quality may function more strongly as a predictor variable than as a moderator in the experience of cancer survivorship. Additionally, this sample reported very high levels of marital quality, which was a reflection on their whole life time marital experience, whereas the questions related to depression and anxiety were more specific to a recent period of a week or two. These couples may have come into the cancer experience and survivorship with already well-established ways of taking care of each other and relating.. Research shows that couples who can act openly, express themselves and solve their problems had lower levels of anxiety and depression (Edwards & Clarke, 2004). Although these behaviors might be happening within the context of a marital relationship, they are more strongly related to coping behaviors. Finally, marital quality may be the variable in the study most affected by the inadequate sample size of the study. The null findings should be interpreted with caution as the statistical methods used in the study are able to detect clearer effects the larger the sample size. Marital quality may play a significant role in the moderation of uncertainty and the outcome variables, but the analyses employed may have benefited from a larger sample size in order to detect these influences.

### Theory

Symbolic interactionism, a theory based on the importance of meaning people attach to various aspects of their life and how this meaning influences themselves and their relationships, allows researchers to examine what meaning uncertainty in illness can have for both cancer survivors and their partners and how that can affect their relationship. Because the theory of symbolic interactionism allows for individuals to ascribe their own personal meaning to events and experiences, it may explain why the partner's uncertainty showed more significant effects for their own outcome variables as well as their partners. Cancer survivors may have had a very clear meaning associated with their cancer experience as they were the ones going through the

most focused and rigorous treatment whereas partners would have been on the fringes of the cancer treatment experience and had more of a sense of uncertainty about what the illness meant.

Another important aspect of symbolic interactionism is the concept of the "role" that an individual may take on at any given time. The findings of the current study that did not show any significant moderation for marital quality may be due to the fact that the "role" of being a spouse/partner was much more stable and well established. The average length of relationship was around 27 years long, providing plenty of time for the couple to develop roles and meaning around what it means to be a couple and how that works in their lives. The role of being someone with a disease or the role of surviving cancer may have had less time to develop stable patterns of relating and may have increased the level of uncertainty.

A hallmark of uncertainty in illness is the inability to make a cohesive meaning for what is happening with a survivor's disease. Another possible way to examine this phenomenon through the lens of symbolic interactionism would be to consider uncertainty in illness the outcome variable and investigate what factors influence the inability to make meaning. If variables related to sense of cohesion or purpose as well as how strongly a patient identifies as a survivor could be identified and examined, it may provide a different frame through which uncertainty in illness could by symbolically interpreted.

### Limitations

Although this study was designed to address a gap in the literature regarding the couple experience of illness when in survivorship, there were several limitations that should be taken into consideration when examining the findings. First, the sample was an open invitation to patients of the Cancer Treatment Center of America and through Facebook advertising. It is possible that the survivors who opted to participate in the study were better adjusted and had a more positive view of their illness, leading to their willingness to engage in the topic. Those with a higher level of uncertainty may have declined participation. Secondly, the sample was relatively homogeneous in regards to certain factors, such as age, race, education, and income. All of these factors may have lead to less variability within the sample and less unique experiences through the cancer treatment process. These factors may have also influenced levels of uncertainty as this sample may have been more educated about their experiences and had more resources to address their medical needs. Third, although the sample population was homogeneous, the greatest sample variation was on cancer type, with 16 different sites identified.

The type of cancer a survivor experienced can influence uncertainty, but with so many different types of cancer present in the sample, the results may have been skewed. Fourth, participants may have answered the questions in a socially desirable manner. For example, participants may not have wanted to appear too affected or distressed by their experience or may not have wanted to report that their marriage or life as unsatisfactory and, therefore, answered questions in a manner that reflected a more positive functioning and mental state. Fifth, the length of time since treatment varied widely among the sample population, with some participants having completed treatment only a year prior to the survey while others had experienced cancer free living for upwards of 15 years. Someone one year past their treatment ending may experience more uncertainty because they've had less time to adjust to being cancer free recently whereas someone who hasn't been actively dealing with cancer for years may have diminished their concerns about the disease coming back. Because this demographic varied widely within the sample population, the impact of uncertainty may have been less clear.

In light of the fact that the sample size of the study did not meet recommended cutoffs to be able to determine statistical significance, all of the analyses that resulted in null findings should be cautiously interpreted. Although it is possible that all the same null results may be replicated in future studies with an adequate sample size, it is also possible and perhaps more likely that the null findings for a number of the research questions are due to sample size being too small to accurately analyze and determine differences.

#### Implications

#### **Implications for Practice**

When it comes to addressing the impact of cancer, it is typically viewed on an individual level targeted at the person who has gone through treatment and is now in remission. Given the indication of the partner's experiences from this study, the focus of treatment, both during the active stage of the disease and into the survivorship stage, should address partners as fully participating members of the disease experience. Therefore, information, support groups, and other resources should be provided to both members of the couple. In some ways, it is not surprising that partner uncertainty influenced more outcomes than survivors, seeing as the survivor has undergone extensive treatment, follow-up, and attention from various medical and health professionals. In addition, many cancer treatment programs have built in support groups, counseling, and mental health initiatives available for survivors during their experience. The

same would not be said for partners going through a cancer experience. Although they may be present at many of the appointments, the focus is not the partner. Even though there may be a caregivers support group available, the number of resources directed at partners is significantly less than directed at survivors. Therefore, both clinicians and medical professionals should seek to address the discrepancy in attention between survivors and partners. This is especially relevant information for a marriage and family therapist (MFT) because working with a couple system is at the root of their systemic training. Often, an individual seeks therapy on their own to deal with their individual experiences. Therapists need to encourage and explain to any individual who has experienced cancer or is the spouse of a cancer survivor why having both members of the couple system present for therapy is needed and more useful.

The findings of the study indicate that depression and anxiety are affected by uncertainty in illness and therefore, clinicians and medical practitioners should be attentive to monitoring all three variables. Professionals should incorporate ways to assess uncertainty, depression, and anxiety when they meet with and treat patients. This could include having couples fill out paper or electronic versions of the instruments used in this study or other validated measures that may provide brief screening information. Another option would be to incorporate assessment questions into their meetings with patients in order to gather information that could indicate an area that needs attention. Professionals need to seek out opportunities to engage with partners around their experience of illness and their levels of uncertainty as the treatment phase is ending and the couple is moving into survivorship. Even providing a brief exit interview with partners at the end of treatment where uncertainty in illness could be measured and questions and concerns could be raised by the partner to the care team might be very helpful. If uncertainty was measured at this point and found to be significantly high, follow up meetings and recommendations for counseling could be provided in an effort to stem the influence of uncertainty over the course of survivorship. From a clinical standpoint, therapists need to also embrace the usefulness of quick assessment tools. If MFTs have a couple attending sessions that have dealt with a cancer diagnosis, the clinician should be using validated measures as well as client self-report to gather an understanding of the situation. Additionally, there is a need for increased collaboration between medical professionals and counseling professionals. If a MFT knows a client couple is having follow up appointments with their medical professional, the

clinician should obtain a release of information in order to discuss findings and inform treatment based on the collective knowledge of all individuals involved in the couple's professional care.

In terms of interventions available for practitioners, knowledge and information can be primary resources for managing uncertainty. With knowledge and information, the survivor can interpret their situation and provide a sense of closure (Mishel et al., 2005). Many couples may receive a good deal of information at their final doctor appointment, but as these medical appointments decrease in frequency to once a year, there may be a gap that allows uncertainty to build. Clinicians need to be aware of this, checking on the frequency of doctor visits and the last time patients and partners received information. Additionally, clinicians may need to help couples be proactive and seek out information, even though their medical professionals are no longer providing detailed facts. Throughout the process of interpreting their disease information and finding a sense of closure, clinicians can assist survivors and partners in their cognitive process and emotional experiences when in remission.

The results from the study regarding how coping skills can moderate the relationship between uncertainty and the outcome variables provided a few important implications for practice. It was found that positive coping could moderate the relationship between uncertainty and depression for survivors and partners as well as moderate uncertainty and satisfaction for partners. This provides some indication that medical and clinical professionals could see the development of positive coping skills for survivors and partners as an easy and active way to influence change in the couple experience of illness. Survivorship groups as well as individual or couple counseling could provide both assessments of coping behaviors to see how a couple is functioning and also integrate skill building and training around the development of healthy coping behaviors. Results of this study indicated that seeking support from others and working on acceptance were two of the biggest factors that influenced positive coping. Marriage and family therapists could easily incorporate questions about these areas into counseling appointments to see how survivors and partners are seeking support in these essential areas. Once the professional has assessed the manner in which couples are utilizing coping skills, interventions could be used to help couples improve their coping skills. Practitioners could identify negative coping strategies at play for the individual or couple system and then guide the couple into developing more positive coping strategies. As seeking emotional support was an effective coping skill, clinicians could instruct couples to turn to each other and discuss what

feelings or fears they were facing, encouraging them to open up and share freely when either member attempted to avoid discussing the difficult parts of their experience. Additionally, because active coping (or doing something about your situation) was rated highly by the sample, clinicians should encourage their couples to set aside special time in the week to spend together, reconnecting and making sure to be checking in with each other. By creating this special time, place, and even activity, couples may feel like they are taking active steps to address their issues.

Although this study did not show that marital quality had an influence on the relationship between uncertainty and the outcome variables, it may be more related to a sampling bias. A study that requires couple participants is naturally going to attract couples who have a positive relationship and attitude towards each other and who are willing to participate in activities together. With the subject of the study being very sensitive illness related items, couples whose marriages were not as strong or positive may have opted out of another partner related stressor. Therefore, this sample may have had a disproportionately large number of happily married couples and perhaps the analysis was skewed and could not distinguish the impact of marital quality. While this study found no moderating effect for marital quality, it may still serve as an important factor in adjustment to survivorship and the impact of uncertainty on the couple.

### **Implications for Research**

Future research might start by addressing the limitations of the current study. The two most important factors to address would be sample size and length since treatment. If future studies could increase the number of participants while at the same time narrow the range of time since treatment, the effects of uncertainty in survivorship may become more discernible. Additionally, another important limitation for future research to address would be the homogeneity of the sample in terms of race and ethnicity. Minority racial/ethnic groups were grossly underrepresented in this study and their disease, treatment, and survivorship experiences need to be examined and understood in order to improve implications for practice.

Although there were significant pathways from uncertainty to the outcome variables, not all of the study hypotheses were confirmed by the data analysis. This does not discredit the indication of previous literature that uncertainty can play a major factor in the adjustment to illness post treatment, but rather signifies a need for researchers to focus efforts on further understanding uncertainty for both partners when in survivorship. The literature involving couples in cancer survivorship is still relatively sparse. Future research must continue to explore

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the dyadic nature and influence of a couple going through treatment into survivorship. Follow up studies are needed to replicate the study design to see if a different sample, when analyzed, can yield similar information for both survivors and partners, as the vast majority of significant pathways in the study were related to partner effects. If future studies reveal more survivor effects, then the model would be more significant and could provide more implications for research. If future research continues to demonstrate a lack of survivor effects, the indication that some significant pathways were found in the model, as well as the correlational evidence by the study variables, suggest that there may grounds for a different relationship among the study variables. The data in this study indicate that uncertainty in illness, depression, and anxiety seems to be the main variables to carry over into future studies. Satisfaction with life did not seem to have a major role when exploring uncertainty in illness.

Study data regarding moderators revealed less useful information, indicating a moderator model for studying uncertainty is not the most useful conceptualization. Future studies may want to examine how marital quality or coping skills can function as independent variables in the model conceptualization. It is important to continue to examine marital quality in dyadic studies due to the nature of the relationship. Finally, it may be beneficial for future studies to incorporate more of a qualitative nature to the study collection. Uncertainty in illness is a complicated experience and may not be fully captured through a questionnaire with limited choices and ways to explain. Further insight into the uncertainty experience could be gained from interviewing participants because it would allow the researcher to ask follow up questions and explore the influence of each partner on uncertainty.

### Conclusion

As treatment advances continue to be made in an effort to eliminate cancer, the number of patients who will move into the survivorship phase will continue to grow. The findings of this study indicate that the partner of the cancer survivor may be the person in the dyad most strongly affected by and influential in the experience of illness during survivorship. It would be useful for additional studies to examine other models or variables that may be able to discern the specific qualities of the cancer experience that affect millions of people who have been declared disease free, with a concerted effort to understand the experience and influence of partners within the committed relationship.

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## **APPENDIX A**

# FLORIDA STATE INSTITUTIONAL REVIEW BOARD APPROVALS

Office of the Vice President For Research Human Subjects Committee Tallahassee, Florida 32306-2742 (850) 644-8673, FAX (850) 644-4392

APPROVAL MEMORANDUM

Date: 10/14/2011 To: Natalie Senatore Address: 225 Sandels Building Dept.: FAMILY & CHILD SCIENCE

From: Thomas L. Jacobson, Chair

Re: Use of Human Subjects in Research The effects of uncertainty for couples in cancer survivorship

The application that you submitted to this office in regard to the use of human subjects in the proposal referenced above have been reviewed by the Secretary, the Chair, and one member of the Human Subjects Committee. Your project is determined to be Expedited per 45 CFR § 46.110(7) and has been approved by an expedited review process.

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

If you submitted a proposed consent form with your application, the approved stamped consent form is attached to this approval notice. Only the stamped version of the consent form may be used in recruiting research subjects.

If the project has not been completed by 10/11/2012 you must request a renewal of approval for continuation of the project. As a courtesy, a renewal notice will be sent to you prior to your expiration date; however, it is your responsibility as the Principal Investigator to timely request renewal of your approval from the Committee.

You are advised that any change in protocol for this project must be reviewed and approved by the Committee prior to implementation of the proposed change in the protocol. A protocol change/amendment form is required to be submitted for approval by the Committee. In addition, federal regulations require that the Principal Investigator promptly report, in writing any

unanticipated problems or adverse events involving risks to research subjects or others.

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

This institution has an Assurance on file with the Office for Human Research Protection. The Assurance Number is FWA00000168/IRB number IRB00000446.

Cc: Wayne Denton, Advisor HSC No. 2011.5760 Office of the Vice President For Research Human Subjects Committee Tallahassee, Florida 32306-2742 (850) 644-8673 · FAX (850) 644-4392

APPROVAL MEMORANDUM (for change in research protocol)

Date: 3/26/2012 To: Natalie Senatore Address: 225 Sandels Building Dept.: FAMILY & CHILD SCIENCE

From: Thomas L. Jacobson, Chair

Re: Use of Human Subjects in Research (Approval for Change in Protocol) Project entitled: The effects of uncertainty for couples in cancer survivorship

The form that you submitted to this office in regard to the requested change/amendment to your research protocol for the above-referenced project has been reviewed and approved.

If the project has not been completed by 10/11/2012, you must request a renewal of approval for continuation of the project. As a courtesy, a renewal notice will be sent to you prior to your expiration date; however, it is your responsibility as the Principal Investigator to timely request renewal of your approval from the Committee.

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

This institution has an Assurance on file with the Office for Human Research Protection. The Assurance Number is FWA00000168/IRB number IRB00000446.

Cc: Wayne Denton, Advisor HSC No. 2012.8023

## **APPENDIX B**

# CANCER TREATMENT CENTERS OF AMERICA INSTITUTIONAL REVIEW BOARD APPROVAL

Midwestern Regional Medical Center Institutional Review Board 2160 Sheridan Road Zion, IL 60099 Tel: (847) 746-4362

March 9, 2012

Christopher G. Lis, MPH Vice President, Chief Outcomes Research Cancer Treatment Centers of America 1336 Basswood Road Schaumburg, IL 60173

RE: Exemption for "Experience of Uncertainty for Couples who are Post Treatment for Cancer" Dear Mr. Lis and Ms. Natalie Senatore:

Thank you for presenting your project during the IRB meeting held on March 7, 2012 and the request seeking exemption of IRB review for your project titled; "Experience of Uncertainty for Couples who are Post Treatment for Cancer." On behalf of the IRB committee, I am pleased to inform you that the IRB reviewed and approved your study. This decision is based on your assurance that data will be de-identified before reporting to any medium. Please inform the IRB if your intention for study, changes in any way. I invite you to inform the IRB of progress in your project on or in about one year from now.

If you have any questions or concerns regarding the above, please feel free to contact me.

Sincerely, Harland L. Verrill, Ph.D. IRB Chairman

# **APPENDIX C**

# SURVIVOR CONTACT LETTER

#### Dear (patient name),

A researcher, and friend of Cancer Treatment Centers of America, is seeking your help with a very important study being conducted through the Department of Family and Child Sciences at Florida State University. The purpose of this study is to learn more about the experiences of cancer patients *and* their partners with whom they have a significant relationship.

In order to address both yours and your partner's thoughts and experiences, the study would involve you AND your spouse or significant other each answering a one-time, brief, online survey that would ask you both about your habits, feelings, and experiences as a couple who are post-treatment for cancer. The online survey is completely secure and should last approximately 30 minutes. All participation is entirely voluntary. Your decision whether or not to participate in this study will have no impact on your medical care. Additionally, you may choose to answer only those survey questions with which you feel comfortable and may drop out at any time. All information will be kept strictly confidential and is protected to the extent of the law.

The assistance of you and your partner in this effort is very much appreciated, as this type of study depends on being able to survey as many couples as possible. Participants who complete the survey will be entered into a drawing for one of four 25.00 Visa Gift Cards.

If you AND your partner are interested or willing to participate in this brief study then please reply by sending an email to <u>CTCAcancerstudy@gmail.com</u>. Include your names, email addresses (for both), and best phone number to be contacted. After we have received your confirmation to participate, a study representative will contact you to further explain the process and answer any questions you may have. If you have questions prior to responding, please contact the researcher (Natalie Senatore) at \_\_\_\_\_\_\_.

Sincerely,

Christopher Lis Vice President & Chief, Outcomes Research Cancer Treatment Centers of America

Tom Lay Director of Survivorship Support Cancer Treatment Centers of America

Natalie M. Senatore, MSMFT Doctoral Candidate The Florida State University

Wayne Denton, PhD, MD Professor and Program Director The Florida State University

# **APPENDIX D**

# SURVIVOR QUESTIONNAIRE

Demographic Questions

Please enter your unique participant ID number in the box below.

Your ID number should be in the form of a letter, followed by three numbers (EXAMPLE: X901).

It can be found in the email that contained the link for this survey.

Please email the investigators at CTCAcancerstudy@gmail.com if you cannot find your participant ID number.

- 1. ID Number
- 2. What is your age? (In years)
- 3. What is your gender?
  - a. Female
  - b. Male
- 4. What is your present relationship status?
  - a. Married
  - b. Cohabitating
  - c. Committed partnership
- 5. How long have you been in this couple relationship?
  - a. If married, how many years married?
  - b. If coupled, how many years in a committed relationship?
- 6. Were you with your current partner when you were diagnosed with cancer?
  - a. Yes
  - b. No
- 7. What is your highest level of education?
  - a. Less than high school
  - b. GED
  - c. High school diploma
  - d. Associate degree
  - e. Bachelors degree
  - f. Masters degree
  - g. PhD
  - h. MD/advanced degree
- 8. What is your ethnicity? (Check one)
  - a. Hispanic or Latino
  - b. Non-Hispanic or Non-Latino
- 9. What is your race?
  - a. Asian
  - b. Black or African American
  - c. American Indian or Alaskan Native
  - d. White (Caucasian)
  - e. Native Hawaiian or Other Pacific Islander
- 10. What is your employment status? (Check one)

- a. Full time
- b. Part-time
- c. Unemployed
- d. Retired
- 11. What is your approximate yearly family income (include yourself and partner)?
  - a. Below 15,000
  - b. 15,001-30,000
  - c. 30,001-45,000
  - d. 45,001-60,000
  - e. 60,001-75,000
  - f. 75,001-90,000
  - g. 90,001-105,000
  - h. over 105,001
- 12. Please indicate how many other cancer related studies you have participated in.
- 13. Were you in a committed relationship with your current partner while you were actively receiving treatment for your cancer?
  - a. Yes, my partner was a part of diagnosis and/or treatment
  - b. No, I met my partner once active treatment had finished

Some people experience a cancer diagnosis once, while others have multiple recurrences. Please indicate below each instance that you have been diagnosed with cancer.

First Diagnosis

- a. Type of Cancer (primary site)
- b. Stage at diagnosis
  - a. Stage 0
  - b. Stage I
  - c. Stage II
  - d. Stage III
  - e. Stage IV
- c. Diagnosis date (month/year)
- d. Date declared disease free (month/year)
- e. Treatment Received
  - a. Chemotherapy
  - b. Radiation
  - c. Surgery
  - d. Other
- Second Diagnosis
  - a. Type of Cancer (primary site)
  - b. Stage at diagnosis
    - a. Stage I
    - b. Stage II
    - c. Stage III
    - d. Stage IV
  - c. Diagnosis date (month/year)
  - d. Date declared disease free (month/year)

- e. Treatment Received
  - a. Chemotherapy
  - b. Radiation
  - c. Surgery
  - d. Other

Third Diagnosis

- a. Type of Cancer (primary site)
- b. Stage at diagnosis
  - a. Stage I
  - b. Stage II
  - c. Stage III
  - d. Stage IV
- c. Diagnosis date (month/year)
- d. Date declared disease free (month/year)
- e. Treatment Received
  - a. Chemotherapy
  - b. Radiation
  - c. Surgery
  - d. Other
- 1. How long have you been in remission since your last diagnosis and treatment? (in years)
- 2. How long has your current partner been a part of your cancer experience? (in years)

## Satisfaction with Life Scale

(SWLS; Diener, Emmons, Larsen, & Griffin, 1985)

Using the 1-7 scale below, indicate your agreement with each item by marking the appropriate answer.

- 1 = strongly disagree
- 2 = disagree
- 3 = slightly disagree
- 4 = neither agree nor disagree
- 5 = slightly agree
- 6 = agree
- 7 =strongly agree
- 1. In most ways my life is close to ideal
- 2. The conditions of my life are excellent
- 3. I am satisfied with my life
- 4. So far I have gotten the most important things I want in life
- 5. If I could live my life over, I would change almost nothing

Marital Quality Scale

(QMI; Norton, 1983)

Please rate how much you agree or disagree with the following statements by circling one of the numbers.

- 1 = very strongly disagree
- 2 = disagree
- 3 = slightly disagree
- 4 = neither agree nor disagree
- 5 =slightly agree
- 6 = agree
- 7 = very strongly agree
- 1. We have a good marriage (relationship).
- 2. My relationship with my partner is very stable.
- 3. Our marriage (relationship) is strong.
- 4. My relationship with my partner makes me happy.
- 5. I really feel like part of a team with my partner.
- 6. On the scale below, indicate the point which best describes the degree of happiness, everything considered, in your marriage (relationship). The middle point, "happy," represents the degree of happiness which most people get from marriage (relationship). The scale gradually increases on the right side for those few who experience extreme joy in marriage (a relationship) and decreases on the left side for those who are extremely unhappy.

1 (very unhappy) 2 3 4 5 (happy) 6 7 8 9 10 (perfectly happy)

Depression Scale (\* = reverse coded item)

## (CES-D Scale; Radloff, 1977)

Using the 1-4 scale below, indicate your agreement with each item by marking the appropriate answer

- 0 = Rarely or none of the time (less than 1 day)
- 1 = Some or a little of the time (1-2 days)
- 2 =Occasionally or a moderate amount of time (3-4 days)
- 3 = Most or all of the time (5-7 days)
- 1. I was bothered by things that don't usually bother me
- 2. I did not feel like eating; my appetite was poor
- 3. I felt that I could not shake off the blues even with help from my family or friends
- 4. I felt that I was just as good as other people\*
- 5. I had trouble keeping my mind on what I was doing
- 6. I felt depressed
- 7. I felt that everything I did was an effort
- 8. I felt hopeful about the future\*
- 9. I thought my life had been a failure
- 10. I felt fearful
- 11. My sleep was restless

- 12. I was happy\*
- 13. I talked less than usual
- 14. I felt lonely
- 15. People were unfriendly
- 16. I enjoyed life\*
- 17. I had crying spells
- 18. I felt sad
- 19. I felt that people dislike me
- 20. I could not "get going"

Anxiety Scale

(GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006)

Using the 0-3 scale below, indicate your agreement with each item by marking the appropriate answer

- 0 = Not at all
- 1 = Several days
- 2 = More than half the days
- 3 = Nearly every day

Over the last 2 weeks, how often have you been bothered by the following problems?

- 1. Feeling nervous, anxious, or on edge
- 2. Not being able to stop or control worrying
- **3.** Worrying too much about different things
- 4. Trouble relaxing
- 5. Being so restless that it is hard to sit still
- 6. Becoming easily annoyed or irritable
- 7. Feeling afraid as if something awful might happen

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- 1. Not difficult at all
- 2. Somewhat difficult
- 3. Very difficult
- 4. Extremely difficult

Mishel Uncertainty in Illness-Survivor Scale (MUIS-S; Mishel, 1997)

This section of questions is about what your life has been like since your treatment. People who have been treated for cancer may feel unsure or uncertain about many things related to their present situation. These next questions will help us find out about the things you are unsure about or things you don't know or fully understand. Read each question and select the one number that tells us how much you agree/disagree with each item TODAY. For medically related questions, think back to your last visit and how you are currently feeling about the information or care you received.

- 1 = Strongly Disagree
- 2 = Disagree
- 3 =Undecided
- 4 = Agree
- 5 =Strongly Agree

Scale items have been removed to respect copyright privileges of the original author.

### Brief COPE

## (Brief COPE; Carver, 1997)

These items deal with ways you cope with stress in your life. There are many ways to try to deal with problems; these items ask what you do to cope. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with your stress. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

- 1 = I haven't been doing this at all
- 2 = I've been doing this a little bit
- 3 = I've been doing this a medium amount
- 4 = I've been doing this a lot
- 1. I've been turning to work or other activities to take my mind off things.
- 2. I've been concentrating my efforts on doing something about the situation I'm in.
- 3. I've been saying to myself "this isn't real."
- 4. I've been using alcohol or other drugs to make myself feel better.
- 5. I've been getting emotional support from others.
- 6. I've been giving up trying to deal with it.
- 7. I've been taking action to try to make the situation better.
- 8. I've been refusing to believe that it has happened.
- 9. I've been saying things to let my unpleasant feelings escape.
- 10. I've been getting help and advice from other people.
- 11. I've been using alcohol or other drugs to help me get through it.
- 12. I've been trying to see it in a different light, to make it seem more positive.
- 13. I've been criticizing myself.
- 14. I've been trying to come up with a strategy about what to do.
- 15. I've been getting comfort and understanding from someone.
- 16. I've been giving up the attempt to cope.
- 17. I've been looking for something good in what is happening.
- 18. I've been making jokes about it.
- 19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
- 20. I've been accepting the reality of the fact that it has happened.
- 21. I've been expressing my negative feelings.
- 22. I've been trying to find comfort in my religion or spiritual beliefs.

- 23. I've been trying to get advice or help from other people about what to do.
- 24. I've been learning to live with it.
- 25. I've been thinking hard about what steps to take.26. I've been blaming myself for things that happened.
- 27. I've been praying or meditating.
- 28. I've been making fun of the situation.

# **APPENDIX E**

# PARTNER QUESTIONNAIRE

Demographic Questions

1. Please enter your unique participant ID number in the box below.

Your ID number should be in the form of a letter, followed by three numbers (EXAMPLE: X901).

It can be found in the email that contained the link for this survey.

Please email the investigators at \_\_\_\_\_\_ if you cannot find your participant ID number.

- 2. ID Number \_\_\_\_
- 3. What is your age? (In years)
- 4. What is your gender?
  - a. Female
  - b. Male
- 5. What is your present relationship status?
  - a. Married
  - b. Cohabitating
  - c. Committed partnership
- 6. How long have you been in this couple relationship?
  - a. If married, how many years married?
  - b. If coupled, how many years in a committed relationship?
- 7. Were you with your current partner when you were diagnosed with cancer?
  - a. Yes
  - b. No
- 8. What is your highest level of education?
  - a. Less than high school
  - b. GED
  - c. High school diploma
  - d. Associate degree
  - e. Bachelors degree
  - f. Masters degree
  - g. PhD
  - h. MD/advanced degree
- 9. What is your ethnicity? (Check one)
  - a. Hispanic or Latino
  - b. Non-Hispanic or Non-Latino
- 10. What is your race?
  - a. Asian
  - b. Black or African American
  - c. American Indian or Alaskan Native
  - d. White (Caucasian)
  - e. Native Hawaiian or Other Pacific Islander
- 11. What is your employment status? (Check one)

- a. Full time
- b. Part-time
- c. Unemployed
- d. Retired
- 12. What is your approximate yearly family income (include yourself and partner)?
  - a. Below 15,000
  - b. 15,001-30,000
  - c. 30,001-45,000
  - d. 45,001-60,000
  - e. 60,001-75,000
  - f. 75,001-90,000
  - g. 90,001-105,000
  - h. over 105,001
- 13. Were you in your current relationship when your partner was diagnosed with cancer? (Check one)
  - a. Yes
  - b. No
- 14. How long has it been since your partner completed treatment? (Estimate in years)
- 15. Have you ever been diagnosed with cancer?
  - a. Yes
    - b. No
- 16. Were you in a committed relationship with your current partner while you were actively receiving treatment for your cancer?
  - a. Yes, my partner was a part of diagnosis and/or treatment
  - b. No, I met my partner once active treatment had finished
- 17. Please indicate how many other cancer related studies you have participated in.

Satisfaction with Life Scale

(SWLS; Diener, Emmons, Larsen, & Griffin, 1985)

Using the 1-7 scale below, indicate your agreement with each item by marking the appropriate answer.

- 1 = strongly disagree
- 2 = disagree
- 3 = slightly disagree
- 4 = neither agree nor disagree
- 5 = slightly agree
- 6 = agree
- 7 =strongly agree
- 1. In most ways my life is close to ideal
- 2. The conditions of my life are excellent
- 3. I am satisfied with my life
- 4. So far I have gotten the most important things I want in life
- 5. If I could live my life over, I would change almost nothing

Marital Quality Scale

(QMI; Norton, 1983)

Please rate how much you agree or disagree with the following statements by circling one of the numbers.

- 1 = very strongly disagree
- 2 = disagree
- 3 = slightly disagree
- 4 = neither agree nor disagree
- 5 =slightly agree
- 6 = agree
- 7 = very strongly agree
- 1. We have a good marriage (relationship).
- 2. My relationship with my partner is very stable.
- 3. Our marriage (relationship) is strong.
- 4. My relationship with my partner makes me happy.
- 5. I really feel like part of a team with my partner.
- 6. On the scale below, indicate the point which best describes the degree of happiness, everything considered, in your marriage (relationship). The middle point, "happy," represents the degree of happiness which most people get from marriage (relationship). The scale gradually increases on the right side for those few who experience extreme joy in marriage (a relationship) and decreases on the left side for those who are extremely unhappy.

1 (very unhappy) 2 3 4 5 (happy) 6 7 8 9 10 (perfectly happy)

Depression Scale (\* = reverse coded item)

## (CES-D Scale; Radloff, 1977)

Using the 1-4 scale below, indicate your agreement with each item by marking the appropriate answer

- 0 = Rarely or none of the time (less than 1 day)
- 1 = Some or a little of the time (1-2 days)
- 2 =Occasionally or a moderate amount of time (3-4 days)
- 3 = Most or all of the time (5-7 days)
- 1. I was bothered by things that don't usually bother me
- 2. I did not feel like eating; my appetite was poor
- 3. I felt that I could not shake off the blues even with help from my family or friends
- 4. I felt that I was just as good as other people\*
- 5. I had trouble keeping my mind on what I was doing
- 6. I felt depressed
- 7. I felt that everything I did was an effort
- 8. I felt hopeful about the future\*
- 9. I thought my life had been a failure
- 10. I felt fearful
- 11. My sleep was restless
- 12. I was happy\*

- 13. I talked less than usual
- 14. I felt lonely
- 15. People were unfriendly
- 16. I enjoyed life\*
- 17. I had crying spells
- 18. I felt sad
- 19. I felt that people dislike me
- 20. I could not "get going"

Anxiety Scale

(GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006)

Using the 0-3 scale below, indicate your agreement with each item by marking the appropriate answer

- 0 = Not at all
- 1 =Several days
- 2 = More than half the days
- 3 = Nearly every day

Over the last 2 weeks, how often have you been bothered by the following problems?

- 1. Feeling nervous, anxious, or on edge
- 2. Not being able to stop or control worrying
- 3. Worrying too much about different things
- 4. Trouble relaxing
- 5. Being so restless that it is hard to sit still
- 6. Becoming easily annoyed or irritable
- 7. Feeling afraid as if something awful might happen

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

- 1. Not difficult at all
- 2. Somewhat difficult
- 3. Very difficult
- 4. Extremely difficult

Mishel Uncertainty in Illness-Survivor Scale

### (*MUIS-S; Mishel, 1997*)

This section of questions is about what your life has been like since your partner ended cancer treatment. Those who have been close to someone treated for cancer may feel unsure or uncertain about many things related to their present situation. These next questions will help us find out about the things you are unsure about or things you don't know or fully understand. Read each question and select the one number that tells us how much you agree/disagree with each item TODAY. For medically related questions, think back to your partner's last visit and how you are currently feeling about the information or care they received.

- 1 = Strongly Disagree
- 2 = Disagree
- 3 =Undecided

4 = Agree 5 = Strongly Agree

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### Brief COPE

(Brief COPE; Carver, 1997)

These items deal with ways you cope with stress in your life. There are many ways to try to deal with problems; these items ask what you do to cope. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with your stress. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says. How much or how frequently. Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

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- 4. I've been using alcohol or other drugs to make myself feel better.
- 5. I've been getting emotional support from others.
- 6. I've been giving up trying to deal with it.
- 7. I've been taking action to try to make the situation better.
- 8. I've been refusing to believe that it has happened.
- 9. I've been saying things to let my unpleasant feelings escape.
- 10. I've been getting help and advice from other people.
- 11. I've been using alcohol or other drugs to help me get through it.
- 12. I've been trying to see it in a different light, to make it seem more positive.
- 13. I've been criticizing myself.
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- 16. I've been giving up the attempt to cope.
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- 19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.
- 20. I've been accepting the reality of the fact that it has happened.
- 21. I've been expressing my negative feelings.
- 22. I've been trying to find comfort in my religion or spiritual beliefs.
- 23. I've been trying to get advice or help from other people about what to do.
- 24. I've been learning to live with it.
- 25. I've been thinking hard about what steps to take.
- 26. I've been blaming myself for things that happened.

- 27. I've been praying or meditating.28. I've been making fun of the situation.

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# **BIOGRAPHICAL SKETCH**

# Natalie M. Senatore

### **EDUCATION**

2013	Ph.D. Candidate, Marriage and Family Therapy The Florida State University, Tallahassee, FL (COAMFTE-accredited) Dissertation: The effect of uncertainty on couples in cancer survivorship Advisor: Wayne Denton, MD, PhD
2008	Masters of Science, Marriage and Family Therapy (MSMFT) Northwestern University, Evanston, IL (COAMFTE-accredited)
2006	Bachelor of Arts, Psychology Judson University, Elgin, IL

### **PROFESSIONAL EXPERIENCE**

### TEACHING

2012 Summer Teaching Assistant for Ecological Contexts (FAD3271, online) Department of Family & Child Sciences, Florida State University Responsible for grading all assignments, responding to student emails/inquiries, test and assignment creation, and providing feedback on class work Teaching Assistant for Family Life and Relationship Development (FAD2230, 2012 Spring online) Department of Family & Child Sciences, Florida State University Responsible for grading all assignments, responding to student emails/inquiries, posting and moderating weekly discussion boards, and providing feedback on class work 2011 Fall Teaching Assistant for Ecological Contexts (FAD 3271) Department of Family & Child Sciences, Florida State University Responsible for grading all class assignments, attendance, and proctoring examinations. 2011 Summer Instructor for Ecological Contexts (FAD 3271) Department of Family & Child Sciences, Florida State University 2010 Summer Instructor for Ecological Contexts (FAD 3271) Department of Family & Child Sciences, Florida State University 2009-2010 Teaching Assistant for Stress and Resilience (FAD 3432, online version) Department of Family & Child Sciences, Florida State University

	Responsible for grading all class assignments, organization of the online blackboard site, and monitoring of discussion board postings
2008-2010	Teaching Assistant for Family Life and Relationship Development (FAD 2230) Department of Family & Child Sciences, Florida State University
	Responsible to provide instruction for recitation session once a week for federally funded grant (Project Relate). Also responsible
	for grading all class assignments, entering attendance, and proctoring examinations.

#### RESEARCH

- 2008-2012 Research Assistant under Carol A. Darling, Ph.D., Florida State University Responsibilities include preparing proposals for presentation and papers for publication, as well as working on a team to prepare a research proposal. Areas of research include family stress, family health, parents of handicapped children, and parental overindulgence.
- 2010-2011 Research Team member for Wayne Denton, Ph.D., Florida State University Areas of research include anxiety, depression, emotionally focused couple therapy, cancer, community mental health, and grant applications.

#### LEADERSHIP

2013 Judson Student Organization Advisor, Judson University, Elgin, IL

- 2010-2011 Program for Instructional Excellence Associate & Department Representative, Florida State University, Tallahassee, FL
  - Attend monthly program meetings, providing feedback regarding graduate level teaching workshop opportunities
  - Assisted in the pilot testing of the Advanced PIE Certificate program, providing feedback, corrections, and suggestions
  - Plan, host, and present a department teaching workshop
  - Plan, host, and present a campus wide teaching workshop
  - Complete work on department appointed projects as directed by the department chair
  - Evaluate multiple portfolio submissions for the Outstanding Teaching Assistant Award
  - Serve as a host for the Celebration of Graduate Student Excellence, an annual spring event honoring outstanding teaching at Florida State University
- 2010-2011 Project Relate/Marriage Education Grant Program Mentor, Florida State University, Tallahassee, FL
  - Weekly observation of current teaching assistants as they provide the instruction for a grant funded treatment program
  - Provide detailed written and verbal feedback regarding teaching style, classroom presence, and quality of instruction each week

- Created, updated, and maintained all supplemental materials for instruction including handouts, power points, videos, and homework assignments
- Assisted in leading weekly meeting to prepare teachers for their weekly instructions

2009-2011 Student & Associate Board Representative for AAMFT Board of Directors

- Attend 3 board meetings in person and multiple conference calls to address current needs of the organization
- Maintain active knowledge and ability to dialogue about the current challenges and opportunities that face the organization by reading all materials provided to the board
- Provide specific feedback to the board regarding the needs of student and associate members
- Actively network with all members of AAMFT whenever possible, being an available information and feedback channel
- AAMFT Awards Committee member
  - Read all materials (including dissertations, theses, and nominations) for the awards committee selection and provide recommendations to the board for award recipients
- AAMFT Strategic Plan Task Force member
- AAMFT Strategic Plan Student/Associate Committee member
  - Develop recommendations and suggestions for the strategic plan from the perspective of both a student/associate and a member at large
- AAMFT Foundation Task Force member

2006-2007 Youth Pastor, Edgebrook Evangelical Covenant Church, Chicago, IL

- Hosted two youth services each week for junior high and high school students
- Attended weekly church staff meetings
- Supervised field trips and service projects, as well as a mission trip
- Planned and implemented biblically based curriculum for both age groups
- Maintained communication with and gathered feedback from parents

2005-2006 Student Life and Leadership Intern, Judson University, Elgin, IL

- Led team of 70+ students to organize, host, execute, and evaluate new student orientation
- Assigned jobs, coordinated teams for service, and delegated tasks
- Communicated with staff and faculty regarding campus events and concerns
- Served on campus committees (student policies committee and general education policy committee)
- Compiled, edited, and emailed campus wide communication

### 2004-2006 Vice President of Social Activities, Judson University, Elgin, IL

- Planned, coordinated, and publicized campus-wide social activities and events
- Led team of 12 people in their assigned jobs and evaluated their performance on a quarterly basis

- Maintained budget of \$15,000
- Planned and executed multiple weekly meetings

2003-2005 Program Director, Covenant Harbor Bible Camp, Lake Geneva, WI

- Supervised and counseled 200 children (ages 10-15) per week
- Supervised, evaluated and helped train collegiate counseling staff of 20+
- Created, modified, and implemented age appropriate programming

### **CLINICAL EXPERIENCE**

2013	Residence Hall Director – Judson University, Elgin, IL
2012	School Social Work Intern – Apollo Elementary School, Des Plaines, IL
2012 Summer	Parent Liaison – Covenant Harbor Bible Camp, Lake Geneva, WI
2011	Marriage and Family Therapy Internship - Rehabilitation Center at Tallahassee Memorial Hospital, Tallahassee, FL
2010 Fall	Provided individual clinical supervision for 2 <sup>nd</sup> year doctoral student, Florida State University, Tallahassee, FL
2008-2010	Marriage and Family Therapy Intern - Center for Marriage and Family Therapy, Florida State University, Tallahassee, FL
2007-2008	Community Program Therapist - Evanston Township High School, Evanston, IL
2007-2008	Mother-Daughter Group Leader - Bette D. Harris Family and Child Therapy Center, Northwestern University, Evanston, IL
2006-2008	Therapist in Training - Bette D. Harris Family and Child Therapy Center, Northwestern University, Evanston, IL

### **PUBLICATIONS**

Darling, C.A., Coccia, C., & Senatore, N. (2012). Women in midlife: Stress, health and life satisfaction. *Stress and Health, 28,* 31-40.

Darling, C.A., Senatore, N., & Strachan, J. (2012). Fathers of children with disabilities: Experiences of stress and satisfaction. *Stress and Health, 28,* 269-278.

Senatore, N. (2011). My experience on the AAMFT board of directors. (Invited manuscript for the Texas Association of Marriage and Family Therapy Online Journal).

### **PRESENTATIONS**

Senatore, N.M., Darling, C.A., & Strachan, J. (2011, September). *Experiences of stress for fathers of disabled children*. Poster presentation at the American Association of Marriage and Family Therapy Annual Meeting, Fort Worth, TX.

Coccia, C.C., Darling, C.A., & Senatore, N.M. (2009, October). *Women in midlife; Stress, health and life satisfaction*. Session presentation at the National Council on Family Relations Annual Meeting, San Francisco, CA.

## LICENSURES AND CERTIFICATIONS

Associate Marriage and Family Therapist, IL (License # 208.000234)

- 2010 Program for Instructional Excellence Advanced certification
- 2008 Program for Instructional Excellence certification
- 2008 Certified PREP Trainer

### **PROFESSIONAL MEMEBERSHIPS**

2006-present Student member of the American Association for Marriage and Family Therapists (AAMFT)

### **AWARDS AND HONRS**

2011 Ruth J. Dales Scholarship Recipient
2008-present Kappa Omicron Nu (KON) Honor Society member
2006 Student Service Award, Judson University
2005-2006 Psi Chi Honor Society Member

## **ADDITIONAL TRAINING**

2011 Semi-Structured Interview Guide for the Inventory of Depressive Symptomatology (IDS-Clinician Rated), Florida State University, Tallahassee, FL

• Trained to conduct interviews for depression severity for clinical and research purposes

2011 Structured Clinical Interview for DSM Disorders (SCID), Florida State University, Tallahassee, FL

• Trained to conduct interviews for depression severity for clinical and research purposes