THE QUALITY OF LIFE OF MEN WITH ADVANCED PROSTATE CANCER TREATED WITH ANDROGEN DEPRIVATION THERAPY AND THEIR PARTNERS

by

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DEDICATION

This dissertation is dedicated to:

My husband, Jeff

My children, Joshua, Jordan, Jeremy, Christopher, James, Abigail and Nathaniel

To my parents, Barbara and John Anderson

And in loving memory of my son, James (1982-1997)

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ABSTRACT

The Quality of Life of Men with Advanced Prostate Cancer Treated with Androgen Deprivation Therapy and Their Partners
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BACKGROUND: Advanced prostate cancer patients treated with androgen deprivation therapy (ADT) have been shown to experience a large number of physiological and psychological sequelae; however, few studies have examined how these sequelae affect the patients' and their partners' quality of life (QOL). PURPOSE: The purposes of this study were: 1) to describe and compare patients' and partners' levels of self-efficacy, symptom distress, communication, appraisal, coping and QOL and 2) to determine if specific antecedent factors (self-efficacy, symptom distress, communication, their partners' QOL), and mediators (appraisal of illness/caregiving, active and avoidant coping) explain a significant amount of variance in the QOL of advanced prostate cancer patients treated with ADT and their partners. THEORETICAL FRAMEWORK: The study was guided by a stress-coping model. METHODS: The study was a cross-sectional, secondary analysis of data obtained from two randomized clinical trials. The study sample consisted of 75 patient-partner dyads. Data were obtained using standardized measures with acceptable reliabilities. Independent *t* tests were used to assess differences between patients and partners scores on major study variables. Bootstrapping was used to assess for mediator effects and structural equation modeling was used to assess the

the models function to predict QOL. RESULTS: Patients and partners were more alike than different. Partners reported worse emotional QOL than patients. Patients and partners had poorer emotional QOL when compared to an age and gender matched normative sample. Appraisal (illness/caregiving) and avoidant coping were significant mediators between antecedents variables and QOL for both patients and partners. Partners' QOL was a significant predictor of patients' QOL. Patients' QOL was not a significant predictor of partners' QOL. Overall, the stress-coping model accounted for a significant amount of variance in patients' and partners' QOL (89% and 74%, respectively). CONCLUSIONS: Findings suggest that advanced prostate cancer patients treated with ADT and their partners are at risk for poorer emotional QOL. Results also indicate that there are a number of potential areas for interventions to improve patients' and partners' emotional QOL: self-efficacy, symptom distress, communication, appraisal and avoidant coping.

CHAPTER I

INTRODUCTION

STATEMENT OF PROBLEM

Among men, prostate cancer is the most frequently diagnosed non-cutaneous cancer. The lifetime risk of developing the disease is one in six with the majority of these diagnoses occurring in men between the ages of 50 and 70. It is estimated that 240,890 new cases of prostate cancer will be diagnosed in 2011 (Siegel, Ward, Brawley & Jemal, 2011). Currently there are over 2.2 million men living in the United States with prostate cancer and this number will greatly increase during the next half century (American Cancer Society, 2007). Mortality due to prostate cancer continues on a downward trend with a current rate of 26 per 100,000 (SEER, 2009). An additional consideration is that the average life expectancy of American men and women continues to increase. The U.S. Census Bureau (Vincent & Velkoff, 2010) estimates that between the years 2000 and 2050, the population of those 65 and older will increase by over 145% whereas the population, as a whole, will only increase by 49%. This shift in population dynamics suggests that the number of men diagnosed with prostate cancer will increase over the next 40 years and that men with prostate cancer will be living longer with extended periods of survivorship. Androgen deprivation therapy (ADT) is the primary treatment for men with advanced prostate cancer, as well as those who have failed first line therapy

(i.e., surgery, radiation). Additionally, ADT is frequently used for men with either locally advanceddisease or biochemical recurrence with a rising prostate specific antigen (PSA) (El-Rayes & Hussain, 2002; Engel & Schally, 2007). The side effects of ADT can be intense and far-reaching. Many men experience loss of libido, erectile dysfunction, hot flashes, body changes, fatigue, emotional and cognitive changes, osteoporosis, anemia, diabetes and metabolic syndrome (Higano, 2006; Holzbeierlein, 2006; Kabir, Mancuso, & Rashid, 2008; Potosky, et al., 2002).

How the side effects of ADT affect patients' quality of life (QOL) and the QOL of their partners' is a relatively new area of research. However, studies addressing QOL among other types of cancer and prostate cancer in general indicate that both patients and partners can be negatively affected (Given et al., 2004; Goldstein, Concato, Fried, Kasl, & Johnson-Hurzeler, 2004; Herr 1994).

Of studies conducted in the prostate cancer population, few have concentrated on QOL of advanced prostate cancer patients treated with ADT and even fewer have included partners of the patients (Couper et al., 2006; Dacal, Sereika, & Greensppan, 2006; Litwin, Shpall, Dorey, & Nguyen, 1998; Northouse et al., 2007a). Many of the existing studies are exploratory studies (e.g. focus groups, pilot studies) (Gray, Wassersug, Sinding, Barbara, & Fleshner, 2005; Harden et al., 2002) and most were based on small sample sizes (Campbell et al., 2004). Finally, few studies are theory driven (Kershaw et al., 2008; Northouse et al., 2007b).

To build the science describing the QOL of advanced prostate cancer patients and their partner, the following specific aims will be addressed in this dissertation:

Specific Aim 1:

To describe the level of self-efficacy, symptom distress, communication, appraisal of illness/caregiving, coping and QOL of advanced prostate cancer patients treated with ADT and their partners.

Specific Aim 2:

To determine if specific antecedent factors (self-efficacy, symptom distress, communication, partners' QOL), and mediators (appraisal of illness, coping) explain a significant amount of variance in the QOL of the advanced prostate cancer patients treated with ADT.

Specific Aim 3:

To determine if specific antecedent factors (self-efficacy, symptom distress, communication, patients' QOL), and mediators (appraisal of caregiving, coping) explain a significant amount of variance in the QOL of the partners of advanced prostate cancer patients treated with ADT.

Methods Used to Meet Dissertation Requirements

The general format of this dissertation uses the three article/paper option. Chapter one examines two theoretical frameworks which lay the groundwork for the conceptual model that guided this research study. Chapter two presents a review of the current research literature as it pertains to the QOL of advanced prostate cancer patients treated with ADT and their partners (Dissertation Paper One). Chapter three describes the levels of self-efficacy, symptom distress, communication, appraisal of illness/caregiving, coping and QOL of advanced prostate cancer patients treated with ADT and their partners (Dissertation Paper Two). Chapter four examines if (1) the Modified Stress-Coping

Model can predict the QOL of advanced prostate cancer patients treated with ADT and their partners (Dissertation Paper Three). Finally, chapter five focuses on results of this dissertation, practice implications and directions for future research.

THEORETICAL FRAMEWORKS

Few studies that examine the QOL of prostate cancer patients and their partners have been guided by a theoretical framework. A small number of theoretical frameworks have been used to guide couples QOL research including: the Transactional Model of Stress and Coping (Bowman, Rose, & Deimling, 2006), and the Resiliency Model of Family Stress, Adjustment and Adaptation (Harden, Northouse & Mood, 2006; Harden et al., 2002; Mellon, Northouse, & Weiss, 2006).

The Modified Stress-Coping Model is the conceptual framework that guided the research study presented in this dissertation (Northouse et al., 2002). The Stress-Coping Model is based on modification of the Transactional Model of Stress and Coping and the integration of the key component of family, which is central to the Resiliency Model of Family Stress, Adjustment and Adaptation. The following section will: (a) review and critique the Transactional Model of Stress and Coping; (b) review and critique the Resiliency Model of Family Stress, Adjustment and Adaptation; and (c) present the Modified Stress-Coping Model.

The Transactional Model of Stress and Coping

The Transactional Model of Stress and Coping is a conceptual framework developed for evaluating the process of coping with stressful events and the related feelings that arise. This model was developed to examine individual coping and adaptation (Lazarus, 1966; Lazarus & Folkman, 1984; Wenzel et al., 2002). The underpinning premise of the

model is that when people are faced with a stressor, such as cancer, they experience a "cognitive appraisal process" which, in turn, directs their coping and ultimately their adaptation to the stressor (Lazarus & Folkman, 1984).

According to the model, appraisal is a two-step process. Initially, when individuals experience a stressor they evaluate the threat created by the stressor (*primary appraisal)*. Primary appraisal includes the individuals' evaluation of the significance of the stressor, their perceived susceptibility to the stressor, and the severity of the stressor. If the stressor is perceived as a significant threat, individuals evaluate their ability to control the situation and manage negative emotional reactions to the stressor (*secondary appraisal)*. The functional and emotional effect of appraisal (primary and secondary) are mediated by coping strategies (Wenzel et al., 2002). Lazarus and Folkman (1984) conceptualized coping strategies as those strategies employed to manage the problem causing the threat and strategies to regulate the emotions created by the stressor. Problem management is referred to as problem-focused coping and these strategies center on changing the stressful situation. Examples of problem-focused coping include active coping, seeking information and problem solving. Regulation of emotions is referred to as emotion-focused coping and it is aimed at changing how the individual thinks or feels about the stressor. Examples include venting of feelings, denial and avoidance (Wenzel et al., 2002). According to Lazarus and Folkman (1984), problem-focused coping strategies are often used when the stressor can be changed, while emotion-focused strategies are best utilized when the stressor cannot be changed or problem-focused coping strategies have failed.

Social factors, according to the model, have a direct effect on appraisal and a direct and indirect effect on the outcome of the model (Lazarus & Folkman, 1984). Social factors are conceptualized in a number of different ways. It has been conceptualized as tangible support (e.g. number of friendships/relationships an individual has) or intangible (e.g. feeling connected to others) (Cohen & Wills, 1985).

Adaptation is the outcome of the model and is conceptualized as emotional well-being, functional status and health behaviors. The outcome represents an individual's adaptation to a stressor. An individual's ability to cope with a stress determines to what extent overall function (QOL) is achieved or compromised. Poor, inadequate or inappropriate coping strategies can lead to poor outcomes (Folkman, Lazarus, Gruen & DeLongis, 1986)

Strengths and Limitations

The Transactional Model of Stress and Coping has been instrumental in generating a large body of research examining coping and adjustment to cancer (Wenzel et al., 2002). A strength of the model is that it recognizes individuality. No two people respond in like manner to a diagnosis of cancer. Appraisal, whether it is primary (i.e. susceptibility or severity) or secondary (i.e. outcome control or emotion control) to a stressor, is from the perception of the individual experiencing the stressor. Appraisal determines if, why and to what degree some people are threatened by a stressor.

A second strength of the Transactional Model of Stress and Coping is that it recognizes the dynamic nature of stress. For many people experiencing a diagnosis of prostate cancer, their journey is paved with many physical and emotional highs and lows.

As stressors increase and decrease, coping strategies may also change (Folkman et al., 1986).

The major limitation of the Transactional Model of Stress and Coping is that it focuses on the individual rather than the family unit. The model emphasizes how a stressor shapes an individual's perceived appraisal, subsequent coping strategies and outcome measures; however, the model minimizes the reciprocal interaction of the family unit. Individuals cope with stressors, but families also cope as a unit with stressors (Manne, Badr, Zaider, Nelson, & Kissane, 2010). Additionally, how one member of a family copes with a stressor can affect how other family members cope with the stressor (Lewis & Deal, 1995).

A second limitation of the Transactional Model is that even though it underscores the dynamic nature of stress, the model does not provide feedback loops from outcomes (adaptation) to new or repeating stressors. Furthermore, the model implies that stressors occur one at a time rather than concurrently with multiple other stressors.

Resiliency Model of Family Stress, Adjustment and Adaptation

The Resiliency Model is a stress and coping framework based on a family systems approach (Bomar, 2004; McCubbin, Cauble & Patterson, 1982). The major concepts of the model are family stressors, resources, appraisal, coping behaviors and adaptation. The major underlying premise of the model is that a serious stressor can have an effect on the whole family. A stressor, such as prostate cancer, can derail the functioning of the marital and family unit, endangering members, their relationships, and their roles.

According to the model, families respond to life events and life changes in two major phases, the adjustment and the adaptation phase (McCubbin et al., 1982). Each phase

describes the family's ability to cope with a stressor by considering the strengths of the family, coping abilities and family resources. The adjustment phase represents short-term adjustment to a stressor. In this phase, a family will make minor adjustments to their routine family patterns to accommodate a stressor. Their ability to adjust is influenced by the following factors: family vulnerability, family function, family appraisal of the stressor, family resources and their problem solving and coping skills. The major goal of this phase is to maintain balance and harmony within the family (McCubbin & McCubbin, 1993). If the stressor causes a major change in the family and the family is not able to adjust, maladjustment can occur, causing crisis in the family. At this point, the family progresses to the second phase of the model.

The second phase, according to McCubbin and McCubbin (1993) represents the families' long-term actions taken to recover from the crisis and to restore a sense of family normalcy. The same factors that influence families' short-term adjustments to stressors also influence long-term adaptation; additionally during the adaptation phase, the model also adds the concept of social support. Like the first phase, the goal of the second phase is adaptation for all members of the family, as well as the family as a unit (McCubbin & McCubbin, 1993). If the family is not able to adapt, *maladaptation* occurs. The outcome of maladaptation is crisis combined with ongoing family stress resulting in a further pile-up of stressors. Examples of maladaptation are family dysfunction, family violence, divorce, separation and alcoholism (Bomar, Denny, & Smith, 2004).

Strengths and Limitations

The Resiliency Model has a number of strengths when used as a framework for guiding QOL research with prostate cancer patients and their partners. Its foremost

strength is that it emphasizes the family. It recognizes that all individuals within a family, such as men diagnosed with prostate cancer and their partners, are affected by the illness. A second strength of the framework is that it recognizes that life is dynamic and influenced by many factors. The model recognizes that life, in general, is multi-faceted, with many stressors often presenting or overlapping at the same time. These factors can be disease specific, such as treatment concerns and/or treatment side effects, or more general, such as stressors that may accompany everyday life and the normal aging process.

A limitation of the Resiliency Model is that the constructs are broader and must be refined and defined to measurable variables. For example family resources, according to the model, interacts with the stressor and the families' perception of the stressor, to produce adaptation or crisis. The construct of family resources is broad and can include many factors such as socioeconomic status, education, communication, family dynamics, and previous coping strategies. The constructs in the Resiliency Model, such as family resources, need to be specified as measureable variables.

THE MODIFIED STRESS-COPING MODEL

The Modified Stress-Coping Model was the conceptual model that guided the development of this QOL study of advanced prostate cancer patients treated with ADT and their partners. The model builds on the Transactional Model of Stress and Coping and the Resiliency Model by extending the effects of the illness to the family. The Modified Stress-Coping Model helps explain how patients and their partners cope and adapt to a stressor or stressful situation, such as advanced prostate cancer (Harden et al., 2002; Northouse, Kershaw, Mood, & Schafenacker, 2004; Northouse et al., 2002;

Northouse, Templin, Mood and Oberst, 1998; Northouse, Laten & Reddy, 1995). The major underlying premise of the Modified Stress-Coping Model is that a serious stressor can have an effect on the whole family. A stressor, such as advanced prostate cancer, can have reverberating effect on the QOL of the entire family, especially the primary caregiver/partner. Furthermore, there is a reciprocal relationship between the patients' QOL and the QOL of their partner (Hodges, Humphris, & Macfarlane, 2005; Northouse, Mood, Templin, Mellon & George, 2000; Phillips et al., 2000).

The model used for this study is comprised of three major components: antecedent factors (personal, social, medical/illness-related), mediators (appraisal of illness/caregiving, coping), and outcomes (patient and partner QOL). As seen in Figure 1.1, the model is a partially mediated model. According to the model, specific antecedent factors (personal, medical/illness-related, social) affect patients' and their partners' cognitive appraisal of the stressor (Bowman et al., 2006; Kershaw et al., 2008; Northouse et al., 2002). If the stressor is appraised by patients or caregivers as taxing or exceeding their resources, and endangering their well-being, individuals then utilize various behavioral and cognitive coping strategies to manage it (Lazarus & Folkman, 1984). How patients appraise the illness and how partners appraise their role as caregiver affects how they cope, which, subsequently affects their QOL (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Additionally, according to the model (Figure 1.1), not all of the antecedents are mediated by appraisal and coping. Personal factors (demographics and self-efficacy) (Northouse et al., 2002), social factors (communication) (Mallinger, Griggs, & Shields, 2006) and medical/illness-related factors (symptom distress) (Kershaw et al., 2008) also have a direct effect on QOL. A stress-coping model in which

the effect of the antecedent variables on QOL outcomes is partially mediated by appraisal factors is supported by the research of Northouse et al. (1988) and Northouse, Templin and Mood, (2001).

This model has been tested in studies with prostate, breast and colon cancer patients and their family caregivers and has been found to predict a significant amount of variance in the QOL (range 24% to 81%) of both patients and partners (Kershaw et al., 2008; Northouse et al., 2000; Northouse et al., 2001; Northouse et al., 2002).

Antecedent Factors

The Stress-Coping Model used for this study has three antecedent factors: personal, medical/illness-related, and social. Personal factors are conceptualized as demographics and self-efficacy, medical/illness-related factors are conceptualized as symptom distress, and the social factor is conceptualized as communication.

Demographics.

The first category of personal factors is demographics (i.e. age, race and education). Qualitative work by Harden et al (2006) explored the impact of prostate cancer on couples in different age categories of adult life. Couples in the late middle age group (ages 50-64) reported higher frustration with the changes the cancer caused in their everyday lives, their inability to meet life goals, and the changes in their future financial security. Couples in the young-old group (ages 65-74) reported more satisfaction with where they were in life. The old-old group (age 75-84) reported longer recuperation periods after treatment but in general, they felt that together they could meet the demands associated with the disease and its treatment. Bowman and colleagues (2006) examined the appraisal of stress among prostate, breast and colorectal patients and their family

members. They found that being older was significantly related to patients' reporting less stressful appraisal of their illness.

Few studies have addressed prostate cancer partners; however, studies of other types of cancers indicate that younger partners experience more changes in their day-to-day activities, including roles, which results in more strain on their mental and psychological health (Baider, Koch, Esacson, & De-Nour, 1998; Nijboer et al., 2000). Another study found that younger partners of prostate cancer patients reported better physical QOL (Kershaw et al., 2008).

Very few studies have examined if and how race affects the QOL of prostate cancer patients and their partners. Even though African American men are diagnosed with prostate cancer at a rate that is 1.6 times that of Caucasian men, they remain under-represented in cancer research (American Cancer Society, 2006; American Cancer Society, 2005; Ramsey et al., 2007). Over 80% of cancer research participants are Caucasian, while African Americans and Hispanics comprise approximately 5% to 10% of participants and only 2% are Asian (National Cancer Institute, 1999). Bowman and colleagues (2006) in their study of appraisal of stress among African American and Caucasian prostate, breast and colorectal patients and their family members, found that being African American was significantly related to a less stressful appraisal by the patients. In a longitudinal study of men who had received a radical prostatectomy, Litwin and colleagues (1999) found that one year after surgery, race was an independent predictor of return to pretreatment physical and social function. Caucasians were more likely than non-Caucasians to return to pretreatment levels of physical and social function.

Some research that examined race indicates that sexuality appears to be a more important consideration for African American men with prostate cancer than Caucasian men with prostate cancer. African American men were more willing to trade off years of survival for the ability to maintain sexual function, while Caucasian men were more willing to trade off survival time for continence as compared to Latinos or Asians (Jenkins, et al., 2004; Saigal, Gornbein, Nease, & Litwin, 2001). The work of Jenkins et al. also suggests a racial difference exists in regard to the impact of sexuality of men treated for localized prostate cancer. Among African American and Caucasian men reporting sexual deficits, African American men were more distressed with these changes than were the Caucasian men. Overall, the conclusions of this study must be viewed cautiously as the enrollment rate in this study was significantly lower for African American men versus Caucasian men (28% and 51%, respectively).

Education has been identified as a factor that contributes to QOL, but the findings are mixed. In a study by Brar and colleagues (2005) of 138 low-income men with prostate cancer, men with less than a high school education, reported greater improvements in their mental well-being than more educated men. In contrast, lower education was related to more depression, pain and anxiety in another study (Carmack-Taylor et al., 2004). Prostate cancer patients receiving ADT, that did not have a college degree, had significantly more depression, anxiety and pain.

The majority of QOL research does not provide key information about the socioeconomic status of the study population. A review of literature by Ramsey and colleagues (2007) found that more than 60% of subjects in QOL research are college educated and over 43% were employed. This area needs further study given the few

existing studies addressing SES and prostate cancer QOL research, as well as the inconsistent findings in the few available studies.

Self-efficacy.

The second category of personal factors is self-efficacy. Self-efficacy refers to an individual's personal belief or confidence in their ability to organize and implement a course of action required to manage or succeed in a given situation (Bandura, 1977; Bandura, 1995). Self-efficacy can play a major role in how an individual approaches a given task, goal or challenging situation. Research indicates that individuals with more confidence in their ability to manage tasks related to their illness adapt better and conversely those with less confidence adapt poorly (Campbell et al., 2004; Kershaw et al., 2008).

In the context of cancer, self-efficacy has been conceptualized as an individual's confidence in managing disease-related symptoms (Campbell et al., 2004). Prostate cancer patients and their partners experience a wide range of potentially life altering events. Not only are they dealing with the uncertainty of the disease, but also the changes it causes in their everyday lives (e.g. employment, activity level, roles, and relationships). Studies in chronic diseases and various types of cancers suggest that patients who have higher levels of self-efficacy, are better able to adjust to the disease and have a better QOL, and less physical and psychological distress (Bisschop, Kriegsman, Beekman, & Deeg, 2004; Eton, Lepore & Helgeson, 2001; Weber et al, 2004). Caregivers/partners with higher levels of self-efficacy related to caring for their partners and their partners' symptoms are at a lower risk for depression and experience less caregiver strain (Fortinsky, Kercher, & Burant, 2002; Keefe et al., 2003; Lev, Paul & Owen, 1999; Yates,

Tennstedt, & Chang, 1999). Studies examining the construct of self-efficacy in the advanced prostate cancer patient treated with ADT and their partners are limited to a study by Northouse and colleagues (2007b) in which advanced prostate cancer patients treated with ADT are a small subset of the larger study population.

Symptom distress.

The second antecedent category is medical/illness-related factors. This factor is conceptualized as the variable symptom distress. Treating advanced prostate cancer patients with ADT results in hypogonadism, which in turn, is associated with multiple adverse side effects. These side effects can be significant and include loss of libido and erectile dysfunction, hot flashes, gynecomastia, breast tenderness, osteoporosis, metabolic syndrome, fatigue and anemia, changes in body composition, and cognitive and emotional changes (Freedland, Eastham & Shore, 2009; Kabir et al., 2008). These symptoms can have a profoundly negative impact on the QOL of the patient. Dacal and colleagues (2006) and Herr and O'Sullivan (2000) compared prostate cancer patients treated with ADT to men not receiving ADT (i.e. prostate cancer patients not receiving ADT and healthy controls). Both studies found that those receiving ADT had significantly worse physical function. Bacon, Giovannucci, Testa and Kawachi (2001) assessed the effects of prostate cancer treatment on general, cancer specific and symptom domains of QOL up to 5 years after diagnosis. Men treated with ADT had a significantly greater decrease in role function. Other studies have found that more illness symptoms were directly related to poorer general and mental health (Dacal et al., 2006), and indirectly related to poorer QOL through decreased social support (Northouse et al., 2007a), increased negative appraisal of the illness (Kershaw et al. 2008) and decreased

sexual function (Herr, Kornblith & Ofman, 1993).

Although there is a growing body of research which indicates that the side effects of ADT have a negative impact on the QOL of the patient, few studies have included the partners of these men (Kershaw et al., 2008; Kornblith, Herr, Ofman, Scher, & Holland, 1994; Northouse et al., 2007a).

Communication.

Social factors, which represent the construct of social support in the original Transactional Model of Stress and Coping, is the third category of antecedent factors and for this study is conceptualized as the variable communication between patient and partner (Lazarus & Folkman, 1984). Communication refers to how the patient and partner interact with each other with regard to their thoughts and feelings about the cancer. Studies suggest that family communication may be important for adjustment to a serious illness. Among breast cancer patients and their partners, Manne et al. (2006) found that mutual constructive communication was associated with greater relationship satisfaction and less distress. Pistrang and Barker (1995) found similar results; they reported that empathetic communication between breast cancer patients and their partners was moderately correlated with helpfulness of disclosure and relationship satisfaction.

Other studies, primarily with breast cancer patients and their spouses, have found that increased expression of thoughts and feelings have been associated with less mood disturbance and better QOL; conversely, poor communication was associated with poorer emotional well-being (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000; Hilton, 1994; Manne, Pape, Taylor & Dougherty, 1999; Manne et al., 2004; Northouse, 1988). Most of the research addressing communication in cancer patients and their

partners concentrates on breast cancer patients and their spouses, however, a few studies suggest that prostate cancer patients appear to be less inclined to talk about their cancer when compared to their wives (Boehmer & Clark, 2001; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). Manne and colleagues (2010) examined cancer-related communication, intimacy and distress in prostate cancer patients with localized disease and their partners. They found that mutual constructive communication was significantly, negatively correlated with distress for both patient and partner. Studies examining the relationship between communication and QOL in the advanced prostate cancer patients and their partners are limited (Northouse et al., 2007b).

Bowman and colleagues (2006) found that in long-term survivors of cancer (i.e. breast, colon and prostate) and their family members, more communication about the life-threatening nature of the cancer was related to greater level of stress appraisal. Dyadic communication about the life-threatening nature of the cancer in long-term survivors may not serve the same function that it does in more recently diagnosed dyads (Manne et al., 2006).

Mediators

There are two mediators (appraisal and coping) in the Modified Stress-Coping Model. According to the model, appraisal and coping mediate the relationship between antecedent factors (personal, medical/illness-related, social) and the outcomes (partner/patient QOL).

Appraisal.

Appraisal, or how an individual perceives and forms "meaning" of a stressor, is a key determinant of the individual's ability to adapt to that stressor (Lazarus, 1966; Lazarus &

Folkman, 1984). How prostate cancer patients' appraise their illness and how caregivers/partners' appraise their role of caregiving, can have a significant effect on the QOL of patients and partners (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999; Kornblith et al., 1994; Schultz & Beach, 1999). Northouse and colleagues (2007a) compared appraisal of illness/caregiving of men with prostate cancer across three phases of the illness (newly diagnosed, biochemical recurrence and advanced disease) and found that patients with biochemical recurrence and advanced disease and their partners had significantly more negative appraisal of illness/caregiving than dyads with newly diagnosed prostate cancer.

Kershaw and colleagues (2008) conducted a longitudinal path analysis utilizing structural equation modeling to assess how multiple factors, including appraisal (as a mediator) affected the QOL of prostate cancer patients and their partners. The researchers found that appraisal was a key variable and explained between 51% and 60% of the variance in their model. They reported that more negative appraisal was related to lower QOL. Results of this study also indicated that appraisal mediated the effects of a number of antecedent variables on the QOL of patients and their partners. Appraisal mediated the effects of self-efficacy on the QOL. They also found that patients and partners who had lower self-efficacy had higher negative appraisal of the illness and caregiving.

Coping.

Coping, like appraisal, is a critical mediator in the Modified Stress-Coping Model. Coping is conceptualized as either active or avoidant coping. Active coping strategies are an individual's efforts to eliminate, circumvent or lessen the effects of the stressor (Carver, Weintraub & Scheier, 1989; Zabalegui, 1999). Examples of active coping

include problem solving, reframing and planning (Lazarus & Folkman, 1984). Avoidant coping strategies are activities that do not focus on solving a problem but rather focus on changing or adjusting an individual's internal or emotional reactions resulting from the stressor. Mental disengagement, substance abuse and denial are examples of avoidant coping (Lazarus & Folkman, 1984).

A number of studies support an association between coping strategies and QOL in men with prostate cancer (Ben-Tovim, Dougherty, Stapleton, & Pinnock, 2002; Bjorck, Hopp, & Jones, 1999). Kershaw and colleagues (2008) found that in prostate cancer patients, their use of active coping strategies were significantly positively correlated with higher mental QOL, while avoidant coping strategies were significantly negatively correlated with lower mental QOL. For their spouses only avoidant coping was significantly negatively correlated with the spouses' mental QOL. Like Kershaw et al.'s work, a study by Green and colleagues (2002) found that in prostate cancer patients treated with ADT, avoidant coping strategies were significantly correlated with greater levels of distress and thus poorer QOL. Interestingly, Green and colleagues found that contrary to Kershaw and colleagues, active coping strategies were significantly correlated to greater levels of distress and therefore poorer QOL. Both of these studies utilized the COPE scale (Carver, 1997), however, Green et al. used the full scale (40-items) (Carver et al., 1989) while Kershaw et al. used the brief COPE (i.e. 27-items) (Carver, 1997). Differences in the results of these two studies may be related to the scales used and/or to how each of the researchers conducted their factor-analysis. Kershaw et al. conducted factor analysis with the entire instrument while Green and colleagues conducted separate factor analysis on problem-focused items and on emotion-focused items.

A handful of studies have examined the coping strategies and QOL of partners of prostate cancer patients (Couper et al., 2009; Kershaw et al., 2008; Ko et al., 2005; Malcarane et at., 2002). Studies by Couper et al. and Ko et al. found that partners' use of self-blame and dysfunctional problem-solving were significantly correlated to increased levels of distress. These findings are consistent with the results of two further studies in which partners' use of maladaptive coping strategies (e.g. avoidant coping, dysfunctional problem-solving, self-blaming) were correlated to worse QOL (Kershaw et al., 2008; Malcarane et al., 2002). Interestingly, Malcarane et al. also reported a significant correlation between partners' use of active (problem-focused) coping strategies and decreased level of partners' distress, while the Kershaw et al. study did not find this relationship. Contrary results in these two studies with regard to the partners' use of active coping strategies may be related to partners allowing patients to utilize whatever coping strategies they want to use, while the partners emotionally suppress their desires to ensure that the patients' needs are met. This is supported by a study of breast cancer patients by Ben-Zur, Gilbar and Lev (2001) which found that the patients used more active coping strategies than did their husbands. Another explanation may be related to the perceived presence of or lack of social support. In the Kershaw et al. study patients reporting more social support used more active coping and had better physical QOL, while there was no relationship between social support and active coping for partners. Patients with social support may be encouraged to utilize active coping strategies.

Though all four of the aforementioned studies included prostate cancer patients in various stages of the disease, only one study (Kershaw et al., 2008) included stage of the disease in their analysis. The researchers tested a predictive model for the QOL of

prostate cancer patients and their partners. They found that, for the patients, stage of disease had an indirect effect on QOL through the mediators appraisal and coping. Patients with later phase disease (i.e. biochemical recurrence or advanced disease) had a better mental QOL if they used more active coping and a poorer physical QOL if they used more avoidant coping. For partners there was no effect (direct or indirect) between patients' stage of disease and partners' QOL.

Outcomes

Quality of life.

QOL (patient or partner), the outcome variable, is defined as an individual's "appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal" (Cella & Cherin, 1988, p. 70). QOL is conceptualized as a multidimensional construct which includes four domains of well-being: physical, social/family, emotional, and functional (Victorson, Barocas, Song, & Cella, 2008). Lazarus and Folkman, (1984) in their work with the Transactional Model of Stress and Coping, proposed two outcome variables, emotional well-being and functional status; however, subsequent research has supported the addition of two further domains to the Modified Stress-Coping Model: physical well-being and social/family well-being. The addition of these domains to the model is supported in the literature (Cella et al., 1993b; Cella, & Tulsky, 1993a, Victorson et al., 2008). QOL (patient/partner), the outcome in this study, is viewed as a separate construct for both patient and their partner (Figure 1.1).

There is a reciprocal relationship between the patients' QOL and the partners' QOL. This relationship is supported in cancer QOL research literature. Studies have shown that

the partners' functional well-being is the strongest determinant of the patients' functional well-being (Manne, 1998; Manne, Taylor, Dougherty & Kemeny, 1997). Northouse and colleagues (2001) studied breast cancer patients and their spouses and found that patients' and spouses' emotional distress and role adjustment had a significant direct effect on each partners' emotional distress and role adjustment. A number of studies show that there is often a significant positive correlation between the psychosocial well-being of the patient and the partner, with each partner's QOL affecting the other partner. A meta-analysis of 21 independent samples of various types of cancer patients and their caregivers found a positive correlation between the patients' and caregivers' psychological distress (Hodges et al., 2005).

Looking at studies specific to prostate cancer, Sanda and colleagues (2008) found that partners of patients with sexual and urinary symptoms reported greater levels of distress. Kornblith et al., (1994) examined patients and partners and found that as the patients' QOL worsened, so did their partners'. A study (Ko et al., 2005) of 171 prostate cancer patients and their spouses, found that there is a significant correlation between spouses' distress and patients' distress: as spouses' level of distress increases so does the patients'. Badr and Carmack-Taylor (2009) also conducted a cross-sectional study of 116 prostate cancer patients and their spouses. They found that marital adjustment and psychological adjustment between patients and partners were moderately correlated.

In summary, the literature has identified a number of antecedent factors and mediators that can influence the QOL of patients and their partners. However, most of the research pertinent to cancer patients and their partners has focused on female breast cancer patients and their male spouses. Differences in gender, cancer type and treatment

side effects limit generalization of research from breast cancer patients and their partners to prostate cancer patients and partners. Moreover, advanced prostate cancer patients treated with ADT present a further challenge as they are no longer considered curable which may affect their appraisal and QOL. However, with better symptom management and palliative care, longer periods of survivorship are reported, making attention to overall QOL imperative. Research examining the QOL of partners/caregivers of advanced prostate cancer patients treated with ADT is sparse even though partners are typically the patients' main source of emotional and physical support (Blanchard, Albrecht, & Ruckdeschel, 1997; Manne, 1994). Furthermore, partners often experience more distress than do patients and frequently ignore their own healthcare needs which may inadvertently impact the QOL of the patient (Cliff & MacDonagh, 2000; Kornblith et al., 1994).

This study builds on existing prostate cancer research by examining factors that can affect the QOL of advanced prostate cancer patients treated with ADT and their partners. Understanding factors that can influence QOL will help with the development of interventions to improve patients' and partners' self-efficacy, communication, appraisal of illness/caregiving, coping and, fundamentally, their QOL.

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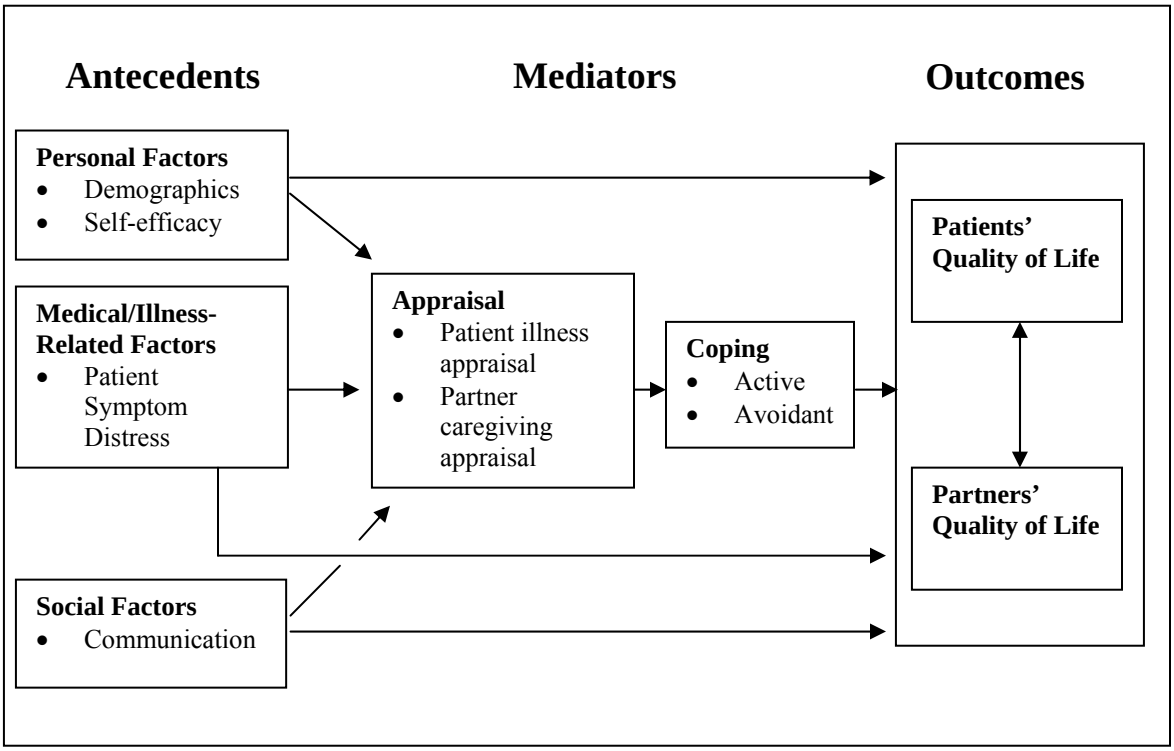
Figure 1.1

The Modified Stress-Coping Model



CHAPTER II

THE QUALITY OF LIFE OF MEN WITH ADVANCED PROSTATE CANCER TREATED WITH ANDROGEN DEPRIVATION THERAPY AND THEIR PARTNERS: A REVIEW OF THE LITERATURE

INTRODUCTION

Largely due to advancements in screening, the majority of men with prostate cancer are diagnosed with localized disease (80%), however, a significant number of men are diagnosed with advanced (biochemical recurrence or metastatic) disease (16%) (Altekruse et al., 2010; Cooperberg, Lubeck, Meng, Mehta, & Carroll, 2004; Trask, 2004). Furthermore, over the next 15-years it is estimated that up to 18% of men with localized disease will progress to advanced disease (American Cancer Society, 2011). In general, men with advanced prostate cancer are not considered curable. Treatment is palliative; consequently, the impact of treatment on the patients' quality of life (QOL) becomes pivotal.

Androgen deprivation therapy (ADT) is the mainstay of the treatment choices available for advanced prostate cancer patients. However, men treated with ADT experience a larger number of physiological and psychological sequelae, than men who are not treated with ADT for prostate cancer. These side effects include loss of libido and erectile dysfunction (Potosky et al., 2002a; van Andel & Kurth, 2003), hot flashes

(Holzbeierlein, 2006), gynecomastia, breast tenderness (See et al., 2002), osteoporosis (Higano, Shields, Wood, Brown, & Tangen, 2004; Wei et al., 1999), metabolic syndrome, fatigue and anemia, changes in body composition (Braga-Basaria et al., 2006; Strum, McDermed, Scholz, Johnson, & Tisman, 1997), and cognitive and emotional changes (Green et al., 2002a; Higano, Ellis, Russell, & Lange, 1996; Oliffe, 2006).

Typically, the partners of prostate cancer patients are the primary source of physical and emotional care, and support (Blanchard, Albrecht, & Ruckdeschel, 1997). Research indicates that there is a reciprocal relationship between the QOL of cancer patients and the QOL of their partners (Eton, Lepore, & Helgeson, 2005; Kornblith, Herr, Ofman, Scher, & Holland, 1994). The QOL of partners of prostate cancer patients is frequently negatively affected by the patients' cancer and its treatments. Several studies report that partners experience significantly more distress, stress and cancer-specific worries than do patients (Cliff & MacDonagh, 2000; Northouse et al., 2007). Kornblith and colleagues (1994) found that as the number of problems (e.g. depression, fatigue, sexual problems, sleep problems) reported by prostate cancer patients increased, the QOL of their partners decreased. Partners also have reported dissatisfaction with dyadic communication, and sexual and relationship intimacy (Boehmer & Clarke, 2001b; Neese, Schover, Klein, Zippe, & Kupelian, 2003).

Despite the physical and psychosocial challenges that advanced prostate cancer patients treated with ADT and their partners face, there is a paucity of research examining how these challenges affect patients' and partners' QOL. A preponderance of QOL research has focused on breast cancer patients; far less research has been done with prostate cancer patients, and much of the existing prostate cancer research concentrates

on the pathophysiology of newly diagnosed localized disease, its treatments and side effects. Many of the challenges faced by advanced prostate cancer patients and patients with localized disease are similar but one of the major differences is that men with advanced disease are not considered curable; therefore, maximizing the remaining QOL of advanced prostate cancer patients and their partners is essential. The purpose of this literature review is to provide an overview of the current research as it pertains to ADT and its effect on the QOL of advanced prostate cancer patients and their partners. More specifically, this paper will examined: (1) the conceptualization of QOL; (2) the QOL of older men without prostate cancer and their partners; (3) the side effects associated with ADT in men with prostate cancer; (4) the QOL of prostate cancer patients receiving ADT and their partners and methodological issues in these studies (5) factors that potentially can influence the QOL of prostate cancer patients receiving ADT and their partners; and (6) gaps in the literature and directions for future research as they pertain to improving the QOL of prostate cancer patients receiving ADT and their partners.

QUALITY OF LIFE DEFINED

QOL is not a new concept but rather a concept in which its terminology and defining characteristics have evolved over time. Much of the early QOL research has its origins in sociology, psychology and economics. Well into the 20th century, QOL was an indicator of societal well-being, and was conceptualized quantitatively. Objective measures (e.g. income, education, housing, safety) were the cornerstone of early QOL research (House, Livingston, & Swinburn, 1975; Schneider, 1975). Objective measures were easily quantified and thought to be appropriate indicators of societal happiness or QOL (Campbell, 1976). This line of thought may have been related to the ever-growing

affluence of post World War II; however, research from the 1970s indicated that even though Americans had higher incomes, more education and greater materialism, they were not necessarily happier (Campbell, 1976; Schneider, 1975). From this research emerged the concept of subjective indicators of QOL (e.g. aspirations, expectations, happiness, satisfaction) (Schneider, 1975). Current definitions of QOL differ in wording, but they share the following underlying premise: QOL is an individual's "appraisal of and satisfaction with their current level of functioning compared to what they perceive to be possible or ideal" (Cella & Cherin, 1988, p. 70).

Research with cancer patients has identified and conceptualized QOL as having five dimensions with the following defining attributes: *emotional well-being* (e.g. life satisfaction, body image, control, happiness, meaning of life, coping ability) (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997); *physical well-being* (e.g. eating, appetite, sleep, fatigue, side effects of treatment) (Ferrell, et al., 1997); *functional well-being* (e.g. ability to carry out activities of daily living, general function) (Cella et al., 1993); *spiritual well-being* (e.g. meaning of illness, religiosity, hopefulness, uncertainty) (Ferrell et al., 1997); and *social well-being* (e.g. social support, relationships, role function, social activities) (Ferrell et al., 1997).

Research indicates that the following dimensions of QOL have been shown to be affected by a diagnosis of prostate cancer, its subsequent treatment, and treatment side effects: emotional well-being, physical well-being and social well-being. Northouse and colleagues (2007) found that patients with either biochemical recurrence or advanced disease had significantly higher emotional well-being and lower physical well-being when compared to their spouses. Kornblith et al. (1994) found that there was a significant

correlation between the symptoms (i.e. pain, fatigue, frequent urination and erectile dysfunction) experienced by prostate cancer patients and the physical, emotional and social QOL of the patients and emotional and social QOL of their partners.

Less research has been conducted on the domains of spiritual well-being and functional well-being. Two studies found that prostate cancer patients reporting higher levels of spirituality also reported better QOL (Hamrick & Diefenbach, 2006; Krupski et al., 2006). A study by Rosenfeld and colleagues (2004) found that stage of prostate cancer (localized, locally advanced and metastatic) was associated with QOL. Men with metastatic disease were found to have the lowest level of functional well-being.

QUALITY OF LIFE OF HEALTHY OLDER MEN AND THEIR PARTNERS

To better understand the effects of ADT on the prostate cancer patients and their partners it is essential to have a working knowledge of the general QOL of older men who do not have prostate cancer. Furthermore, having a general knowledge of the QOL of older women (the typical partners of older men) may illustrate how changes in the QOL of the prostate cancer patients treated with ADT can affect the partners' QOL.

Quality of Life of Older Healthy Men

The median age of men diagnosed with prostate cancer is 67 (Howlader, Noone, Krapcho, Neyman, Aminou et al., 2010). In the United States most men over the age of 65 are either looking forward to the freedom of retirement or are already enjoying retirement. Men in this stage of life are enjoying their leisure time, traveling, starting new hobbies or picking up old hobbies, interacting with children and grandchildren and/or participating in various physical and sports related activities (Antonucci, & Akiyama, 1997; Harden, 2004; Leggett, 2007). Comorbidities, such as hypertension, diabetes, and

hyperlipidemia, are very common among this age group; however, with dietary changes, exercise and medication, many of these men are still able to enjoy active and fulfilling lives (Gillespie, Kuklina, Briss, Blair, & Hong, 2011; NCHS, 2009).

Moods among men age 65 and older are more stable than that of younger men (Harlow & Cantor, 1996). Contentment and increased spirituality are also found in this age group (Harlow & Cantor, 1996; Wink & Dillon, 2003). Myers aptly describes this time in life as less of an emotional rollercoaster and more like a gentle canoe ride (2004).

To better understanding the QOL of men with prostate cancer, Litwin studied the QOL of 268 men without prostate cancer (1999). The study found that older men without prostate cancer reported good health-related quality of life (HRQOL), with a tendency toward slightly higher emotional well-being than physical well-being (76.9 vs. 68.9, respectively [scored from zero to 100 with higher scores representing better QOL]). A limitation of this study was that the population was obtained from a large managed care plan, which may differ from other populations such as Medicare or Medicaid.

Studies suggest that some men over the age of 65 have accepted some degree of sexual dysfunction as a normal function of aging (Blanker et al., 2001; Litwin, 1999; Neese et al., 2003). Data from the Massachusetts Male Aging Study (n = 1410) indicated that among men aged 40-70 years, 34.8% had moderate to complete erectile dysfunction, and these results were significantly related to age, health status and emotional well-being (Laumann, Paik, & Rosen, 1999). However, Gray et al. (2000) challenge this assumption. Findings from their qualitative study of prostate cancer patients (N = 34) treated with prostatectomy, indicated that post-prostatectomy men may not accept their decreased sexual function but instead they maybe more reluctant to disclose and discuss issues

related to masculinity and sexuality. They found that men's concerns were centered on maintaining appearances of normalcy. It remains unclear whether this means that men have not accepted aging and changes in their sexuality or if men want others to believe that they do not have any sexual problems.

Quality of Life of Partners of Healthy Older Men without Prostate Cancer

Women, in Western countries, have an average life expectancy well into their 80's. Women generally live longer than men do, but with this longevity, they experience a greater number of years with physical disabilities, which can curtail their daily lifestyles (Gillespie et al., 2011). As women move through these middle and later years, many of the co-morbidities they experience are similar to those of men of similar age. There is a high prevalence of hypertension, hyperlipidemia, and diabetes, additionally; women have higher rates of osteoporosis than do men (Gillespie et al., 2011; NCHS, 2009).

In addition to health issues, many women also experience various developmental and situational changes as they age. Often grown children leave home resulting in an "empty nest," however, contrary to the common pervasive thought that this is a sad or depressive time for women, research suggests that most women welcome their children moving out and view it as an opportunity for self-growth (Dare, 2011; Mitchell & Lovegreen, 2009). Another role change that can place greater demands on women is the aging and increased dependence of elderly parents. Many women take on the role of caring for aging parents or aging in-laws (Leonard & Burns, 2006). Some women are retiring from the workforce while others, after raising their children, choose to return to the work force. Sometimes the choice to work is solely for financial needs and for others it is a new phase in life (Young & Cochrane, 2004). Other women begin to enjoy the fruits of their labors:

grandchildren, hobbies, and traveling. Many women, in a relationship, look forward to spending more time with their partners and enjoying life as a couple (Harden, 2005).

In a descriptive study by Kenney (2000) of 299 women, researchers found that older women ($\geq$ 46) reported less stress than younger women (19-29) and middle-age women (30-45). Older women reported fewer unhealthy personality traits, fewer stressors and higher levels of hardiness compared to younger and middle-age women. Kenney also measured women's perception about their relationships, occupations, and health. Older women reported higher positive perceptions of their relationships with children, friends and neighbors than middle-age or younger women, but lower satisfaction on their relationships with their husbands. Older women, compared to younger and middle-aged women, reported higher positive perceptions of their careers/occupations and health, suggesting that as they age women may develop a better sense of self and "inner balance" (p. 647). Generalization of these results should be cautious as the sample population was primarily upper middle-class, college-educated Caucasians.

A large number of women remain sexually active until the end of their life, provided they are relatively healthy and have an adequate partner (Kaplan, 1990). However, research does suggest there is some decline in sexual frequency with increased years of marriage and increased age of husband and wife (Brewis & Meyer, 2005). A study by Laumann and colleagues (1999) measured sexual dysfunction and the QOL of men and women, results showed that individual sexual dysfunction was associated with poorer QOL. Interestingly, results indicated that the impact was more severe for women than men. The researchers did not assess the impact of sexual dysfunction of one partner on the other partners QOL. Other predictors of sexual desire and sexual intercourse for

women were marital satisfaction, depression and stress. Poor marital satisfaction, the presence of depression and increase levels of stress were associated with decreased sexual desire and less frequent sexual intercourse (Dennerstein, Dudley, & Burger, 2001). Hartmen and colleagues (2004) reported that older women, as compared to younger women, felt obliged to meet the sexual desires of their partners; these women had an underlying fear that they might lose their partners if they did not meet their sexual needs and desires. Perhaps this is related to older women, in general, outliving men and therefore, greater numbers of older women not having a life partner.

ANDROGEN DEPRIVATION THERAPY AND ITS SIDE EFFECTS

Before examining the effects of ADT on men with prostate cancer and their partners, it is helpful to have a basic working knowledge of the treatment. The following sections present a brief synopsis of the primary types of ADT and the side effects often associated with the treatments.

Luteinizing Hormone-Releasing Hormone Agonists

Luteinizing hormone-releasing hormone agonists (LHRH-A) work by directly inhibiting the production of testosterone through the pituitary-testicular axis by stopping the pituitary gland from releasing luteinizing hormone (LH). Without LH the testicles cannot produce testosterone, thus decreasing the level of circulating testosterone down to that of surgical castration (Amling & Moul, 2005). Examples of LHRH-A are leuprolide acetate and goserelin acetate.

Anti-androgens

Anti-androgens (e.g. bicalutamide, flutamide) work by stopping the prostate cancer cells from utilizing testosterone produced by either the testicles or the adrenal glands.

Anti-androgens are administered in combination with either LHRH-A or orchiectomy (Amling & Moul, 2005).

Bilateral Orchiectomy

Orchiectomy or bilateral orchiectomy is the surgical removal of one or both testicles. An orchiectomy results in an almost immediate decrease of circulating testosterone; however, it is not a complete ablation because the adrenal glands still produce androgens. The major difference in orchiectomy versus LHRH-A is that the orchiectomy is not reversible (Amling & Moul, 2005).

Other Androgen Suppressing Drugs

Diethylstilbestrol (DES) is a synthetic estrogen and its mechanism of action is that it inhibits luteinizing-hormone releasing hormone through the hypothalamic-pituitary axis, which results in decreased release of testosterone. DES is not typically used as a first-line agent because of its cardiovascular side effects (El-Rayes & Hussain, 2002). Two final androgen suppressing drugs are aminoglutethamide and ketoconazole. The mechanism of action for both drugs is to decrease the production of androgens by the adrenal glands (Richie, 1999). All three of these drugs are typically not used as first-line agents but rather are considered second-line and are used for men with prostate cancer that is no longer responding to their initial ADT (Amling & Moul, 2005).

Combination Hormone Therapy

The final category of ADT is combination hormone therapy. The goal of combination hormone therapy is complete androgen deprivation. This is accomplished with either a LHRH-A or a bilateral orchiectomy plus daily antiandrogens, such as bicalutamide, flutamide, or nilutamide (Amling & Moul, 2005).

Specific Side effects Associated with ADT

Removing, suppressing or inhibiting the utilization of androgens in men with prostate cancer results in male hypogonadism, which in turn is associated with multiple adverse side effects. These side effects can be significant and include loss of libido, erectile dysfunction, hot flashes, gynecomastia, breast tenderness, osteoporosis, metabolic syndrome, fatigue, anemia, changes in body composition, and cognitive and emotional changes.

Loss of Libido and Erectile Dysfunction

Androgens play a pivotal role in male sexual desire (libido) and erectile function. Hypogonadism is associated with a decrease in libido and erectile performance. Potosky and colleagues (2002a) compared sexual function among men who were receiving ADT versus men who received no treatment. Only men that reported good sexual function at baseline were included in this analysis (total $n = 311$; ADT arm, $n = 88$ patients; no therapy arm, $n = 223$ patients). At the one-year mark, 68 of the ADT patients (80%) versus 60 of the no therapy patients (30%) reported impotency ($p < .001$). A study by van Andel and Kurth (2003) reinforced the results of the Potosky et al. study. van Andel and Kurth assessed erectile dysfunction, sexual interest, activity and pleasure among men with prostate cancer treated with ADT or no therapy. Results indicated that the ADT group ($n = 31$) reported significantly worse erectile dysfunction, sexual desire, sexual activity and sexual pleasure compared to the group receiving no therapy ($n = 45$). In general, studies indicate that more than 80% of men treated with ADT report decreased libido and erectile dysfunction (Clark, Wray, & Ashton, 2001; Potosky et al., 2001).

Hot Flashes

The precise etiology of hot flashes is not known, but it is speculated that it is a dysfunction of the thermoregulatory centers located in the hypothalamus. This dysfunction results in dilation of the peripheral vascular system causing flushing and sweating (Shanafelt, Barton, Adjei, & Loprinzi, 2002). Hot flashes are one of the most common side effects among prostate cancer patients treated with ADT: up to 80% report experiencing them (Holzbeierlein, 2006).

Gynecomastia/Mastodynia

Gynecomastia in men treated with ADT is believed to be related to the decreased levels of circulating androgens, which results in an increased estrogen/androgen ratio. Gynecomastia is also associated with breast pain (mastodynia). Mastodynia can be mild or extremely painful and can cause the breast and nipples to be very sensitive to the touch. Determining an incidence rate of gynecomastia among prostate cancer patients treated with ADT can be a challenge to ascertain since idiopathic gynecomastia is common in the elderly male population (Dobs & Darkes, 2005). The anti-androgen bicalutamide (Casodex) was examined in two large randomized, double-blinded, placebo, clinical trials to determine its effectiveness in treating advanced prostate cancer (See et al., 2002; Wirth et al., 2001). In both studies, the most frequently reported adverse event associated with bicalutamide was gynecomastia and mastodynia (47.5% and 53.1%, respectively). Incidence of gynecomastia and mastodynia in the control groups was significantly lower (2.1% and 2.9%, respectively). In both studies, the most frequent reason given for withdrawing from the studies was gynecomastia and/or mastodynia.

Potosky and colleagues (2001) studied the adverse events of LHRH-A versus orchiectomy ($N = 401$). Men receiving LHRH-A reported significantly more gynecomastia than the orchiectomy group (24.9% vs. 9.7%, $p < .01$). The researcher, however, did not report whether the men reporting gynecomastia had pretreatment gynecomastia, nor did they address accrual issues related to the adverse side effects.

Adipose Redistribution

A number of studies have shown that ADT is associated with increased body fat mass and decreased lean body mass. Basaria et al. (2002) compared men receiving ADT with two age-matched groups: (1) prostate cancer patients treated with prostatectomy and/or radiation (non-ADT group); and (2) normal healthy men (control group). The ADT group had significantly higher body fat mass than the non-ADT group and the control group. No differences in lean body mass were found between the three groups. However, other studies have shown that, in addition to an increase in body fat mass, there is a significant decrease in lean body mass (Berruti et al., 2002; Boxer, Kenny, Dowsett, & Taxel, 2005; Smith, 2003). Overall, these studies suggest that when prostate cancer is treated with ADT there can be an increase in body fat mass ranging from 9% to as high as 50%.

Metabolic Syndrome

It is believed that adverse changes in the body composition of men treated with ADT contribute to metabolic syndrome (Braga-Basaria et al., 2006; Keating, O'Malley, & Smith, 2006). Metabolic syndrome is characterized by the following five factors: abdominal obesity, dyslipidemia, decreased high-density lipoproteins, hypertension, and elevated fasting plasma glucose. A diagnosis of metabolic syndrome or any combination

of its defining characteristics is associated with cardiovascular disease and thus an increased risk of mortality (Arden & Janssen, 2007; Eckel, Grundy, & Zimmet, 2005).

Osteoporosis

Osteoporosis in both men and women is associated with a high level of morbidity and mortality secondary to fractures and immobility. Typically, the rate of bone loss is more rapid for women, particularly in the first few years following menopause; however, after the age of 60, the rate of decline for men and women is similar (Higano, 2003). Multiple studies suggest that ADT can further exacerbate morbidity and mortality among men and has been shown to decrease their bone mineral density. Studies have shown that men treated for 12 to 24 months with ADT can experience from a 2.1% to 17% decrease in their bone mineral density, while the average loss in men not receiving ADT is approximately 0.17% (Daniell et al., 2000; Greenspan et al., 2005; Higano et al., 2004). Additionally, multiple studies have shown that osteopenia and osteoporosis are common findings in men with prostate cancer prior to initiating ADT (Shahinian, Kuo, Freeman, & Goodwin, 2005). Consequentially, ADT can exacerbate these preexisting conditions (Smith et al., 2001; Wei et al., 1999). Like postmenopausal women, decreased bone mineral density in men receiving ADT is related to increased risk of bone fractures (Shahinian et al., 2005) and increased mortality secondary to fractures. One year after a hip fracture, the mortality rate is actually greater among men than women (31% vs. 17%, respectively) (Campion & Maricic, 2003).

There are two contributing factors to the rising concern about osteoporosis among the prostate cancer population. First, in addition to being the mainstay treatment for metastatic prostate cancer, ADT is now being used for men with high risk localized

prostate cancer, locally spread prostate cancer and men with biochemical recurrence. The second factor is that men, in general, are living longer. Because men are living longer, are diagnosed earlier with prostate cancer, and are receiving long-term ADT, the long-term consequences of ADT in men with prostate cancer are a growing concern.

Cognitive Changes

Cognitive and emotional changes in prostate cancer patients treated with ADT are an emerging area of research. Studies among healthy men suggest that decreased levels of testosterone adversely affect cognition and emotion; however, studies addressing cognitive and emotional changes secondary to ADT in prostate cancer patients have had mixed results (Barrett-Connor, Von Muhlen, & Kritz-Silverstein, 1999; Cherrier et al., 2001). Green and colleagues (2002a) randomized sixty-five men to one of four groups (two groups receiving LHRH analogues, another group receiving steroidal antiandrogens and a control group). Cognitive functions measured were as follows: memory, attention, executive function, and intelligence quotient. Results showed that almost half (48%) of the men randomized to the three treatment groups had a significant decline on at least one cognitive task and a decline on two or more tasks was found in 14% of the treatment group. The increased rate of cognitive deterioration was statistically significant in the groups treated with ADT versus control. None of the patients randomized to the control group had a decline in cognitive function. Baseline measures of age, level of education, estimated IQ, PSA, testosterone and current or past illnesses did not differ between groups (Green et al., 2002a). It is worth noting that the control group was comprised of volunteers which may have favored more cognitively sound individuals.

Similar results were found in a pilot study by Jenkins and fellow researchers (2005). The study examined the effect of temporary treatment (three to five months) with an LHRH-A on men with localized prostate cancer. Significant cognitive decline (in at least one cognitive task) was reported in 47% of the experimental group and only 17% of the control group at three months. Interestingly, there was no significant difference at nine months. This might suggest that a period of cognitive recovery occurred between the three and nine-month data collection points.

In contrast to the above studies, two recent studies conducted in Canada and Turkey found no significant change in cognitive function, over time, for men treated with ADT (Joly et al., 2006; Salminen et al., 2003). The study conducted in Turkey followed men over 12 months of ADT in conjunction with radiation therapy. The Canadian study required that the men be treated with at least three months of ADT but duration of treatment was not addressed. Both studies had small sample sizes (n = 25; n = 57).

Emotional Changes

Research addressing ADT and emotional function is sparse. Much of the research is based on qualitative studies, case reports, and pilot studies. The emotional changes that have been reported related to ADT in prostate patients are: depression (Pirl, Siegel, Goode, & Smith, 2002), tearfulness (Ng, Kristjanson, & Medigovich, 2006; Rosenblatt & Mellow, 1995), anxiety, fatigue, and labile mood. Of interest is that many of these emotional changes in men are reported by their partners rather than the patient themselves (Higano, Ellis, Russell, & Lange, 1996). Oliffe (2006) conducted an ethnographic study of 16 men treated with ADT and found that the men described their moods as more labile; they stated their moods would swing erratically and said it was not

unusual for them to cry. Some studies report that the incidence of depression is higher among men treated with ADT when compared to age matched healthy men (Almeida, Waterreus, Spry, Flicker, & Martins, 2004; Pirl et al., 2002). According to the Pirl et al. study ($N = 45$), the prevalence of depression in prostate cancer patients receiving ADT (12.8%) is eight times that of the national rate of depression (1.6%) in men. Of note in this study was the strong association between those subjects who had a past history of depression and those reporting current major depression while treated with ADT. These results might suggest that a past history of depression is a risk factor for developing depression, however, these results should be interpreted cautiously since the study sample was small and the number of patients reporting a history of depression was even smaller ($n = 5$).

Not all research supports the association between ADT and depression. Shahinian and colleagues (2005) conducted a secondary analysis of over 15,000 men treated with ADT which they compared to a control group of over 50,000 men without cancer. Results suggested initially that depression occurred more often in patients receiving ADT, however, when variables such as co-morbidities, patient age and cancer characteristics were controlled in the analysis, the rate of depression became non-significant. A limitation of this study is that they may not have accurately captured depression because primary care providers (PCP) do not always inquire about depression, nor do patients always inform their PCP about depressive symptoms. It is also important to note that Medicare reimbursement is driven by procedures rather than by diagnoses, therefore, complications (e.g., depression) that are not addressed with a procedure may not be noted in the chart resulting in the increased likelihood that depression is under recorded.

Furthermore, under Medicare, depression is not a billable diagnosis so the patient may not be assessed for the disorder (Potosky et al., 2002b).

Anemia and Fatigue

Anemia and fatigue are often interrelated and frequently experienced by men with prostate cancer receiving ADT. Anemia in these men is thought to be related to lack of testosterone, which is necessary for erythropoietin production (Strum et al., 1997). Few studies have been conducted to evaluate the incidence, prevalence and impact of anemia on prostate cancer patients receiving ADT. Strum and colleagues examined the incidence and prevalence of anemia in men receiving complete androgen blockade ($N = 133$). The researchers found that over 90% of patients had at least a 10% decrease in hemoglobin and 13% of the patients experienced a hemoglobin drop greater than or equal to 25%.

Fatigue in cancer patients is the focus of more studies than anemia. Among cancer patients, fatigue has been described as profound and at times incapacitating. Fatigue is often secondary to anemia but there can be other causes such as poor nutritional status, non-hormone related treatment (e.g., radiation therapy, chemotherapy), depression and stress (Higano, 2006; Morant, 1996; Smets, Garssen, Cull, & de Haes, 1996; Stone, Richards, & Hardy, 1998; Watanabe & Bruera, 1999).

Results of two longitudinal studies found that men treated with ADT, over time, reported significantly higher levels of fatigue than the control groups (Herr & O'Sullivan, 2000; van Andel & Kurth, 2003). Another study examined the severity and correlations of fatigue in men receiving ADT. Since the average age of men diagnosed with prostate cancer is mid-to late sixties, it is possible that fatigue would be present as energy levels often wane as age increases. However, Stone and colleagues (2000) found no significant

association between the patients' age and severity of reported fatigue. These studies suggest that fatigue among prostate cancer patients receiving ADT is a significant problem and has the potential to negatively affect their QOL.

QUALITY OF LIFE OF PATIENTS TREATED WITH ANDROGEN DEPRIVATION THERAPY AND THEIR PARTNERS

It is evident, from this literature review, that patients treated with ADT can experience a wide range and severity of adverse side effects. However, the extent to which these side effects impact patients' and their partners' QOL is a relatively new area of research. Much of the QOL research specific to prostate cancer focuses on newly diagnosed men treated with either a prostatectomy and/or radiation. Furthermore, many of the side effects experienced by patients receiving ADT are unique to this treatment group. The following section will examine current literature as it pertains to the QOL of prostate cancer patients treated with ADT and their partners.

Quality of Life of Advanced Prostate Cancer Patients Treated with ADT

When comparing various types of prostate cancer treatment, many studies report that men receiving ADT have overall worse QOL, poorer physical and sexual function, greater fatigue, and more hot flashes compared to men treated with prostatectomy or radiotherapy (Basaria et al., 2002; Dacal, Sereika, & Greenspan, 2006; Fowler, McNaughton-Collins, Walker-Corkery, Elliott, & Barry, 2002; Joly et al., 2006; Smith et al., 2000).

The following section presents the literature as it pertains to longitudinal studies evaluating the QOL of prostate cancer patients receiving ADT. A major strength of these studies is that they measure QOL variables over time, which is a more accurate

representation of real life than cross-sectional studies. The majority of these studies suggest that prostate cancer patients receiving ADT experience a decrease in their QOL (Herr & O'Sullivan, 2000; Potosky et al., 2002a; van Andel & Kurth, 2003), but not all the studies are in total agreement (Lubeck, Grossfeld, & Carroll, 2001).

Green and colleagues (2002b) compared men ($N = 65$) randomized to one of four treatment groups (observation, goserelin, leuprorelin, and cyproterone) to healthy men without prostate cancer. Health-related QOL was measured pre-treatment and six months after treatment started. Interestingly, there was a significant decrease in HRQOL in all groups, including the control group. This may be attributed to the natural aging process since it occurred in all groups. The greatest group effect, over time, was a decrease in sexual function in the ADT group. Overall, the study showed that ADT was associated with a decrease in QOL in the following domains: sexual, social/role function, and cognitive function.

A small number of studies compared prostate cancer patients receiving ADT to prostate cancer patients receiving no treatment. Potosky and colleagues (2002a) assessed disease-specific and general QOL in men newly diagnosed with localized prostate cancer ($N = 661$) at 6 and 12 months. At 12 months post-diagnosis, more of the men receiving ADT, than the group receiving no treatment, reported no interest in sexual activity (54% vs. 13%, respectively). For men, that reported potency before diagnosis, significantly more ADT patients reported impotency one year later than the no treatment group. Additionally, at 12 months post-diagnosis, men receiving ADT reported significantly more gynecomastia and hot flashes than men receiving no treatment. Overall, the ADT

patients had significantly more discomfort and greater loss of vitality than the no treatment group.

Decreased physical function and greater fatigue were the common outcomes of two other longitudinal studies (Herr & O'Sullivan, 2000; van Andel & Kurth, 2003). Both studies assessed QOL at two time points (six months and either 12 or 18 months after ADT was started). Herr and O'Sullivan examined the QOL of men who had chosen ADT or no treatment after having received local therapy for either locally advanced prostate cancer or biochemical recurrence. Overall, the men receiving ADT were found to have poorer QOL, decreased physical function, and more fatigue, psychological distress, and sexual problems. van Andel and Kurth (2003) assessed QOL of lymph node positive prostate cancer patients ($N = 91$) either receiving initial treatment of ADT or no therapy. Results suggested that, in the ADT group, there was a significant overall decrease in QOL at six months post diagnosis but not at 18 months. While the studies had similar findings, the samples were different with the men in the Herr and O'Sullivan study having been initially treated with local therapy (i.e. prostatectomy or radiation) while in the van Andel and Kurth study, ADT was the initial treatment.

A study by Lubeck and colleagues (2001), compared men ($N = 1178$) receiving ADT, radical prostatectomy, radiation therapy or surveillance. The researchers examined the ADT and the surveillance groups comparing them at baseline and one year. After one year, the ADT group reported significantly worse sexual function and sexual bother. Contrary to the previous four studies, no significant difference was found in physical function, role, social function, general health, and fatigue.

All of the aforementioned studies (Green, Pakenham, Headley, & Gardiner, 2002b; Herr & O'Sullivan, 2000; Lubeck, Grossfeld, & Carroll, 2001; Potosky et al., 2002a; van Andel & Kurth, 2003), shared a common finding of decreased or worsening sexual function. Only one of the studies examined the concept of sexual bother; yet a study by Helgason et al. (1996) emphasizes how important this concept may be to prostate cancer patients, as well as the general male population. In this study, the researchers compared sexual function in men diagnosed with prostate cancer ($n = 431$) to randomly selected age matched men without prostate cancer ($n = 435$). Participants were asked how willing they were to trade a longer life expectancy for sexual function if the possibility of cure was uncertain. Less frequent sexual activity and significantly higher incidence of physiological impotence were reported in the prostate cancer group; however, over 60% of both groups said they would trade years of life for the ability to function sexually.

A study by Stone et al. (2000) found that men treated with ADT reported increased fatigue, but contrary to the findings of Herr and O'Sullivan (2000), fatigue was not associated with a decline in functional status or overall QOL. Stone et al. did not report the sample demographics, thus, differences in demographics may account for the different results. Additionally, the Stone et al. study measured outcomes at three months while Herr and O'Sullivan measured outcomes at six months.

HRQOL outcomes were the focus of a study by Potosky et al. (2001). The researchers compared prostate cancer patients ($N = 431$) who had received either an orchiectomy or a LHRH-A as primary therapy. At 12 months post diagnosis, more men receiving a LHRH-A than those with orchiectomies reported a statistically significant problem in the following areas: sexual function, gynecomastia, physical discomfort, worry about

prostate cancer, and fair to poor health. There was no significant difference in the prevalence of hot flashes between groups, though across groups over 56% of the men reported experiencing hot flashes. Across both groups, over 40% of the patients reported limitations in activities of daily living and over 50% of both groups reported that they were bothered by their health.

Moinpour et al. (1998) conducted a randomized double-blinded trial to compare the QOL of prostate cancer patients ($N = 739$) treated with orchiectomy plus either flutamide or placebo. More of the men in the flutamide versus the placebo arm reported gynecomastia across all data collection points (baseline, one, three & six months); however, reports of concerns over their changing bodies was not significant. At three and six months, the flutamide arm reported significantly worse emotional functioning than the placebo arm. Finally, there was no significant difference in physical function between the two arms.

Only one study included role function as a variable, however, this study was a cross-sectional analysis of a longitudinal study of over 50,000 male health professionals (Bacon et al., 2001). The researchers assessed a subgroup ($n = 146$) of men diagnosed with localized prostate cancer and the effects of prostate cancer treatment on general, cancer specific and symptom domains of QOL up to five years after diagnosis. Men treated with ADT had a significantly greater decrease in role function (e.g. work-related activities and activities of daily living), than men without prostate cancer.

The literature addressing the affect of ADT on the QOL of prostate cancer patients is still in its infancy; therefore, results must be interpreted cautiously. Existing literature suggests that ADT often has a negative impact on the QOL of prostate cancer patients.

The greatest impact appears to be on physical (fatigue, sexuality, hot flashes, and gynecomastia) and emotional domains (distress) but again not all studies are in agreement. There is a paucity of literature addressing other domains such as functional, emotional, social and family well-being.

Other limitations of the reviewed studies include the lack of randomized controlled trials examining the effect of ADT on patients QOL. Only one study was a randomized controlled trial (Moinpour et al., 1998); the remainder were either cross-sectional or longitudinal consisting of randomly selected or convenience samples. The majority of the studies only assessed QOL for six to 12 months. Only one study assessed QOL 18 months into treatment (van Andel & Kurth, 2003). The literature indicates that men are being treated for longer periods of time; therefore, it is imperative that the long-term effects of ADT on QOL be studied. Racial characteristics of the samples were not identified in most studies, and in those that did, the majority of the participants were Caucasian, even though research has shown that African American men have the highest prevalence of prostate cancer, more metastatic cancer, and the highest mortality rate (Gilligan, Wang, Levin, Kantoff, & Avorn, 2004; Lambert, Fearing, Bell, & Newton, 2002; Watts, 1994).

Quality of Life of Partners of Advanced Prostate Cancer Patients Treated with ADT

Compared to the amount of research available on the QOL of men with prostate cancer, there is relatively little research examining the QOL of their partners. Yet, in studies of other types of cancer, partners are most often identified as the primary source of physical and emotional support for the patient (Blanchard et al., 1997; Harrison, Maguire, & Pitceathly, 1995; Manne, 1994). In the few studies of prostate cancer patients

that do include partners, there is often a significant correlation between the psychosocial well-being of the patients and the partners with an additional important finding that the partners' QOL affects the patient (Banthia et al, 2003; Eton et al., 2005; Northouse et al., 2007).

In some studies, the partners of prostate cancer patients are significantly more distressed and can have greater levels of stress than patients. It is not always clear how much of this distress is related to the cancer in general versus the side effects the patient is experiencing (Baider, Koch, Esacson, & De-Nour, 1998; Cliff & MacDonagh, 2000; Eton et al., 2005; Kornblith et al., 1994). Among studies on other cancers that have reported on partners/caregivers at different stages of the disease trajectory, researchers have found high levels of depression (Grunfeld et al., 2004; Kim, Duberstein, Sorensen, & Larson, 2005). Studies examining distress and depression in the partners of prostate cancer patients treated with ADT are sparse.

The literature suggests that many of the side effects of ADT affect the patients' QOL, but few studies have examined how these side effects affect the QOL of the partner. Partners appear to put the needs of the prostate cancer patient above their own needs. For example, partners of prostate cancer patients experiencing sexual dysfunction focus on building up the patient's sense of manhood rather than their own sexual needs and desires (Boehmer & Clark, 2001a; Boehmer & Clark, 2001b). Kornblith and colleagues (1994) found that partners were more distressed by urinary incontinence than the prostate cancer patient was. This may be related to the negative impact urinary incontinence can have on social QOL (Cliff & MacDonagh, 2000; Street et al., 2009). In contrast, a qualitative

study by Maliski and colleagues (2001) found that spouses did not feel that incontinence directly affected them.

Partners with poor problem-solving skills and less self-efficacy report more distress, depression, anxiety, fatigue (Campbell et al., 2004; Malcarne et al., 2002) and some partners report dissatisfaction with their sexual relationship (Heyman & Rosner, 1996; Neese et al., 2003). Partners, when compared to patients, seek out more information about the disease (Echlin & Rees, 2002) and want to actively participate in decision-making about the disease and its treatment. However, final health decisions are typically made by the patients (Lavery, & Clarke, 1999). Northouse et al. (2007) found that partners had more uncertainty about the illness and treatments and less social support than patients.

The bulk of the research examining the QOL of partners of prostate cancer patients does not focus on specific types of treatments but rather encompasses all treatments and more often than not fails to report treatment modalities. However, as the literature supports, many of the side effects experienced by men treated with ADT are unique to the treatment, unique to the patient and by default unique to the patients' partner.

No randomized controlled trials were identified that focus on partners of patients receiving ADT. Only a few studies examined and/or included partners of patients treated with ADT. Three of the studies were qualitative (Boehmer & Clark, 2001a; Heyman & Rosner, 1996; Navon & Morag, 2003) and two were exploratory (Campbell et al., 2004; Kornblith et al., 2001).

Boehmer and Clark (2001a) conducted separate focus groups with prostate cancer patients treated with ADT and their spouses and found that the men believed that their

loss of sexual function did not affect their wives. This perception was based on the fact that their wives did not complain. Wives, in turn, said they concentrated their energies on making their husbands feel masculine even though they were not able to have sexual intercourse. However, Neese and colleagues (2003) challenge the impression that partners are not bothered by lack of sex. Results of their study suggested that 38% of the partners (n = 62) of prostate cancer patients were concerned about their sexual relationship and were at least somewhat dissatisfied with it. It is possible that partners may be reluctant to report dissatisfaction with their sexual relationship, fearing it may have a negative effect on the patient.

Focus groups, which included some patients treated with ADT and their partners, were conducted by Heyman and Rosner (1996); however, the authors did not differentiate their findings based on treatment regimens. Many of the participants (patients and partners) in the study echoed the fact that the side effects experienced by the men served as a constant reminder that they had no control over the disease, which in turn intensified their feelings of uncertainty. Some of the partners spoke of a diffuse sense of anger which they kept inside themselves because they perceived their role as one of "emotional stabilizer" (p. 41).

A final qualitative study was done by Navon and Morag (2003). They conducted interviews exploring spousal relationship with prostate cancer patients treated with ADT. According to about half of the men, their bodies had changed to the point that their partners were disgusted with their appearance and refused to have any physical contact with them. About half of the men stated that their partners took over their roles which diminished their worth in the eyes of their children. This study had two major limitations:

sample size (N =15) and the fact that spouses were not interviewed, rather the spousal relationship was assessed from the perspective of the patient. Therefore, results should be interpreted cautiously. However, the study does suggest that there are other variables (e.g. marital communication, strength of martial relationship, self-efficacy) which moderate how these men view themselves and their relationship with their partner.

The QOL of prostate cancer patients treated with ADT and their partners' was the focus of a study by Kornblith et al. (2001). QOL measures were assessed four times over a six-month period. Partners' level of anxiety significantly decreased over time, which was related to improvements in the patients' clinical response and their physical and emotional states. An unexpected finding was that there was no significant decrease in the partners' level of caregiver burden over time. It is possible that even though patients' physical and emotional state improved, it was not enough to change the partners' perception of burden. This study's findings also raise the question about how burden and anxiety are related in partners of prostate cancer patients.

Patients receiving ADT and their partners were one of the treatment groups included in a study by Campbell et al. (2004). The authors hypothesized that partners with higher self-efficacy for symptom-control would have better QOL. This hypothesis was supported; partners that had greater confidence in their ability to care for the patient reported less depression, anxiety and fatigue. Additionally a negative correlation was found between self-efficacy and caregiver strain. There was also a negative correlation between the patients' level of self-efficacy for physical activities and physical function and the partners' level of caregiver strain and anxiety. This reinforces the importance of

self-efficacy for both patients and partners. Thus, further research is needed to ascertain the relationship between self-efficacy and QOL in partners of patients treated with ADT.

In addition to sexual dysfunction, prostate cancer patients treated with ADT often experience other adverse side effects such as hot flashes, body changes, fatigue, emotional and cognitive changes, osteoporosis, anemia, diabetes and metabolic syndrome. It remains unclear if and how these side effects impact the QOL of the advanced prostate cancer patient's partner as these issues are not addressed in current literature.

FACTORS AFFECTING THE QUALITY OF LIFE OF ADVANCED PROSTATE CANCER PATIENTS AND THEIR PARTNERS

When examining QOL of prostate cancer patients treated with ADT and their partners, there are a large number of potential independent variables that could affect QOL. The following represents a brief review of the current state of research literature as it pertains to specific independent variables; demographics (i.e. age, race, education, marital status), medical/illness (i.e. symptom distress, stage of disease) and psychosocial (i.e. self-efficacy, social support/communication, appraisal of illness/caregiving, coping).

Demographic Factors

Age.

Qualitative work by Harden, Northouse and Mood (2006) explored the impact of prostate cancer on couples in different adult age categories. Couples in the late middle age group (ages 50-64) reported higher frustration with the changes the cancer caused in their everyday lives, their inability to meet life goals, and the changes in their future financial security when compared to older age groups. Couples in the young-old group

(ages 65-74) reported more satisfaction with where they were in life. The old-old group (age 75-84) reported longer recuperation periods after treatment but in general, they felt that together they could meet the demands associated with the disease and its treatment. Bowman and colleagues (2006) examined the appraisal of stress among prostate, breast and colorectal patients and their family members. They found that being older was significantly related to having less stressful appraisals by the patients.

Looking specifically at partners, studies of other types of cancers indicate that younger partners experience more changes in their day-to-day activities, including roles, which results in more strain on their mental and psychological health (Baider et al., 1998; Nijboer et al., 2000). Studies examining partners' age and QOL are limited. Campbell et al. (2004) found that the age of partners of prostate cancer had a significantly negative correlation to caregiver strain; however, partners' age was not related to patients' QOL. A study by Kershaw et al. (2008) also found a significant negative correlation between partners' age and partners' physical QOL, however, this study also found no significant direct relationship between partners age and patients QOL. Finally, Kornblith et al. (1994) also found no relationship between the age of partners of prostate cancer patients and patients' QOL.

Race.

Very few studies have examined if and how race affects the QOL of prostate cancer patients and their partners. Even though African American men are diagnosed with prostate cancer at a rate 1.6 times that of Caucasian men, they remain under-represented in cancer research (American Cancer Society, 2006; American Cancer Society, 2005; Ramsey, Zelladt, Hall, Ekwueme, Penson, 2007). Over 80% of cancer research

participants are Caucasian, while African Americans and Hispanics comprise approximately 5% to 10% of participants and only 2% are Asian (National Cancer Institute, 1999). Bowman and colleagues (2006) in their study of appraisal of cancer related stress among African American and Caucasian prostate, breast and colorectal patients and their family members found that being African American was significantly related to less stressful appraisal of the illness by patients. The investigators speculate that African Americans may appraise their prostate cancer as less stressful than Caucasians because they have a more fatalistic view of cancer. A longitudinal study by Litwin and colleagues (1998) of men who had received a radical prostatectomy, found that one year after surgery, race was an independent predictor of return to pretreatment physical and social function. Caucasians were more likely than non-Caucasians to return to pretreatment levels of physical and social function.

Race also appears to be a factor with regard to the type of treatment prostate cancer patients receive. Several large studies have shown that African American men were less likely to receive aggressive therapy compared to Caucasian men (Harlan et al., 1995; Zeliadt, Potosky, Etzioni, Ramsey, & Penson, 2006). Zeliadt et al. found that patients living in geographic areas with 'low-use' of adjuvant ADT had lower incomes, were predominantly African American and were treated less frequently with ADT. Results of other studies suggest that African Americans and Caucasians receive comparable treatment for prostate cancer (Demark-Wahnefried et al., 1998; Lubeck et al., 2001).

Some research that examined race indicated that sexuality appears to be a more important consideration for African American patients with prostate cancer than

Caucasian patients. Jenkins et al., (2004) recruited African American and Caucasian men (n = 120; n = 1089, respectively) with localized prostate cancer and found that preserving erectile function was a major determinant in their choice of treatment. In another study, African American patients reported they were willing to trade years of survival for the ability to maintain sexual function, while Caucasian patients were willing to trade survival time for continence as compared to Latinos or Asians (Saigal, Gornbein, Nease, & Litwin, 2001). Jenkins et al. also reported that among African American and Caucasian patients with sexual deficits, African American patients were more distressed with these changes than Caucasian patients. Conclusions of this study must be viewed cautiously as the enrollment rate in this study was significantly lower for African American men versus Caucasian men (28% and 51%, respectively). Overall, these studies suggest that race can be a pertinent factor in differences in QOL of men with prostate cancer and consequently the QOL of their partners.

Socioeconomic factors.

Although socioeconomic factors (SES) such as education and income have been identified as contributing to the QOL, findings are mixed. A study by Brar and colleagues (2005) of 138 low-income prostate cancer patients, with less than a high school education, reported greater improvements in their mental well-being than more educated men. In contrast, lower education was related to more depression, pain and anxiety in another study with patients receiving ADT (Carmack-Taylor et al., 2004). Contradictory results from these two studies may be attributed to various social and psychological characteristics found in different income and educational levels. Additionally, Carmack-

Taylor et al. did not measure income; rather, SES was based on some college education or no college education.

Much of prostate cancer QOL research does not provide key information about the SES of the study population. A review of literature by Ramsey and colleagues (2007) of 184 prostate cancer QOL studies found that more than 95% of the studies did not include key socioeconomic and demographic factors. The most frequently omitted was SES. Income was reported in less than 10% of the studies. A final problem is evident when attempting to compare SES across studies: there is no consistency in how information is grouped and recorded. This area needs further studies that include SES, as well as the inconsistency in reporting this information across studies.

Marital status.

Marital or partnership status was shown to have a positive impact on patients in a number of mixed cancer studies (Broeckekl, Jacobsen, Balducci, Horton, & Lyman, 2000; Chen, Chu, & Chen, 2004; Ganz, Lee, & Siau, 1991; Kugaya, Akechi, Okamura, Mikami, & Urchitomi, 1999). Prostate cancer patients in established relationships or with higher marital satisfaction were more likely to return to pretreatment levels of general health and social well-being (Banthia et al., 2003; Litwinet al., 1998). A study by Gore and colleagues (2005) found similar results; partnered patients had better mental health, lower symptom distress and higher spirituality than unpartnered patients. Banthis et al. found a stronger marital relationship acted as a buffer for intrusive thoughts. Prostate cancer dyads that reported more intrusive thoughts and a stronger marital relationship were less distressed than those dyads who reported more intrusive thoughts and a poorer

marital relationship. This suggests that having a partner or spouse and a strong relationship buffers some of the distress associated with prostate cancer and its treatment.

There is a paucity of research on prostate cancer among homosexual men. Research, in general, appears to suggest that having a partner has a positive effect on the QOL of the patient, though in virtually all the studies the partner is a female. It is estimated that over 5,000 homosexual or bisexual men are diagnosed with prostate cancer each year and that there are another 50,000 living with the disease (Blank, 2005). However, only one study was located that included same sex partners and this study was limited to only one same sex couple (Neese et al., 2003). Further research is needed to assess the impact of prostate cancer on the QOL of men and their same sex partners.

Medical Factors

Symptom distress.

Prostate cancer patients treated with ADT frequently experience a number of adverse side effects including: loss of libido, erectile dysfunction, hot flashes, gynecomastia, breast tenderness, fatigue, osteoporosis, metabolic syndrome, changes in body fat and muscle mass and cognitive and emotional changes (Freedland, Eastham, & Shore, 2009; Kabir, Mancuso, & Rashid, 2008). A number of studies have shown that these side effects can cause distress for patients, which can have a profound negative impact on their QOL (Fowler et al., 2002). Kershaw and colleagues (2008) reported that symptom distress in men with prostate cancer was directly related their mental and physical QOL. Men with more symptom distress reported significantly worse mental and physical QOL. Herr and O'Sullivan (2000) compared locally advanced prostate cancer patients either treated with ADT (n = 79) or not receiving ADT (n = 65). Results indicated that the men

receiving ADT reported significantly more fatigue, sexual problems and worse physical QOL. A study comparing the QOL of men with localized prostate cancer treated with either ADT, prostatectomy, external radiation, brachytherapy, or watchful waiting (Bacon et al., 2001) showed that the men treated with ADT had significantly worse QOL in the following domains: physical, functional, emotional and social.

Among the few studies that included the partners, existing evidence is mixed as to whether or not there is an association between the symptoms experienced by patients and the QOL of their partners (Kershaw et al., 2008; Kornblith et al., 1994; Northouse et al., 2007; Sanda, Dunn, Michalski, Sandler, Northouse et al., 2008). In their study of predictors of QOL in couples with prostate cancer, Kershaw et al. reported that spouses of patients with greater symptom distress used more avoidant coping strategies and had worse mental QOL. As expected, spouses' physical QOL was significantly related to their own symptoms due to their co-morbidities, but interestingly, it was not related to patients' symptom distress. This may suggest that patients do not put great physical demands on their partners or perhaps spouses internalize their feelings about their husbands' symptoms, as indicated by their lower mental QOL. Sanda and colleagues (2008) examined determinants of QOL for patients and partners following primary treatment for prostate cancer. Results indicated that partners of patients with worse symptoms (e.g. sexual function, urinary and bowel problems and vitality) reported greater levels of distress. Studies by Kornblith et al. (1994) and Northouse et al. (2007) reported that dyads with advanced prostate cancer experienced significantly more symptom distress. According to Kornblith et al. as the number of patients' symptoms increased, the partners' distress level increased and QOL decreased. Contrary to the results of Kershaw

et al., the study by Northouse et al. revealed that there was no relationship between spouses' perception of their husbands' symptoms, phase of illness and whether spouses reported that patients' symptoms created a problem for themselves. Different results may be due to the fact that the Northouse et al. study was cross-sectional while the Kershaw et al. study was longitudinal, thus the Kershaw et al. study may be a better representation of the population.

Stage of disease.

The stage of the patients' prostate cancer is one variable that has been associated with QOL. Not surprisingly, studies suggest that, in general, men with advanced disease report a lower QOL as compared to locally spread or biochemical recurrent prostate cancer (Albertsen, Aaronson, Muller, Keller, & Ware, 1997; Kornblith et al., 1994; Namiki et al., 2007; Northouse et al., 2007). It is worth noting that the Northouse et al. study was a comparison study that included men from all three stages of prostate cancer (localized, biochemical recurrence, advanced) and their partners. In their study, patients with advanced prostate cancer had the lowest physical QOL of all patients, and their spouses had the lowest mental QOL of all study participants (patients and spouses). Dyads with advanced disease were at significant risk for increased distress as compared to newly diagnosed or biochemical recurrent patients and partners. No other studies were located that examined QOL of patients receiving ADT across all stages of disease or QOL of their partners.

Psychosocial Factors

A large number of studies have been undertaken to examine various psychosocial factors in the cancer population and the impact of those factors on QOL. Examples

include: self-efficacy (Northouse et al., 2002), social support, communication, anxiety, depression (Manne et al., 2004; Parker Baile, DeMoor, & Cohen, 2003), appraisal (illness/caregiver) (Kershaw et al., 2008), and coping (Kershaw, Northouse, Kritpracha, Schafenacker & Mood, 2004). Yet, much of the research on psychosocial factors has occurred in the breast cancer population. Many conclusions have been generalized from this population to other cancer populations; however, these generalizations may not be accurate for specific cancer populations, such as prostate cancer patients receiving ADT and their partners, who differ in gender and types of treatments.

Self-efficacy.

Self-efficacy, according to Bandura (1977) is defined as "the conviction that one can successfully execute the behavior required to produce the outcomes." (p. 193) In the context of cancer patients, it refers to their confidence to manage the cancer and cancer-related demands, treatments, symptoms and side effects and for partners it refers to their confidence to manage the demands, challenges and uncertainty related to caring for their ill spouse (Harden et al., 2008). In a study by Campbell et al. (2004), there was a significant correlation between higher self-efficacy for symptom control and better physical and mental QOL. When either patients or partners reported more self-efficacy, their partners reported less strain, depression, fatigue and anxiety. The study also found a significant negative relationship between patients' self-efficacy (for symptom control and physical function) and partners' rating of mood and caregiver strain. As patients reported higher self-efficacy, partners reported less mood disturbances and caregiver strain.

Northouse and colleagues (2007) examined stage of disease and self-efficacy. Results indicated that prostate cancer patients with biochemical recurrence and metastatic disease

had significantly less self-efficacy (134.1 and 134.7 < 144.7) than newly diagnosed patients did. A surprising finding was that partners of patients with biochemical recurrence and metastatic disease reported significantly less self-efficacy than the patients. Finally, Kershaw et al. (2008) conducted a longitudinal analysis and determined that prostate cancer patients and partners with higher levels of self-efficacy reported better QOL. Kershaw and colleagues found that prostate cancer patients who reported lower self-efficacy at baseline had more negative appraisal of illness, hopelessness and uncertainty at four months and lower QOL at eight months. Partners with less self-efficacy at baseline also had more negative appraisal of caregiving, hopelessness and uncertainty at four months and poorer QOL at eight months.

Social Support/Communication.

Social support is defined as "an interpersonal transaction involving one or more of the following: (1) emotional concern (liking, love, empathy), (2) instrumental aid (goods or services), (3) information (about the environment), or (4) appraisal (information relevant to self-evaluation)" (House, 1981, p. 39). Social support can be provided by a partner, children, family members, friends, co-workers and from community ties and social support groups (Taylor, Falke, Shoptaw, & Lichtman, 1986). Literakture has shown that positive social support can have a protective effect on physical and emotional well-being (Fuhrer, & Stansfeld, 2002; Northouse, 1988). Kornblith and colleagues (2001) showed that social support directly affected stress levels among breast cancer patients. Northouse (1988) assessed the relationship between social support and adjustment in the husbands of women newly diagnosis with breast cancer. Results indicated that husbands with more social support had fewer adjustment problems when compared to husbands with less

support. However, multiple studies have shown that partners and caregivers perceive that they receive low levels of social support (Davis-Ali, Chesler, & Chesney, 1993; Northouse, 1988; Northouse, Templin, Mood, & Oberst, 1998; Sharpe, Butow, Smith, McConnell, & Clarke, 2005). Additionally, some studies have shown that as cancer progresses and the demands of managing the disease increase, the level of social support drops off even further (Weitzner, McMillian, & Jacobsen, 1999). A decrease in social support may occur simply because, as caregiving demands increase, free time decreases, therefore, restricting access to the caregiver's social support network.

The effects of social support in the advanced prostate cancer population are not well documented. Available research suggests that men with prostate cancer typically rely on their partners for social support (Arrington, Grant, & Vanderford, 2005); however, a study (N = 661) by Helgason and colleagues (2001) indicated that one in five prostate cancer patients had no one to confide in. Furthermore, the researchers found that three out of 10 prostate cancer patients in a relationship could not confide in their partner leading to feelings of being more depressed, worn out, sad, and less energetic. In a study of patients with localized prostate cancer, higher social support was significantly correlated with higher emotional well-being; additionally, prostate cancer patients reporting higher levels of social support at diagnosis reported significantly higher levels of emotional well-being two years later (Zhou et al., 2010). In a study of 94 prostate cancer patients, including advanced prostate cancer patients (n = 33), it was found that higher social well-being was significantly correlated with physical well-being (Balderson & Towell, 2003). It is apparent that social support plays an integral role in both the cancer patient and their

partner, yet there remains a gap in the literature related to social support and advanced prostate cancer patients and their partners.

Communication is a form of both social and emotional support. Communication between cancer patients and their partner has been shown to be related to positive adaptation when faced with a life threatening disease (Badr & Taylor, 2009; Mallinger, Griggs, & Shields, 2006). Studies suggest that cancer-related communication is often limited between patients and partners because they try to shield and protect each other by not sharing their true feelings and thoughts (Gray, Fitch, Phillips, Labrecque & Fergus, 2000; Northouse et al., 2002).

Much of the current research on cancer-related communication in patients and their partners focus on breast cancer patients, and in general, women appear to be more inclined to want to share cancer-related thoughts and feelings with their partners (typically men) (Harrison et al., 1995). Manne et al. (2006) found that in couples coping with breast cancer, mutually constructive cancer-related communication was associated with less distress and a more satisfactory relationship while demand-withdrawal cancer-related communication and mutual avoidance was associated with more distress.

Among the few communication studies with prostate cancer patients, Boehmer and Clark (2001b) conducted focus groups with patients and their wives and found that there was very little spousal communication about cancer related emotions, worries and fears. Patients avoided cancer-related communication because they wanted to move on or "to be done with the disease" (p. 229); whereas, partners hid their own concerns and avoided cancer-related communication because they wanted to protect their husbands. A study by Badr and Taylor (2009) examined the association between sexual dysfunction, marital

adjustment and dyadic communication in prostate cancer patients and their partners. Results indicated that mutually constructive communication was significantly related to better marital adjustment for patients and partners. Partners reporting more mutual avoidance communication reported more distress. In patients who reported more erectile dysfunction, partners reported more spousal mutual avoidant communication. This might suggest that partners want to discuss sexual issues with the patients but patients do not want to discuss these issues with their partners. Patients may choose to avoid the topic of sexuality, however, the literature suggests that partners (typically females) respect the patient's wishes. However, the literature suggests that if given the option, partners would rather communicate openly about sexuality (Boehmer & Clark, 2001b). Results of a study by Manne and colleagues (2010) partially support the research of Badr and Taylor. In a study of men with localized prostate cancer and their partners (n = 75), Manne et al. found that patients and partners with more cancer-related communication reported less distress and greater intimacy. These studies suggest that it may be more difficult for dyads to communicate about the illness when men are experiencing problems.

Kershaw et al. (2008) found that, from the perceptive of partners, more cancer-related communication between patients and partners was associated with partners experiencing less hopelessness and uncertainty. Interestingly, they also found, from the partners perceptive, that more patient-partner communication was associated with higher patient uncertainty. This might suggest that the level of communication reported by patients and partners is influenced, in part, by the characteristics of each person and how they cope with illness.

Appraisal.

Appraisal is defined as a cognitive process whereby an individual evaluates a stressful event or situation in respect to their well-being (e.g. QOL) (Lazarus & Folkman, 1984). This definition is well supported in cancer research, as is the association between appraisal and a number of antecedent factors such as age, SES, self-efficacy, communication, symptom distress, social support (Bjorck, Hopp, & Jones, 1999; Bowman, Deimling, Smerglian, Sage, & Kahana, 2003; Northouse, Mood, Templin, Mellon, & George, 2000; Kershaw et al., 2008). Research in the prostate cancer population has shown that more negative appraisal of the cancer is significantly correlated with age and race. Older African Americans were less likely to appraise prostate cancer as a stressful event (Bowman et al., 2003). In another study of prostate cancer patients and their spouses, it was found that young-old dyads (65-74 year olds) had less negative appraisal of the cancer than younger (50-64) and older (75-84) dyads (Harden et al., 2008). Results reported by Northouse and colleagues (2007) indicated that dyads with advanced prostate cancer (biochemical recurrence or metastatic) reported more negative appraisal of the disease and caregiving when compared to dyads with newly diagnosed disease (2.7 and 2.6 > 2.2).

A number of studies have shown that appraisal is a key mediator between specific antecedent variables and outcome variables. Wootten et al. (2007) reported that appraisal mediated the relationship between sexual bother and mood disturbance in a study of localized prostate cancer patients and their partners. Appraisal as a mediator was also supported by the research of Kershaw et al. (2008). The researchers found that appraisal mediated the effects of the prostate cancer patients' age, self-efficacy and current

concerns on the patients physical QOL. Younger patients with less self-efficacy and more current concerns had a more negative appraisal of their disease and poorer physical QOL. Furthermore, a number of antecedents (self-efficacy, current concerns, age, symptoms and disease stage) had an indirect effect on coping (active and avoidant) and QOL (physical and mental) through the mediator appraisal. Younger patients with less self-efficacy, more current concerns, more symptoms, and more advanced disease had more negative appraisal of the cancer and poorer physical QOL. Additionally, if they utilized more active coping, they had a better mental QOL; but, if they utilized avoidant coping, they had poorer mental QOL. For partners in the Kershaw et al study, results indicated that appraisal mediated partners' self-efficacy and current concerns on mental QOL, and there was also an indirect effect on avoidant coping and mental QOL. Partners with less self-efficacy and more current concerns had a poorer mental QOL. Additionally, partners with less self-efficacy and more current concerns had more negative appraisal of their role as caregivers and if they utilized avoidant coping strategies, they had a poorer mental QOL.

Coping Strategies.

The use of coping strategies has been more extensively examined in various types of chronic illnesses including cancer; however, few studies have focused on couples coping with advanced prostate cancer, even though research strongly supports the reciprocal relationship between patients and partners (Manne, 1998). Dodd, Dibble and Thomas (1992) compared the coping strategies of cancer patients receiving chemotherapy to the coping strategies employed by their family members and found that both groups used similar strategies. Both patients and partner/caregivers used active coping strategies such

as seeking information and social support. However, the authors also found that the caregivers' coping strategies were less varied than the patients'. A study of prostate cancer patients (all stages) and spouses (N = 121) found that greater use of active coping and less use of avoidant coping strategies was significantly related to patients' increased mental QOL. While for the spouses, less use of avoidant coping was the only type of coping strategy significantly related to spouses' higher mental QOL (Kershaw et al., 2008). Ko and colleagues (2005) examined coping strategies and distress in prostate cancer patients (all stages) and their spouses. Results indicated there was a significant relationship between spouses' dysfunctional coping (avoidance coping) and spouses' and patients' higher distress. These studied suggest that interventions designed to decrease the use of avoidant coping may be pivotal in helping couples increase their mental QOL. Banthia et al. (2003) examined the effects of dyadic strength and coping strategies on distress in couples experiencing prostate cancer (all stages). Results suggested that the relationship between patients' use of dysfunctional coping and distress was moderated by the strength of the dyadic relationship. In other words, there was less use of dysfunctional coping in couples with better relationships. This implies that patients experiencing prostate cancer may benefit from interventions aimed to enhance their relationship. Interestingly, the results for the spouses showed that a strong marital relationship did not moderate dysfunctional coping and distress. This might suggest that not only may couples benefit from couples' focused interventions but they may also benefit from individual focused interventions. No studies were found that examined the coping strategies of partners of prostate cancer patients treated with ADT.

KNOWLEDGE GAPS AND DIRECTION FOR FUTURE RESEARCH

It is apparent from the foregoing literature review that there are a number of factors that can contribute to the QOL of prostate cancer patients and their partners. However, this literature review also found a number of gaps in the literature related to the QOL of advanced prostate cancer patients treated with ADT and their partners. The following seven points represent these gaps.

First, few studies in the advanced prostate cancer population are based on theory, even though theory can lay the fundamental groundwork and direction for research, intervention development and ultimately practice implementation. Without a theoretical basis for research, there is a lack of conceptual clarity and increased difficultly connecting new knowledge with existing knowledge (DePoy & Gitlin, 2011). To maximize the understanding and improvement of the QOL of advanced prostate cancer patients and their partners there needs to be an amalgamation of past, present and future research, theory driven research will help to achieve this goal.

Second, this literature review shows that there are some studies that examine how ADT affects the QOL of prostate cancer patients (Green et al., 2002b; Lubeck et al., 2001; Potosky et al., 2002a; van Andel & Kurth 2003) but few which include the patients' partner (Boehmer & Clark, 2001b; Kershaw et al., 2008; Navon & Morag, 2003; Northouse et al., 2007). By far the majority of research examining the impact of cancer on the QOL of patients and partners has focused on breast cancer patients and their husbands/partners. Results cannot be generalized from breast cancer patients and partners to prostate cancer patients and partners. More research is needed which examines how

ADT affects the QOL of advanced prostate cancer patients and their partners. With this research, interventions geared toward the specific needs of the dyad can be developed.

Third, many of the studies evaluating the effect of ADT on QOL are cross-sectional using data collected at only one time (Albertsen et al., 1997; Knight et al., 1998). Furthermore, a number of the studies do not include pretreatment information for analysis. For example, research indicates that as men age there is often some decline in sexual function (Litwin, 1999), therefore, if pretreatment sexual function is not measured and controlled for, results will not accurately reflect treatment related side effects. There is a need for longitudinal studies of the effects of ADT on the QOL of the patients and their partners that control for pretreatment QOL prior to starting ADT.

Fourth, few studies control for comorbidities. The side effects of ADT often coexist with other age-related healthcare problems. Comparisons of age-matched cancer free population are essential so that there is a clearer understanding of age-related QOL decline compared to cancer-related QOL decline.

Fifth, all but a very few of the studies in this literature review were comprised primarily of Caucasian participants; however, the incidence of prostate cancer in African American men is disproportionally higher than that of Caucasian men. Additionally, few studies included other minorities (i.e. Asian/Pacific Islanders, American Indians/Alaska Natives, and Hispanics). Future studies are needed that address the effects of ADT on the QOL of minority prostate cancer patients and their partners.

Sixth, the literature has identified a number of demographic, psychosocial and medical variables which potentially could influence the QOL of prostate cancer patients and their partners. Few of these variables have been examined in the context of prostate

cancer patients and, in particular, advanced prostate cancer patients receiving ADT and their partners. Studies are needed which examine these variables so that healthcare providers can supply prostate cancer patients and their partners with the knowledge necessary to make informed decisions regarding prostate cancer treatment.

Finally, researchers need to focus on moving their research to the next level, intervention research. Few studies in the prostate cancer population and even fewer in advanced prostate cancer patients and their partners have achieved this goal. Yet, without the translation of research into interventions, benefits to the patients' and their partners' QOL are limited.

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CHAPTER III

DESCRIPTION OF THE SELF-EFFICACY, SYMPTOM DISTRESS, COMMUNICATION, APPRAISAL, COPING STRATEGIES AND QUALITY OF LIFE OF ADVANCED PROSTATE CANCER PATIENTS TREATED WITH ANDROGEN DEPRIVATION THERAPY AND THEIR PARTNERS

INTRODUCTION

Advanced prostate cancer is no longer considered curable, thus the focus of treatment is to prolong survival time and maximize quality of life (QOL). Androgen deprivation therapy (ADT) is the primary treatment for men with advanced prostate cancer (metastatic disease or biochemical recurrence) (El-Rayes & Hussain, 2002). Yet the treatment is not without difficulties, as ADT is known to cause a large number of adverse side effects such as: loss of libido, erectile dysfunction, body changes, hot flashes, lethargy and extreme fatigue, emotional and cognitive changes, osteoporosis, diabetes and metabolic syndrome (Higano, 2006; Holzbeierlein, 2006; Kabir, Mancuso, & Rashid, 2008; Potosky et al., 2002). Additionally, for men with advanced disease, bone is one of the two most frequent sites of metastases and bone metastases are often associated with high levels of pain (Gomez, Manoharan, Kim, & Soloway, 2004; Lindqvist, Widmark, & Rasmussen, 2006; Nuhu, Odejide, Adebayo, & Yusuf, 2009). Both cancer symptoms and treatment-related side effects are associated with greater depression and poorer overall

QOL (Herr & O' Sullivan, 2000; Pirl, Siegel, Goode, & Smith, 2002). In one study greater depression in men with prostate cancer was associated with a fourfold increase in suicide (Llorente et al., 2005) while in other studies (Karvonen-Gutierrez et al., 2008; Maisey et al., 2002) poorer QOL has been shown to be a predictor of decreased overall survivorship.

The symptoms associated with advanced prostate cancer and the side effects of ADT also can affect the QOL of partners (Given et al., 2004; Herr 1994; Navon & Morag, 2003). Studies indicate that partners of cancer patients report increased emotional distress (Kornblith, Herr, Ofman, Scher, & Holland, 1994), depression (Couper et al., 2006), poorer sexual function (Badr & Taylor, 2009), and overall poorer emotional QOL (Kornblith et al., 1994). In spite of these effects, little information is available on patients and their partners' self-efficacy to manage the illness and its treatment, the extent to which dyads communicate about the cancer, their appraisal of the disease and the caregiving required, ways that they cope with the illness and the effects of ADT treatment on their QOL.

According to the goals established by the National Cancer Institute (NCI, 2006) and the Institute of Medicine (IOM, 2003), reducing the burden associated with cancer by improving the QOL of cancer patients and their families is a priority. To meet this goal, a better understanding is needed about the effects of prostate cancer in patients and their partners. Therefore, the purpose of this is study is to enhance the current body of knowledge of advanced prostate cancer patients treated with ATD and their partners. This study will: 1) describe the levels of self-efficacy, symptom distress, communication, appraisal of illness/caregiving, coping and QOL in advanced prostate cancer patients

treated with ADT and their partners and 2) determine if there are differences between patients and partners responses to the illness and its treatment.

CONCEPTUAL MODEL

This study was guided by the Modified Stress-Coping Model, which is based on a synthesis of key components of two well-tested theoretical models, the Transactional Model of Stress and Coping (TMSC) (Lazarus, 1966; Lazarus & Folkman, 1984) and the Resiliency Model of Family Stress, Adjustment and Adaptation **(**McCubbin, Cauble, & Patterson, 1982). Both the TMSC and the Resiliency Model have been widely used in the social sciences, including among cancer patients and their families (Harden, Northouse & Mood, 2006; Laubmeier, Zakowski, & Bair, 2004; Northouse et al., 2002). According to the framework which guided this study - the Modified Stress-Coping Model (Figure 3.1), there are a number of specific antecedent factors (i.e. personal, medical/illness, social) which influence how individuals appraise a stressor (e.g. advanced prostate cancer) and specific coping strategies which are utilized to manage the stressor. In turn, how individuals appraise and cope with the cancer affects their QOL and the QOL of their partners. The Modified Stress-Coping Model has been tested in studies with breast, colon and prostate cancer and has been shown to predict a significant amount of the variance, from 24% to 81%, in the QOL of patients and partners (Kershaw et al., 2008; Northouse et al., 2000; Northouse et al., 2002; Northouse et al., 2001).

For this study, the Modified Stress-Coping Model was used to guide the selection of variables examined in patients and partners: antecedent personal factors (demographics, self-efficacy), medical/illness-related factors (symptom distress), social factors (communication), appraisal (illness or caregiving), coping (active, avoidant) and QOL.

LITERATURE REVIEW

A small number of studies have been conducted to determine whether specific factors help explain why some prostate cancer patients and/or their partners experience poorer QOL than others. Results of these studies, in conjunction with the Modified Stress-Coping Model, have identified a number of potential factors; however, none of these studies focus on only advanced prostate cancer patients treated with ADT and their partners.

Self-efficacy

Self-efficacy refers to a person's confidence to organize and implement certain actions required to manage or succeed in a given situation (Bandura, 1977). Individuals with more confidence in their ability to manage specific tasks adapt better and conversely those with less confidence adapt poorly (Campbell et al., 2004).

Depending on the treatment modality, prostate cancer patients can experience bowel, bladder and sexual dysfunction and body image changes (Eton & Lepore, 2002). Men treated with ADT, often are left with feelings of decreased masculinity or total emasculation (Arrington, 2003; Wassersug, 2009). These side effects can present as a challenge to patients and partners as they attempt to come to terms and cope with the changes. However, many prostate cancer patients and partners report low levels of self-efficacy and are unable to master these added challenges (Campbell et al., 2004). Furthermore, studies of various types of cancer have shown that patients with low self-efficacy for managing symptoms report lower emotional, functional, physical and social QOL (Eller et al., 2006; Kreitler, Peleg, & Ehrenfeld, 2007) and more depression (Weber, Roberts, Mills, Chumbler, & Algood, 2008).

Navon and Morag (2003) conducted interviews with advanced prostate cancer patients on ADT and one theme that emerged was loss of masculinity and accompanying that loss of masculinity was a loss of the "fighting spirit". The following quote from an advanced prostate cancer patient summed these thoughts up "…I've become passive. All of a sudden, my chief masculine quality – my fighting spirit – simply disappeared." (p. 76) In a second qualitative study, loss of masculinity was also found; however, equated with this loss the men reported feelings of loss of control and lack of confidence in managing treatment-related side effects (Chapple & Ziebland, 2002).

Only a few studies have explored self-efficacy in the partners of cancer patients. These studies report that partners want to help patients manage the side effects of the cancer and its treatments. However, they frequently report lower levels of self-efficacy than patients (Northouse et al., 2007) and express feeling overwhelmed, helpless and uncertain how best to meet the patient's needs (Fletcher, Lewis, & Haberman, 2010).

Symptom Distress

Some studies have compared the QOL of prostate cancer patients receiving ADT to those not receiving ADT and have found that patients treated with ADT report poorer QOL (Dacal, Sereika, & Greenspan, 2006; Fowler et al., 2002). One of the most difficult symptoms experienced by men on ADT is loss of libido and sexual function. Studies indicate that up to 80% of men treated with ADT report decreased or no libido and erectile function (Clark, Wray, & Ashton, 2001; Potosky et al., 2001). Changes in libido were very disturbing to a large number of men. The words of one man expressed these thoughts (Chapple & Ziebland, 2002) " …I feel that I've lost all masculinity. I'm not a man any more…" (p. 833) Other men, even though they had been told they would lose

their sex drive, were surprised by the total ablation of all libido "One of the side effects was supposed to be that you lose your sex drive, well, I certainly did that. There was no, you know, even inclination to even sort of think about sex or anything like that." (Chapple & Ziebland, p. 832) Other physical changes reported include fatigue (Holzbeierlein, 2006). One patient stated that he felt like he was on a "tranquillizer", while others described a total loss of enthusiasm for life (Navon & Morag, 2003, p.76).

Most research pertaining to treatment-related symptoms focus on patients even though patients' symptoms can have an effect on their partners. Kornbltih et al. (1994) reported a significant relationship between the number of problems (i.e. physical, psychological, sexual symptoms) reported by the patients and the partners' QOL. A qualitative study by Street et al. (2010) found that some female partners had a hard time accepting the loss of their "sexual life" (p. 238), and changes to their social life. In addition to patients' symptoms, partners of men with prostate cancer often have symptoms of their own related to comorbid conditions and the effects of aging; however, symptoms experienced by partners have seldom been assessed in prior studies.

Communication

A few studies indicate that a disconnect exists between patients and partners regarding cancer-related communication (Badr & Taylor, 2009; Manne, Badr, Zaider, Nelson, & Kissane, 2010). Prostate cancer patients are often reluctant to discuss the disease, its symptoms and associated emotions, many prefer to maintain a facade of normalcy (Gray et al., 2000), while their partners (typically females), if given the choice, would rather have more open communication about the disease, symptoms and emotions (Harrison, MaGuire, & Pitceathly, 1995). Kershaw and colleagues (2008) found that

partners who reported more cancer-related communication with patients experienced less hopelessness and less uncertainty.

Other studies in prostate cancer populations suggest that patients and partners try to protect and shield each other by not sharing their true thoughts and feelings (Arrington, 2005; Hawes et al., 2006). Boehmer and Clark (2001) conducted separate focus group interviews with prostate cancer patients with metastatic disease and their intimate partners. When patients were asked if changes in their loss of libido impacted their partners, patients responded by saying their partners had not said anything, therefore, they assumed the loss did not bother them. In this same study when wives were asked if they had discussed treatment-related changes with their husbands they responded by saying "…I don't want to bring up something, uh, I don't want to look for a problem." (p. 229)

Appraisal of Illness/Caregiving

According to the Modified Stress-Coping Model, when faced with a potential stressful situation, individuals appraise the situation. If the situation is appraised as threatening or harmful, resources are mobilized to cope. In prostate cancer patients, higher threat appraisal has been associated with poorer QOL. Green et al. (2002) found that patients who reported more threat pertaining to prostate cancer and its symptoms had more distress and decreased physical, role and social function. Conversely, lower threat was related to better health-related QOL.

Few studies in the prostate cancer population have included partners; however, among those that have, an association between appraisal of caregiving and QOL has been reported. In a study of prostate cancer patients and their spouses, use of positive

reappraisal was significantly correlated with decease general distress, while greater appraisal of illness uncertainty was significantly correlated with higher general and cancer-specific distress (Eton, Lepore, & Helgeson, 2005). Kershaw et al. (2008) found that appraisal mediated partners' self-efficacy and current concerns on mental QOL.

Coping

Although there are similarities between prostate cancer and other types of cancer, there remain unique aspects to prostate cancer which set this population apart. In particular those prostate cancer patients treated with ADT, which essentially causes chemical castration (Aucoin & Wassersug, 2006), results in the alteration of what is typified as male gender identity (Kiss & Meryn, 2001). A second unique aspect of ADT is that the treatment (e.g. daily pills, quarterly injections), unlike other types of cancer which require daily and weekly infusions, can go unnoticed and unseen by individuals that interact with patients. Coping with prostate cancer can be a challenge for all involved, yet, compared to breast cancer, far fewer studies have examined the variability in coping strategies utilized by advanced prostate cancer patients and their partners as they contend with the life changing aspects associated with the disease and its treatment with ADT.

Coping, as seen in the Modified Stress-Coping Model, is a key component of adapting to stressful situations. Ko et al. (2005) reported that greater use of avoidant coping by patients and partners was significantly negatively correlated with their own mental QOL. In the decision making phase of newly diagnosed prostate cancer, Gray and colleagues (1999) found that patients and partners utilized active coping (i.e. information seeking); however, after treatment decisions were reached, the use of information

seeking, stopped or was greatly reduced. A few studies have examined coping and partners of prostate cancer patients. Street and colleagues (2010) explored specific coping strategies of partners and found that among those that had poor adaptation avoidant coping was frequently utilized. The most frequent form of avoidant coping was distancing. This was seen in comments such as, "It really didn't have a big impact on me …it was his problem" and "I had to let him deal with it." (p. 239)

Quality of Life

QOL, an outcome of this study, is comprised of four domains of well-being: physical, functional, social and emotional (Zahn, 1992). Research has shown that overall QOL and its individual domains can be negatively affected by cancer, its treatments and treatment related side effects (Kershaw et al., 2008; Kornblith et al., 1994; Northouse et al., 2007). Additionally, research has established that there is a reciprocal relationship between the QOL of patients and the QOL of their partners (Banthia et al, 2003; Eton et al., 2005).

Research examining the QOL of advanced prostate cancer patients treated with ADT and their partners is growing, but in comparison to other types of cancer (e.g. breast cancer) or stages of prostate cancer (e.g. newly diagnosed), there is a considerable lag. Men with advanced prostate cancer are considered a vulnerable population as they are no longer considered curable; therefore, maximizing their QOL becomes a central focus. Furthermore, QOL has been shown to be a prognostic indicator of overall survival (Karvonen-Gutierrez et al., 2008; Movsas et al., 2009).

It is apparent from this literature review that self-efficacy, symptom distress, communication, appraisal of illness/caregiving and coping are important components of dyadic prostate cancer QOL research. However, there is a dearth of research examining

these variables in the advanced prostate cancer population. To this end, further psychosocial research pertinent to advance prostate cancer patients treated with ADT and their partners is needed. To address the gaps in the literature relevant to the study population this paper will focus on the following aims: 1) describe the levels of self-efficacy, symptom distress, communication, appraisal of illness/caregiving, coping and QOL in advanced prostate cancer patients treated with ADT and their partners and 2) determine if there are differences between patients and partners responses to the illness and its treatment.

METHODS

Design

Secondary analysis was conducted using data from two National Cancer Institute sponsored randomized clinical trials (RCTs). One study was conducted with prostate cancer patients and their partners in different phases of the disease (R01 CA-90739). The other study was a family-based intervention study of advanced cancer patients (i.e. breast, colorectal, lung and prostate) and their family caregivers (R01 CA-107383). The present study utilized only patients from the two prior studies who had advanced prostate cancer treated with ADT and their partners (N = 75, patient-caregiver dyads). The sample is comprised of 52 dyads from the first RCT and 23 dyads from the second RCT. A descriptive design was utilized for this secondary analysis; data were collected from baseline measures in both studies to eliminate any effects of the intervention on the variables assessed in this study.

Criteria for study inclusion was as follows: patients had to be at least 30 years old, speak English, live within 75 mile radius of one of the participating research sites, have

been diagnosed with advanced prostate cancer (metastatic disease or biochemical recurrence, post-primary treatment) within the last six months and currently being treated with ADT. Partners had to be identified by the patient as their primary source of emotional and physical care, at least 21 years old, speak English, no diagnosis of cancer within the past year or current cancer treatment and willing to participate. This secondary analysis was approved by the Institutional Review Boards of the University of Michigan and the participating cancer centers.

Sample

The sample (Table 3.1) was comprised of men diagnosed with prostate cancer (n = 75) and the individual they identified as their primary source of emotional and physical support, most often their life partners (n = 75; all partners in this analysis were women). All patients, in the previous six months, had either progression of their disease (n = 66) or a new diagnosis of advanced prostate cancer (n = 9). The majority of the men, 99% (n = 74), were receiving continuous ADT, only one patient was receiving intermittent ADT.

Normative Sample

Holzner et al. (2004) investigated a sample of 968 people in a random selection of the Austrian population aged 18 and older using a German version of the FACT-G (version 6). The aims of the study were to provide normative data on the FACT-G, to investigate the impact of sociodemographic variables on QOL and compare normative QOL scores with those of various groups of cancer patients. For the purpose of comparing normative data with the data set examined in this paper a subset (i.e. men and women $\geq$ 50 years of age), of the normative data was extracted to more closely resemble the gender and age of this studies data set.

Measures

Demographics and health information

Demographics were measured with the Omega Screening Questionnaire (OSQ), which assesses demographics, health history, current concerns and symptoms (Mood & Bickes, 1989). The demographic section addresses age, race, education and income. A medical history questionnaire assessed participants' health and co-morbidities.

Self-efficacy

Self-efficacy was measured using the 1996 a measure asking patients and partners how confident they are in managing their cancer and its treatments (Lewis, 1996). Total scores ranged from 17 to 170 with higher scores indicating greater self-efficacy. The original scale had an internal consistency alpha of .97 and content and criterion validity have been reported (Lewis). Reliability alphas ranged from .96 to .98 for patients and .91 to .98 for partners (Northouse et al., 2007; Northouse, 2011, under review). The reliability alphas for the current study were .97 for patients and .97 for partners.

Symptom distress

Symptom distress was measured with the Symptoms Scale section of the OSQ. This is a 16-item measure in which patients and partners each rated their own symptoms (e.g. pain, fatigue, sleeping problems, mental distress, sexual problems) as either *no trouble*, *some trouble* or *a lot of trouble*. Total scores ranged from 0 to 32 with higher scores indicating more symptom distress. The reliability alphas for the parent studies were .76 to .80 for patients and .76 to .83 for partners (Northouse et al., 2007; Northouse, 2011, under review). For the current study, reliability alphas were .73 and .70 for patients and partners, respectively.

Communication

Communication was measured with the 23-item Lewis Mutuality and Interpersonal Sensitivity Scale (MIS Scale). The MIS assesses the cancer patients' and their spouses' perception of illness–related communication (Lewis, 1996). The MIS is a 5-point Likert scale with responses ranging from 1 (never true) to 5 (always true). Summative scores range from 23 to 115 with higher scores indicating that the respondent perceives that there is more open cancer-related communication with their partner. Reliability alphas for the parent studies were .90 to .94 for patients and .91 to .93 for caregivers (Northouse et al., 2007; Northouse, 2011, under review). For the current study, reliability alphas were .92 for patients and .90 for partners.

Appraisal of illness/caregiving

Patients' appraisal of illness was assessed with the 32-item Appraisal of Illness Scale which measured the patients' perceived threat associated with the cancer (Oberst, 1999a). Their partners' perceived threat associated with caring for patients was measured with the 27-item Appraisal of Caregiving Scale (Oberst, 1999b). Factor analysis was conducted for both scales and for patients' Appraisal of Illness all components loaded on one factor. Partners' Appraisal of Caregiving results yielded a two factor solution: threat (13-items), and benefits (7-items). Seven items did not load on the partners scale, and the benefits scale was eliminated because it was found to have an unacceptable level of reliability (alpha = .52). Only the 13-item threat subscale was used. Total scores for patients ranged from 20 to 100 and for partners total scores ranged from 13 to 65. Higher scores on both scales indicated more negative appraisal. Means were determined by dividing total means by number of items. Alpha reliabilities for parent studies ranged from .90 to .94 for

patients and .89 to .91 for caregivers (Northouse et al., 2007, Northouse, 2011, under review). Alpha reliabilities for this study were .92 for patients and .86 for partners.

Coping

Coping strategies were assessed with the 28-item Brief Coping Orientations to Problems Experienced Scale (COPE) (Carver, 1997). The Brief COPE measures 14 coping strategies (2-items each) on a 4-point Likert scale. Respondents' choices range from 1 (not at all) to 4 (a lot). Factor analysis was conducted; two factors were specified in the procedure since there was a priori expectation. Previous factor analysis of the COPE scale indicated a two-factor solution; active and avoidant coping strategies (Northouse et al., 2007; Northouse, 2011, under review). Reliability alphas for these studies range from .60 to .87 for patients and .61 to .88 for partners. In the current study all items loaded on two factors, labeled as active and avoidant. However, 3-items in the patient's COPE scale and 6-items in the partner's COPE scale had loadings of less than .40. According to Nunnally and Bernstein (1994) items that do not reach the .40 criterion are considered small and should be interpreted cautiously, therefore, 3-items were removed from the patient scale and 6-items removed from the partner scale. On the subscale active cope, patients' total scores ranged from 15 to 60 and partners' total scores ranged from 12 to 48. On the subscale avoidant coping, patients' total scores ranged from 10 to 40 and partners total scores ranged from 10 to 40. Higher scores on subscales indicate more use of the specific coping strategy. Reliability alphas for the patient scale were .85 for the active subscale and .74 for the avoidant subscale. For the partner's scale, alphas were .81 for the active subscale and .64 for avoidant subscale.

Quality of life

The Functional Assessment of Cancer Therapy-General (FACT-G) was used to assess overall QOL of patients and partners (Cella et al., 1993). The FACT-G (version 4.0) has 27-items covering well-being in four subscales: physical, social/family, emotional, and functional. All four subscales can be summed for a total score or subscales can be scored individually. Total score ranges from 0 to 108 with higher scores indicating better overall QOL. Total scores ranged from 0 to 28 for three of the subscales (i.e. physical, social/family, functional) and for the subscale emotional well-being total scores ranged from 0 to 24. Higher scores on each subscale indicated better QOL in that domain. Reliability and validity of the FACT-G have been reported in other cancer populations (e.g. breast, colorectal, lung) (Cella et al., 1993; Dharma-Wardene et al., 2004; Northouse et al., 2007). Reliability alphas for the total FACT-G in the parent studies were .89 to .91 for patients and .90 to .92 for partners (Northouse et al., 2007; Northouse, 2011, under review). For the current study, total alphas were .90 for patients and .92 for partners, subscales for patients and partners ranged from .72 to .87.

Analysis

Data analysis was conducted utilizing SPSS (Version 17.0). Descriptive statistics were used to characterize the sample population and specific medical characteristics. Mean scores and standard deviations were conducted for each of the measures. Paired samples *t* test was used to assess differences between patients and partners on demographics, self-efficacy, symptom distress, communication, coping and QOL. Because patients' appraisal of illness and partners' appraisal of caregiving were measured with different instruments, they were not compared. Independent *t* test was used to assess

differences between patients and partners QOL and a normative sample of men and women without cancer.

RESULTS

Demographics and Co-morbidities

Demographics and medical characteristics are presented in Table 3.1 and 3.2. The average age of the patients was 67 +/- 9.5 (range, 47-90) and the average age of partners was 62 +/- 9.8 (range, 43-84). Patients were significantly older than partners, $t(74) = 7.03$, $p = .01$. Ninety-two percent of the dyads were married ($n = 69$), and 8% were living as married ($n = 6$). The majority of patients and partners were Caucasian (82.7%), while 17.3% were African American.

In the sample, 77.3% ($n = 58$) of the patients and 58.9% ($n = 43$) of partners had at least some college education and 65.3% ($n = 36$) of the patients and 38.4% ($n = 28$) of the partners had a four year degree or higher. Patients were significantly more educated than partners, $t(74) = 2.69$, $p = .01$. The majority 81.4% ($n = 57$, dyads) had an annual income ≥$30,001. Thirty-six percent of patients worked either full or part-time and 64% were retired. The majority of partners (40%) were retired, 38.7% were working either full or part-time and 21.3% were homemakers.

One hundred percent of patients and 77.3% of partners reported at least one other comorbidity (e.g. arthritis, back pain, heart disease, hypertension, diabetes). Thirty-two percent of patients ($n = 24$) and 4% of partners ($n = 4$) reported four or more other comorbidities health problems. The most frequently reported health problems for patients were: back problems, arthritis and hypertension; partners' most frequently reported health problems were: arthritis and hypertension.

Aim 1: Descriptions of study variables for patients and partners. Means are reported in Table 3.3. Self-efficacy means for patients and partners were above what would be considered neutral (i.e. 85), indicating that patients and partners had more confidence than lack of confidence in dealing with the cancer experience. Most patients (97.3%) and partners (98.7%) reported "no trouble" to "some trouble" with symptom distress. Patients reported the highest symptom distress for sexual problems followed by sleeping problems and then mental distress. Partners reported the highest symptom distress for sexual problems followed by mental distress and then sleeping problems.

Mean cancer-related communication scores for patients and partners suggest that patients and partners "sometimes" to "frequently" participated in open cancer-related communication - with each other. Appraisal (illness/caregiving) was assessed on a 1 to 5 scale, with 3 representing a neutral opinion and overall higher scores indicating more negative appraisal. Means indicate that patients and partners had more positive appraisal than negative. Means for coping indicated that patients and partners used a "little bit" to "a medium amount" of active coping strategies while their use of avoidant coping strategies was very close to "not at all". Overall patients and partners used more active coping strategies than avoidant coping strategies.

To describe patients' and partners' levels of QOL, means (Table 3.4) were converted to match the original 0 to 4 scale. Results showed that all patients QOL scores (i.e. total and subscales) had means between 3.0 and 3.41, indicating higher rather than a lower QOL. All, except two subscales for partners (i.e. emotional and social well-being), had means ranging from 3.0 to 3.56, again indicating a higher rather than a lower QOL. Two

QOL subscales for partners, emotional and social, had means between 2.7 and 2.93, indicating lower levels of emotional and social QOL.

Aim 2: Differences in patients and partners scores on study variables. A series of paired *t* tests (Tables 3.3 and 3.4) were used to compare patients' and partners' mean scores on the study variables. No significant difference was found between patients' and partners' levels of self-efficacy, symptom distress, communication and coping. There was a trend that approached a difference in their levels of self-efficacy ($p = .08$), with patients reporting a higher mean score than partners. Additionally, patients and partners each utilized significantly more active coping than avoidant coping, $t(74) = 16.09$, $p = .01$ and $t(74) = 14.79$, $p = .01$, respectively.

There was no significant difference in total QOL mean scores between patients and partners on the FACT-G, however, there was a trend toward significance ($p = .06$), with patients reporting a slightly higher QOL than partners. When comparing patients and partners mean scores on the FACT-G subscales, only one significant difference was found. Paired *t* test revealed a significant difference between patients and partners emotional well-being, $t(74) = 4.06$, $p = .01$, with patients having significantly higher emotional well-being than their partners.

Independent *t* tests were used to compare total QOL and subscales with a normative sample of men without cancer. Although no differences was found in their overall QOL scores, significant differences were reported in emotional $t(74) = -1.96$, $p \leq .05$, and social well-being $t(74) = 4.21$, $p \leq .05$, subscales. Mean score for men's emotional well-being in the comparison group was significantly higher than prostate cancer patients' scores. For the subscale social well-being, patients mean score was significantly higher

than the comparison group. There was a trend toward significance ($p = .06$) in the physical function with patients tending to report lower physical QOL than men without prostate cancer.

Independent *t* tests were used to compare partners with a normative sample of women without cancer. Results showed that no significant difference was found in total QOL but there was a significant difference found in three of four subscales (i.e. physical, emotional and social well-being). Partners of prostate cancer patients had significantly better physical, $t(74) = 2.82$, $p \leq .05$, and social well-being, $t(74) = 3.11$, $p \leq .05$, than the comparison group of women. Partners had significantly worse emotional well-being compared to the comparison group, $t(74) = 3.73$, $p \leq .05$.

DISCUSSION

This study examined demographics (i.e. age, education), self-efficacy, symptom distress, communication, appraisal of illness/caregiving, coping and QOL in advanced prostate cancer patients treated with ADT and their partners. Results indicated that patients and partners were more similar than different.

Demographics and Co-morbidities

Similar to other studies, patients were significantly older than partners (Campbell et al., 2004; Northouse et al., 2007). This difference in age may, in part, account for patients reporting more co-morbidities than partners as older persons generally report more chronic illness than younger persons (Pal & Hurria, 2010; Yancik, 1997), although women typically report more chronic conditions than men of the same age (Newman & Brach, 2001). Similar to other studies (Banthis et al., 2003; Northouse et al., 2007) the male patients had a higher level of education than their female partners.

Descriptive Findings

Self-efficacy.

Given that the side effects of advanced prostate cancer treated with ADT can be severe and life-altering and research suggests that many patients and partners struggle with these changes (Eton et al., 2005; Kornblith et al., 1994; Potosky et al., 2002; van Andel & Kurth, 2003), a surprising finding was that both patients and partners reported relatively high levels of self-efficacy. This may be because the majority of men gradually progressed to advanced disease, rather than being diagnosed with advanced disease, it is plausible that patients and partners may have already gained some degree of self-efficacy during earlier localized phase of illness.

Symptom distress.

Another surprising finding was that patients and partners both reported very low levels of symptom distress even though ADT can cause a number of potentially distressful adverse side effects (Decal et al., 2006). Though the instrument used to measure symptom distress (Symptom Scale) was generic rather than prostate-specific a number of issues relevant to ADT were assessed (e.g. fatigue, sleeping problems, mental distress, sexual problems, weight changes). However, there were a number of other potential symptoms it did not assess (e.g. genitalia changes, fat redistribution, breast tenderness, hot flashes, loss of body hair), which may have accounted for the lower than expected symptom scores. Consistent with other studies (Badr & Taylor, 2009; Kornblith et al., 1994), sexual concerns were the most commonly reported symptom by both patients and partners suggesting the need for related interventions. Future studies should also consider measures more sensitive to the impact of ADT, such as the Expanded

Prostate Cancer Index Composite that measures prostate-specific symptoms (Wei, Dunn, Litwin, Sandler, & Sanda, 2000).

Communication.

Studies suggest that the amount of open cancer-related communication between prostate cancer patients and partners is generally low following diagnosis and treatment decision making (Boehmer & Clark, 2001; Gray et al., 2000) and that low levels of cancer communication are associated with poorer outcomes (Manne et al., 2010). However, the means reported for open cancer-related communication by patients and partners in this study were higher than the lower levels of communication reported in the literature (Boehmer & Clark; Gray et al., 2000). Since all dyads in the study had either a progression of the cancer or a change in their treatment during the past six months, they may have had greater cancer-related communication to address further treatment decisions. Another explanation may be, that those dyads that agreed to participate in the original parent studies from which this current study population was drawn, may have been more open with their communication than those that declined the study resulting in a selection bias.

Appraisal of illness/caregiving.

A finding that was unexpected was that patients and partners reported lower levels of negative appraisal of the illness/caregiving. Few studies have examined appraisal in dyads with advanced prostate cancer, however, those that have suggest that patients and partners with advanced illness report more negative appraisal of the illness and caregiving when compared to dyads with localized prostate cancer (Northouse et al., 2007). An explanation for this divergence maybe that even though the majority of the

men had been living with advanced cancer, during the previous six months they had further progression of the disease. Therefore, it is possible that these patients and partners had had an extended period of time to adjust and accept their cancer, its treatment and limited prognosis. A second explanation may be related to the older age of patients and partners in this study. A number of studies suggest that age and past experience impact appraisal. For example Sharot and colleagues (2010) examined factors that were related to decreased averse responses to illness and found that peoples negative responses were decreased when they had previous exposure to the situation and second if they had made a choice to encounter the circumstances in the future. Therefore, as patients' disease progressed patients and partners may have carried over their previous experiences into their new situation, thus decreasing negative appraisal. Age and its accompanying experience may also provide patients and partners with a source of resiliency (Burke, Lowrance, & Perczek, 2003; Holland et al., 2009).

Coping.

It is interesting to note that results of this study indicated that both patients and partners used more active coping than avoidant coping (Table 3.3). Other studies have shown that the use of active coping strategies, for patients and partners is associated with lower levels of distress - therefore, the use of more active coping strategies than avoidant in this study's population would suggest a more positive way of dealing with the illness (Blanchard, Toseland & McCallion, 1996; Malinski, Heilemann, & McCorkle, 2002; Thornton & Perez, 2006). The higher use of active coping for patients and partners in this study may be related to their reported lower symptom distress. In other studies, couples

reporting more symptom distress also reported using more avoidant coping strategies (Badr & Taylor, 2009).

Quality of life.

When comparing patients and partners, clearly partners are at risk for poorer QOL, related to poorer emotional health; however, when patients and partners are compared to normative samples it becomes apparent that the risk of poorer emotional QOL extends to the patients too. Causality cannot be determined and it is possible that these results may not be related to ADT, however, the results may also suggest that advanced prostate cancer patients treated with ADT and their partners are in need of support programs to help them cope with the emotional challenges of the disease, its treatments and side effects. Further research is needed to establish causality.

Comparative Analysis of Patients' and Partners' Scores

Self-efficacy.

Although there was not a significant difference between patients' and partners' levels of self-efficacy, there was a trend toward significance. Patients reported more self-efficacy in managing disease-related symptoms and side effects than partners did in helping patients manage symptoms and side effects. Contrary to these results, a study by Campbell et al. (2004) found that partners of prostate cancer patients reported more self-efficacy. Differences between levels of patients' and partners' self-efficacy in the two studies may be attributed to time since diagnosis, current treatment and stage. In the Campbell et al. study the average time since completion of treatment was 17.9 months, while in this study patients had had a change in their treatment or progression of their disease within the previous six months and 100% of the patients were still actively

receiving ADT. A second consideration is stage of disease. In the Campbell study the majority of men had localized prostate cancer compared to all of the current studies sample population having advanced disease. Having advanced prostate cancer may add additional dimensions to disease management (e.g. mortality, emotional upheaval, increased symptoms related to metastatic disease) which could further challenge patients and partners perceptions of their own self-efficacy.

Symptom distress.

Patients with advanced prostate cancer treated with ADT experience a wide range of disease and treatment-related side effects which, according to the literature, can have a profound effect on their QOL (Dacal et al., 2006; Herr & O'Sullivan, 2000). Therefore, it would be expected that patients' level of symptom distress, in general, would be higher when compared to partners. However, the patients in this study reported relatively low symptom distress and there was no significant difference between patients and partners. This may be because a generic rather than prostate cancer-specific measure was used. Future QOL research may benefit from utilizing questionnaires which specifically assess the side effects commonly associated with ADT. Another explanation which might explain patients and partners rating their symptom distress similarly is that partners may not be taking care of their own health, therefore, experiencing levels of symptom distress close to the levels experienced by patients (Cliff & MacDonagh, 2000).

Communication.

No significant difference was found between patients' and partners' perceptions of cancer-related communication. These results are interesting because, contrary to the results of this study, cancer research suggests that partners have higher levels of cancer-

related communication (Gray et al., 2000; Harrison et al., 1995). In this study, though not significant, patients perceived having more illness-related communication than partners. This lack of difference may be explained by men having had a lower expectation for open communication. A second explanation for lack of differences may be related to the study population as few studies have concentrated on advanced prostate cancer patients treated with ADT and their partners and among those that have included this population none have examined dyadic communication needs and stage of disease, therefore, results of this study may be unique to the population. A third explanation may be that partners desire more cancer communication, but as supported in the literature, they avoid cancer related communication for fear of upsetting patients, instead they acquiesce to the patients' preference not to discuss the illness. The questionnaire utilized in this study (MIS) may have assessed current level of communication, but not the adequacy and specific nature (helpful or harmful communication) of that communication (Manne et al., 2010). Future studies may benefit from ascertaining whether or not partners feel that their level of dyadic cancer communication is adequate and if it meets their own psychosocial needs. Additionally, future studies will profit by examining the benefits and harms associated with the use of specific types of communication.

Appraisal of illness/caregiving.

Since different instruments were used to measure appraisal of illness and caregiving, between patients and partners, no comparisons could be made. However, patients means from this study were compared with means reported by advanced breast cancer patients (Northouse et al., 2005) and suggested that advanced prostate cancer patients treated with ADT have less negative appraisal of the illness than do advanced breast cancer patients.

This divergence may be a factor of age, gender and type of disease. In the breast cancer study patients were younger females and it has been reported by other investigators that older cancer patients report less negative appraisal of their illness than younger patients (Harden et al., 2008). Furthermore, it has been suggested that female patients often manage many roles, thus experiencing greater disruption in their daily lives, which may contribute to a more negative appraisal of their cancer (Northouse et al., 2000).

The mean for partners' appraisal of caregiving in this study was very similar to the means reported in a study of family caregivers (62% husbands) of breast cancer patients (Northouse et al., 2005). It was somewhat surprising that a divergence in means was not found in these two study populations since a difference was found when comparing appraisal of illness of patients in the same studies.

Coping.

Though there was no significant difference between levels of patients and partners use of coping strategies, there was, however, a significant difference between patients and partners individual use of specific coping strategies (i.e. active vs. avoidant). Both patients and partners utilized significantly more active coping than avoidant coping. In studies of general cancer and a few specific to prostate cancer, greater use of active coping strategies has been associated with better QOL for patients (Ko et al., 2005) and partners (Eton et al., 2005). Similarities in findings for patients and partners suggest that, in this population, dyads may be more alike than different in their use of coping strategies. This may well be related to length of marriage and a melding of individual coping strategies over time.

Because of the unique nature of the physical and psychosocial problems experienced by advanced prostate cancer patients treated with ADT and their partners further studies to assess the relationships between specific coping strategies and QOL outcomes would provide further insight into the needs of this population. Gaining a better understanding of other strategies advanced prostate cancer patients treated with ADT and partners utilize to cope with the stress of the disease and its treatments will advance intervention research to promote psychosocial well-being for this population.

Quality of life.

Results of *t* tests for the outcome variable QOL, indicated that, though there was no significant difference detected between patients' and their partners' total QOL mean scores, there was a trend toward significance. Of the four domains of QOL (i.e. physical, emotional, functional and social) a significant difference in patients' and partners' means scores was evident on only one domain, emotional well-being. This finding is consistent with the literature as previous studies have shown that partners of prostate cancer patients are often more psychologically distressed than patients (Cliff & MacDonagh, 2000; Couper et al., 2006; Kornblith et al., 1994). Differences between prostate cancer patients' and partners' emotional QOL may be explained by partners' tendency to internalize their feelings rather than discuss them with the husbands. Other studies suggest that prostate cancer patients frequently avoid discussing difficult issues related to the cancer which further increases their partners' emotional distress (Navon & Marag, 2003). Another explanation may be related to the tendency of some male cancer patients to minimize the emotional impact of the disease by maximizing their sense of overall control, thus denying or suppressing their own emotional distress, but heightening their partners

(Chapple & Ziebland, 2002). Finally, these results may reflect gender differences in vocal expression of emotions and emotional issues (Kornblith et al., 1994).

There was a trend toward patients' having a higher total QOL when compared to partners. This is a surprising finding, since it might be expected that patients would have reported worse QOL related to the disease, its treatment related side effects and the number of comorbidities reported by patients generally exceeding the number reported by partners. Additionally, contrary to expectations, when patients total QOL was compared to a normative sample, no significant difference was found. In line with the Stress-Coping theory results of this study could indicate that patients have achieved adaptation, by shifting their expected QOL so it more closely resembles their perceived QOL, while their partners may not have achieved this transition.

Two further QOL domains trended toward significance, physical and social well-being. Partners' reported better physical well-being than patients, and patients reported higher social well-being than partners. These findings are consistent with other cancer studies (Kim et al., 2008; Northouse et al., 2000).

Overall, it would appear that this studies sample of advanced prostate cancer patients on ADT and their partners have more self-efficacy, less symptom distress, more cancer-related communication, more positive appraisal and better total QOL then might be expected from the literature. There may be a number of general explanations for the divergence in these finding. First, patients and partners may actually be doing better than expected. Second, the sample in this study may not be a fair representation of the overall population. Sample biases may have occurred in the original studies, since patients and partners had the option to or not to participate in the studies, those patients and partners

experiencing more difficulties may have decided not to participate. Third, even though some studies suggests that older patients are more concerned with QOL than length of life (Kiebert et al., 1996; Voogt et al., 2005) the patients in this study may have been more willing to accept side effects in exchange for increased length of life. Fourth, age and resiliency may be contributing factors. Older persons typically have more life experiences which may make them more resilient to life challenges such as advanced prostate cancer, its treatments and side effects (Burke, Lowrance, & Perczek, 2003). Finally, the small sample size may have been too small to capture differences.

QOL and Clinical Significance

Translating QOL studies from research to practice requires differentiating between statistical significance and clinical significance. Norman and colleagues (2003) have demonstrated that approximately one-half of a standard deviation difference can serve as a proxy for ascertaining the minimally important difference for the FACT-G. Using one-half standard deviation (Table 3.4) as a cut of point for this study indicates that there was a clinically significant difference between patients' and partners' emotional QOL, with patients reporting better emotional well-being. This would emphasize that, in the clinical setting, not only should the patients' emotional QOL be assessed but also the partners. Furthermore, when interventions are designed particular attention should be directed toward partners.

LIMITATIONS

This study was a secondary analysis of data sets from two RCTs hence specific scales used to measure constructs were limited to those used in the two primary studies. Utilization of a prostate specific symptom scale would have strengthened this study.

Second, the sample size is small, and therefore, the study may not have had sufficient power to detect a difference between patients and partners for a number of the variables. Third, this study was cross-sectional and could not measure changes over time as could a longitudinal design. Despite these limitations, few studies have focused solely on comparing self-efficacy, symptom distress, communication, appraisal of illness/caregiving, coping strategies and QOL among advanced prostate cancer patients treated with ADT and their partners.

PRACTICE IMPLICATIONS

In spite of the limitations of this study, there are implications for clinicians and healthcare providers of advanced prostate cancer patients treated with ADT and their partners. The findings suggest that both patients and partners, but especially partners, are at risk for poorer emotional QOL and since research has shown that there is a reciprocal relationship between patients and partners QOL, clinicians and healthcare providers should be cognizant of the emotional needs of patients and partners. A second clinical implication of this study is that sexual problems are a major concern for patients and also their partners. These results suggest that clinicians and healthcare providers should assess and address the emotional and sexual needs of both patients and partners.

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Table 3.1

Demographic Characteristics (n = 75 dyads)

Variable	
Age, years	
Patient	
Mean (SD)	66.7 (9.5)
Partner	
Mean (SD)	62.4 (9.8)
Education, years	
Patient	
Mean (SD)	14.8 (2.7)
Partner	
Mean (SD)	14.2 (2.7)
Race, %	
Patient	
Caucasian	82.7
African American	17.3
Partner	
Caucasian	82.7
African American	17.3
Family Income, %	
< $5,000	2.7
$5,000-$15,000	5.3
$15,001-$30,000	9.3
$30,001-$50,000	22.7
$50,001-$75,000	14.7
>$75,001	38.7
Length of marriage, years	
Mean (SD)	36.0 (15.1)
Employment status, %	
Patient	
Full/Part-time	36
Retired	64
Partner	
Full/Part-time	39
Retired	40
Homemaker	21

Table 3.2

Medical Characteristics (n = 75 dyads)

Variable	
Other health problems, %	
Patient	
no health problems	0
1 health problem	100
2 health problems	76
3 health problems	52
4 or more health problems	32
Partner	
no health problems	22.7
1 health problem	77.3
2 health problems	53.3
3 health problems	22.7
4 or more health problems	4
Diagnosis at study enrollment, *n*	
Progression of disease	66
Newly diagnosed with metastatics disease	9

Table 3.3

Descriptive Data on Other Study Variables (n = 75 dyads)

	Patient			Partner			Matched *t*
Variables	*M*	(SD)	Range	*M*	(SD)	Range	F
Age (years)	66.70	(9.5)	47 - 90	62.40	(9.8)	43 - 84	7.86 *
Education (years)	15.00	(2.6)	9 - 20	14.20	(2.7)	9 - 22	2.69 *
Self-Efficacy	139.40	(26.3)	41.00 - 170.00	132.60	(29.2)	56.65 - 170.00	1.80
Symptom Distress	7.50	(4.0)	0.00 - 16.96	6.72	(4.0)	0.00 - 20.96	1.43
Communication	3.70	(.71)	1.43 - 4.96	3.50	(.63)	2.22 - 4.91	1.92
Appraisal Illness/Caregiving	2.60	(.91)	1.00 - 4.41	2.60	(.82)	1.00 - 4.58	0.54
Coping							
Active	33.60	(8.5)	15.00 - 52.95	25.30	(6.2)	12.96 - 42.96	1.04
Avoidant	11.70	(3.3)	10.00 - 26.70	11.70	(3.1)	10.00 - 23.33	0.18

* $P \leq .05$

Table 3.4

Descriptive Data on Quality of Life

	Patient		Partner		Matched *t*		Patient Comparative [a]		Two Sample Independent *t*		Partner Comparative [b]		Two Sample Independent *t*	
Variables	*M*	(SD)	*M*	(SD)	F		*M*	(SD)	*t*		*M*	(SD)	*t*	
Quality of Life - FACT-G														
Physical Well-Being	23.9	(4.4)	24.9	(3.0)	1.73	.09	24.9	(4.4)	-1.91	.06	23.9	(4.8)	2.82	*
Functional Well-Being	21.0	(5.7)	21.0	(5.1)	0.17	.87	21.1	(5.4)	-0.19	.85	19.8	(5.9)	1.81	.74
Emotional Well-Being	18.8	(4.6)	16.2	(5.6)	4.06	*	19.8	(4.4)	-1.96	*	18.3	(5.4)	-3.73	*
Social Well-Being	21.8	(5.0)	20.5	(5.3)	1.67	.09	19.3	(6.1)	4.21	*	18.6	(6.6)	3.11	*
FACT-G Total	85.4	(15.1)	82.0	(14.8)	1.88	.06	85.5	(15.1)	-0.06	-.06	80.7	(18.2)	0.75	.46

NOTE: Matched *t* compares patients' and partners' scores; two-sample independent *t* compares patients' and historical control group scores and partners' and historical control group scores.

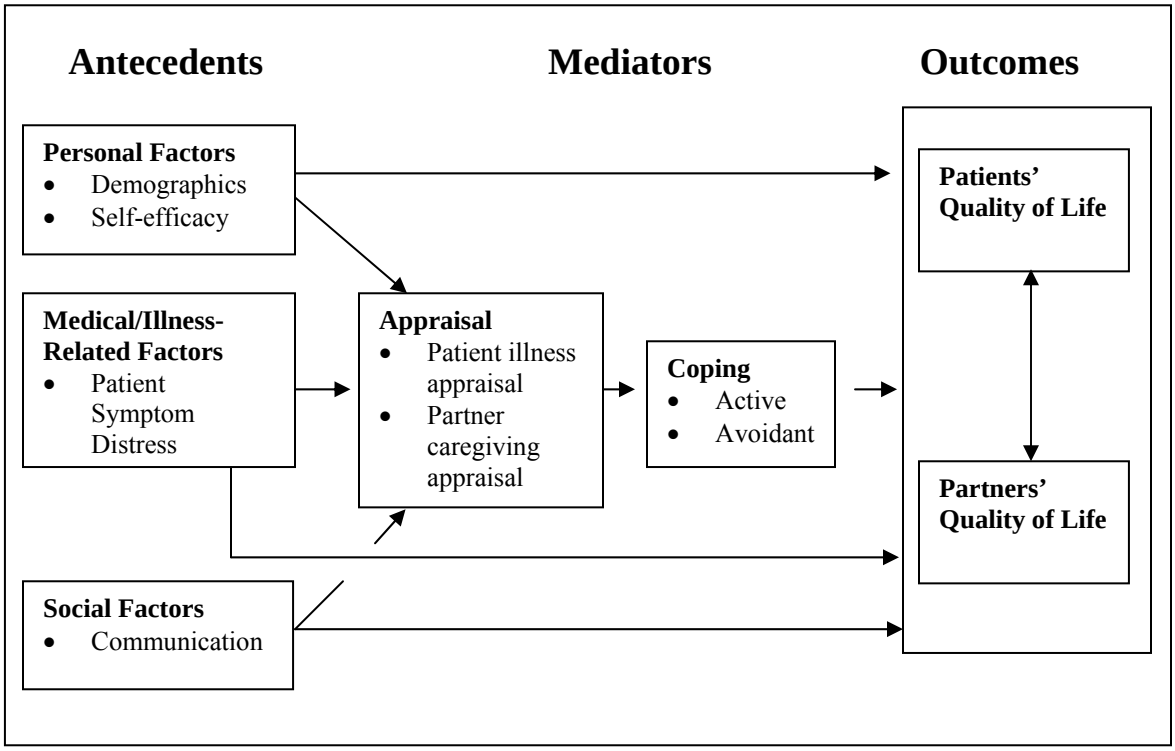
* $P \leq .05$

[a] Sample of 230 men without cancer, age 50 and older, 78.7% described themselves as healthy, 13.4% described themselves as mildly chronically ill and 7.9% described themselves as severely chronically ill (Holzner et al., 2004).

[b] Sample of 200 women without cancer, age 50 and older, 81.4% described themselves as healthy, 10.7% described themselves as mildly chronically ill and 7.8% described themselves as severely chronically ill (Holzner et al., 2004).

Figure 3.1

The Modified Stress-Coping Model



CHAPTER IV

PREDICTORS OF QUALITY OF LIFE IN ADVANCED PROSTATE CANCER PATIENTS TREATED WITH ANDROGEN DEPRIVATION THERAPY AND THEIR PARTNERS: TESTING OF THE STRESS-COPING MODEL

INTRODUCTION

Cancer of the prostate is the most common noncutaneous cancer diagnosed in men in the United States. It is estimated that over 240,890 men were diagnosed with the disease in 2011 (Siegel, Ward, Brawley, & Jemal, 2011). Sixteen percent, almost 35,000, of these men were diagnosed with advanced disease (Altekruse et al., 2010; Cooperberg, Lubeck, Meng, Mehta, & Carroll, 2004). Advanced prostate cancer is generally not considered curable, thus treatment is palliative and the objective is to prolong life while maximizing the quality of that life. Androgen deprivation therapy (ADT) is the foundation of this treatment; however, a number of adverse side effects are associated with ADT (e.g. loss of libido, erectile dysfunction, hot flashes, body changes, fatigue, emotional andcognitive changes, osteoporosis, diabetes and metabolic syndrome) (Higano, 2006; Holzbeierlein, 2006; Kabir, Mancuso, & Rashid, 2008; Potosky, et al., 2002). For advanced prostate cancer patients and their partners, these side effects are known to impact a number of quality of life (QOL) domains including physical, emotional, functional and sexual (Alibhai, Gogov, & Allibhai, 2006). Research indicates that some patients and their

partners appear to manage these side effects without major changes to their lives, while others can be overwhelmed and experience levels of stress beyond their coping capacities which can lead to poorer QOL. Few studies have examined what factors are related to the QOL of men on ADT and their partners. Therefore, guided by a stress-coping model, the purpose of this study was to: 1) determine if specific antecedent factors (self-efficacy, symptom distress, communication, partners' QOL), and mediators (appraisal of illness, coping) explain a significant amount of variance in the QOL of the advanced prostate cancer patients treated with ADT, and 2) determine if specific antecedent factors (self-efficacy, symptom distress, communication, patients' QOL), and mediators (appraisal of caregiving, coping) explain a significant amount of variance in the QOL of the partners of advanced prostate cancer patients treated with ADT.

To address the first aim: It is hypothesized that, in this sample of advanced cancer patients treated with ADT, specific antecedent factors (self-efficacy, symptom distress, communication, and partners' QOL) will influenced specific mediators (appraisal of illness and coping strategies) and these antecedents and mediators will explain a significant amount of the variance in patients' QOL. To address the second aim: It is hypothesized that, in this sample of partners of advanced prostate cancer treated with ADT, specific antecedent factors (self-efficacy, symptom distress, communication, and patients' QOL) will influenced specific mediators (appraisal of caregiving and coping strategies) and these antecedents and mediators will explain a significant amount of variance in partners' QOL.

CONCEPTUAL MODEL

The Modified Stress-Coping Model was used to guide this study (Northouse et al.,

2002). This model is a synthesis of key components from two well-utilized stress and coping models: the Transactional Model of Stress and Coping (TMSC) (Lazarus & Folkman, 1984) and the Resiliency Model of Family Stress, Adjustment and Adaptation (McCubbin & McCubbin, 1993). The major premise for the TMSC and the Resiliency Model is that stressors are demands made by the internal and/or external environment; these demands can upset life's balance and, therefore, disrupt physical and psychological well-being (Lazarus & Cohen, 1977; McCubbin & McCubbin, 1993). The desired outcome of both models is adaptation or well-being. The major difference between the two models is that the TMSC is from the perspective of the individual while the Resiliency Model is from a family perspective. Underlying assumptions for both models are that when an individual or family is faced with a stressful situation they appraise the stressor, and if it is perceived as a threat, the individual/family utilizes specific coping strategies to regulate the stressor.

There are three major components to the Modified Stress-Coping Model: antecedent factors, mediators and outcomes. According to the model, appraisal and coping partially mediates the relationship between antecedent factors and the outcomes. In addition, each partners' QOL has an effect on the other person's QOL (Figure 4.1).

LITERATURE REVIEW

Antecedents

A number of general and prostate specific cancer studies support the choice of variables and their placement in the Modified Stress-Coping Model. Studies, primarily cross-sectional, of prostate cancer patients indicate that poorer QOL is reported by older men (Shabbir et al., 2010), African American men (Litwin, McGuigan, Shpall, &

Dhanani, 1999), men with advanced disease (Rosenfeld, Roth, Gandhi, & Penson, 2004), and men with multiple comorbidities (Dacal, Sereika, & Greenspan, 2006). Some studies suggest that less education is associated with poorer QOL (Caramack-Taylor et al., 2004) while others found that less education is related to greater QOL (Brar, Maliski, Kwan, Krupski, & Litwin, 2005). Few studies have addressed the partners of prostate cancer patients, however, studies of other types of cancer indicate that younger partners, when compared to older partners, experience worse emotional QOL (Nijboer et al., 2000), but better physical QOL (Bergelt, Koch, & Petersen, 2008; Kershaw et al., 2008).

Self-efficacy (Bandura, 1977) refers to an individual's "judgments of their capabilities to execute given levels of performance and to exercise control over events." (p. 563) In the context of cancer, studies show that self-efficacy plays an important role in health outcomes (Beckham, Burker, Lytle, Feldman, & Costakis, 1997; Campbell et al., 2007). Patients with more perceived self-efficacy for managing the disease and its treatment related sequelae are better able to adapt (Porter et al., 2002), report less depression (Weber et al., 2004), less anxiety and better QOL (Campbell et al., 2004). Partners with more self-efficacy for helping patients manage side effects reported less strain and more positive moods (Keefe et al., 2003), and better emotional QOL (Offerman, Schroevers, van der Velden, de Boer, & Pruyn, 2010) and overall QOL (Campbell et al., 2004).

Studies suggest that higher symptom distress in prostate cancer patients treated with ADT has been associated with poorer QOL. Dacal et al. (2006) found that prostate cancer patients with more body fat and less muscle mass reported worse role function, while a study by Fowler and colleagues (2002) showed that prostate cancer patients with less

energy and more body image concerns reported significantly worse emotional QOL. Fewer studies have included partners; however, among those that have, there appears to be a relationship between patients' symptoms and partners QOL. Kornblith and colleagues (1994) found that as the number of symptoms experienced by prostate cancer patients increased partners' level of distress and decreased their QOL.

Research shows that greater utilization of open cancer-related communication is associated with less distress, less caregiver burden and higher levels of dyadic empathy, intimacy and better overall well-being (Badr & Taylor, 2009; Manne, Badr, Zaider, Nelson, & Kissane, 2010; Porter, Keefe, Hurwitz, & Faber, 2005; Song et al., 2011). However, a number of studies suggest that prostate cancer patients and their partners limit their communication about the disease, its treatments and treatment sequelae (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). Many of the side effects of treatment, in particularly ADT, are often perceived as emasculating and/or embarrassing by patients and therefore, they are often reluctant to openly talk with others, including their partners, about the disease and its side effects (Harrington & Badger, 2009). Partners, in turn, are also reluctant to broach these subjects with patients for fear of upsetting them or implying that they, the partners, are dissatisfied with some aspect of the disease, its treatments or outcomes (Gray et al., 2000; Northouse et al., 2002).

Mediators

According to the Modified Stress-Coping Model there are two mediators that influence QOL: appraisal and coping (Ben-Tovim, Dougherty, Stapleton, & Pinnock, 2002; Green, Pakenham, Headley, & Gardiner, 2002; Kershaw et al., 2008; Northouse, Mood, Templin, Mellon, & George, 2000). In colon cancer patients' appraisal (assessed

with hopelessness and uncertainty) was shown to be significantly related to role adjustment (Northouse, Mood, Templin, Mellon, & George, 2000). A few studies of prostate cancer patients and partners indicated that more negative appraisal of the illness by patients was associated with poorer physical and social QOL (Green et al.; Kershaw et al.), while more negative appraisal of caregiving by partners was associated with poorer mental QOL (Bowman, Rose, & Deimling, 2006; Kershaw et al.).

There is a large body of research examining coping with chronic disease, however; there is limited research in the coping patterns of prostate cancer patients (Ben-Tovim et al., 2002; Kershaw et al., 2008). A study by Ben-Tovim et al. found that patients utilizing more positive problem-solving (active coping) had significantly more optimism and better physical and over-all QOL, and less anxiety and depression. A longitudinal analysis, by Kershaw and colleagues, of predictor variables, and mediators (appraisal and coping) on QOL found that, in patients, greater use of active coping strategies was significantly associated to better mental QOL. Also in patients, greater use of avoidant coping strategies was significantly associated with poorer mental QOL.

From the few studies that have been conducted on the use of coping strategies and their impact on the QOL of partners of prostate cancer patients, it is apparent that maladaptive strategies can have a negative impact on partners. A small number of studies indicated that more use of avoidant and dysfunctional coping strategies was significantly correlated with greater levels of psychological distress and poorer mental QOL (Couper et al., 2009, Ko et al., 2005). Interestingly, both of the preceding studies also assessed active or constructive problem solving, but for partners, there was no significant relationship with QOL. However, Ko and colleagues found a significant relationship

between partners use of constructive coping (active coping) and patients level of distress. More use of constructive coping by partners was significantly correlated to a decrease in patients' distress.

Outcomes

Patients' and partners' QOL were the outcome variables of this study. There are a limited number of studies that focus on advanced prostate cancer patients and their partners' QOL (Green et al., 2002; Kornblith, Herr, Ofman, Scher & Holland, 1994; Northouse et al., 2007; Sneeuw, Albertsen, & Aaronson, 2001). However, existing studies comparing the QOL of men with prostate cancer treated with different treatment modalities have shown that men receiving ADT reported overall worse QOL (van Andel & Kurth, 2003), and poorer QOL in the following domains: physical (Herr & O'Sullivan, 2000), social (Green et al., 2002), functional (Potosky et al., 2002) and emotional well-being (Herr & O'Sullivan, 2000). Few studies have examined the QOL of partners of advanced prostate cancer patients treated with ADT, and those which have are primarily of qualitative design (Boehmer & Clark, 2001; Campbell et al., 2004; Heyman & Rosner, 1996; Navon & Morag, 2003; Kornblith et al., 2001). These studies suggest partners report struggles with emotional (Heyman & Rosner, 1996), sexual and functional well-being (Navon & Morag, 2003).

In summary, while there are studies examining predictors of QOL in cancer patients, few have concentrated on advanced prostate cancer patients and even fewer have focused on specific treatment modalities such as ADT. Additionally, few studies have examined QOL predictors of the partners of advanced cancer patients.

METHODS

Design

This study was a secondary data analysis of two National Cancer Institute sponsored randomized clinical trials (RCT) examining the effects of a family-based intervention designed to improve the QOL of life of cancer patients and their partners. The first parent study (R01 CA-90739) focused on prostate cancer patients in different phases of the disease and their family caregivers. The second parent study (R01 CA-107383), focused on advanced breast, colorectal, lung and prostate cancer patients and their family caregivers. A descriptive correlational design was utilized; data were collected from baseline measures prior to study randomization, to eliminate any possible effects of the intervention on this study's variables.

Sample and Setting

This study utilized only men, from the aforementioned two RCT's, with advanced prostate cancer (biochemical recurrence or metastatic disease) treated with ADT and their partners; 52 dyads were from the first parent study and 23 dyads were from the second parent study yielding a total of 75 dyads. Inclusion criterion were those patients that: where at least 30 years old, speak English, lived within 75 miles of one of the participating research sites (University of Michigan Comprehensive Cancer Care; Karmanos Cancer Institute; St. Joseph Mercy Hospital, and St. John Providence Hospital), and had a diagnosis of advanced prostate cancer or progression to advanced prostate cancer within the last six months and currently receiving ADT. Inclusion criteria for partners was as follows: identified by the patient as their primary source of emotional and physical care, at least 21 years old, speak English, did not have a diagnosis of cancer

within the past year and were not currently receiving cancer treatment. These secondary analyses were approved by the University of Michigan Institutional Review Board and the participating cancer centers.

The sample (Table 4.1) for the current study consisted of men (n = 75) with advanced prostate cancer (metastatic or biochemical recurrence) receiving hormonal treatment (i.e. luteinizing hormone-releasing hormone agonists, anti-androgens) and the individual (n = 75) they identified as their primary source of emotional and physical support. All of the patients during the previous six months, had either been diagnosed with advance prostate cancer or had progression of their disease. Ninety-nine percent of the men (n = 74) were receiving continuous ADT and $\geq$ 1% (n = 1) were receiving intermittent ADT.

Measures

Antecedents.

Personal factors (i.e. age, race, marital status, education and income) and health history (i.e. comorbidities) were assessed with the Omega Screening Questionnaire (OSQ) (Mood & Bickes, 1989). Patients and partners each filled out this questionnaire during the initial data collection session of both parent studies.

Self-efficacy was assessed with the 17-item modified Lewis Cancer Self-Efficacy Scale (CASE) (Lewis, 1996). This measure assesses patients and partners confidence in managing the effects of the cancer. Total scores range from 0 to 170, with higher scores indicating higher levels of confidence. Internal consistency alpha for the original scale was .97 (Lewis, 1996). Reliability alphas for the parents' studies range from .96 to .98 for patients scale and .91 to .98 for partners scale (Northouse et al., 2007; Northouse, 2011, under review).

Symptom distress for patients and partners was assessed with the Symptoms Scale of the OSQ (Mood & Bickes, 1989). Patients and partners each rated the degree to which they were experiencing 16 symptoms (e.g. pain, fatigue, sleeping and sexual problems). Total scores range from 0 to 32, with higher scores indicating greater symptom distress. For the parent studies reliability alphas ranged from .76 to .80 for patients and .76 to .83 for partners (Northouse et al., 2007; Northouse, 2011, under review).

The 23-item Lewis Mutuality and Interpersonal Sensitivity Scale (MIS Scale) was used to assess patients' and partners' perceptions of dyadic cancer–related communication (Lewis, 1996). Total scores range from 23 to 115, with higher scores indicating more open cancer communication. The parent studies reported reliability alphas ranging from .90 to .94 for patients and .91 to .93 for partners (Northouse et al., 2007; Northouse, 2011, under review).

Mediators.

Patients' appraisal of illness was assessed with the 32-item Appraisal of Illness Scale (Oberst, 1999a) and partners' perceived threat related to caring for patient was assessed the 27-item Appraisal of Caregiving Scale (Oberst, 1999b). Factor analysis was conducted with both scales. Results indicated that for the patient scale (i.e. appraisal of illness) all components loaded on one factor. A two-factor solution: threat (13 items), and benefits (7-items), was found for the partners' scale. Seven items did not load and the benefits subscale (7-items) and it had an unacceptable level of reliability (alpha = .52) and therefore, was eliminated. Only the 13-item threat subscale was used for partners while the full 32-item scale was used for patients. Total score for the patients' scale ranged from 32 to 160 and for the partners' scale the range was 13 to 65, for both scales

higher scores indicated more negative appraisal. Alpha reliabilities in the parent studies were .90 to .94 for patients and .89 to .91 for partners (Northouse et al., 2007; Northouse, 2011, under review).

Coping strategies were assessed with the 28-item Brief Coping Orientations to Problems Experienced Scale (COPE) (Carver, 1997). The Brief COPE measures patients and partners use of 14 coping strategies. Factor analysis was conducted; two factors (i.e. active and avoidant) were specified in the analysis as there was an a priori expectation. Previous factor analysis by Northouse et al. (2005) indicated a two-factor solution: active coping and avoidant coping strategies. Total scores ranged from 28 to 112, with higher scores on subscales indicating more use of that specific coping strategy based on how many items used (as some were eliminated). Reliabilities alphas for the parent studies ranged from .80 to .87 (active) and .60 to .78 (avoidant) for patients, and for partners .80 to .88 (active) and .61 to .78 (avoidant) (Northouse et al., 2007; Northouse, 2011, under review).

Outcomes.

Patients' QOL was assessed with the Functional Assessment of Cancer Therapy-General scale (FACT-G; version 4; Cella, 2010) and partners QOL was measured with a modified version of the FACT-G. The 27-item FACT-G measures overall QOL and its four subscales (i.e. physical, emotional, functional and social) (Cella et al., 1993). Total overall scores for the FACT-G range from 0 to 108, with higher scores indicating better QOL. The FACT-G has been validated in many types of cancer. In the parent study the FACT-G's reliability alphas for overall QOL ranged from .89 to .91 for patients and .90 to .92 for partners (Northouse et al., 2007; Northouse, 2011, under review).

Analysis

SPSS (version 17) was used for all analyses. Descriptive statistics (e.g. means and frequencies) were computed for all variables. Error variances were computed as follows: error variance equals one minus the reliability of each scale multiplied by the observed variance of each scale (i.e. error variance = [1 – reliability] x observed variance).

To assess for the significance of the indirect effects (i.e. mediator effects) in each model (patients and partners), bootstrapping was utilized. Bootstrapping is a statistical method of analysis which involves repeated sampling generated from a given sample (e.g. this study used 2,000 bootstrap samples for each model) (Preacher & Hayes, 2004). Results suggest that if zero is not part of the 95% confidence interval for the estimates then there is a significant mediation effect (Preacher & Hayes).

To assess the models function to predict the QOL of advanced prostate cancer patients treated with ADT and their partners, structural equation models (SEM) were estimated using SPSS AMOS (version 17). Correlation matrix and maximum likelihood estimations were used to assess both patient and partner models. Goodness of fit, for each model, was assessed using the following fit indices: 1) the chi-square (χ^2), 2) goodness-of-fit index (GFI), 3) comparative fit index (CFI), and 4) the root mean square error of approximation (RMSEA). Chi-square is a reasonable measure of fit for models with less than 200 cases (Kenny, 2010). The chi-square goodness-of-fit index reflects the difference between the observed correlations matrix derived from the data and that predicted by the model. A small and nonsignificant chi-square value indicates a good fit (Byrne, 2010). The chi-square test is sensitive to sample size, with smaller samples ($N <$ 100) nonsignificant probabilities are frequently seen, thus there is an increased risk of

Type II error (i.e. low power to detect statistically significant differences between observed and predicted correlation matrix). Therefore, additional goodness-of-fit indices were used to assess the models (Schumacker & Lomax, 2010). GFI is the percentage of the observed correlations explained by the correlations implied by the model. Values closer to 1.00 are indicative of a good model fit (Byrne, 2010). The CFI is derived from a comparison of the hypothesized model with the independence (null) model, which assumes that the variables are uncorrelated (Byrne, 2010). Values near .95 represent a good-fitting model (Hu & Bentler, 1999). The RMSEA was also used, which evaluated the 'residual' correlations (i.e. what is the magnitude of deviations between the observes and predicted correlation index). RMSEA is sensitive to the complexity of a model. A desirable RMSEA value is $\leq$.05, indicating a good fit, to as high as .08, indicating a fair fit (Byrne, 2010). A RMSEA value of 0 would indicate that the model perfectly explains the observed correlations.

RESULTS

Demographic and Medical Characteristics

The analysis was completed on 75 advanced prostate cancer patients treated with ADT and 75 partners. Demographic and medical characteristics of patients and partners are shown in Table 4.1. Patients ranged in age from 47 to 90 years with a mean of 67 years. Partners' age ranged from 43 to 84 years with a mean of 62 years. Eighty-three percent were Caucasian and 17% African American. A total of 92% of patients and partners were married, 4% were living as married, 2.7% were divorced or separated and 1.3% were widowed. The majority of participants (68%) had some college education, and 76% had an annual household income of over $30,000. More than 50% of patients had at

least three co-morbidities, while 50% of partners had at least two co-morbidities. None of the demographic or co-morbidity variables considered were significantly correlated with the outcome measures (QOL); thus, they were not included in the analysis. There was no significant difference between the means of the QOL of the dyads in which the patients were receiving continuous ADT compared to the one dyad in which the patient was receiving intermittent ADT.

Mediation

Results indicated that both the patients' and partners' models were partially mediated by appraisal and avoidant coping (Table 4.2). In the patient model (Figure 4.2) appraisal of illness and avoidant coping mediated the effects of self-efficacy and patients' symptom distress on patients' QOL. In the partner model (Figure 4.3) appraisal of caregiving and avoidant coping mediated the effects of self-efficacy and patients' symptoms on partners' QOL.

Patient Quality of Life

Two patient models were computed; the first model included all the patients' variables and partners' QOL as seen in Figure 4.1. This initial model had a less than adequate fit ($\chi^2 = 24.531$, $p = .011$, $df = 11$, RMSEA = .129, 90% CI = .059 -.198, GFI = .936, CFI = .936). The path from active coping to QOL was not significant; therefore, this path and the path from appraisal to active coping were removed from the model. The removal of these paths (Figure 4.2) resulted in a very good model fit ($\chi^2 = 5.1$, $p = .54$, $df = 6$, RMSEA = .000, 90% CI = .000 - .140, GFI = .98, CFI = 1.00). Modification indices did not indicate the need to add any additional paths.

The final model accounts for 66% of patients' variance in appraisal, 33% of avoidant coping and 89% of the variance in patients' QOL. Patients with lower self-efficacy (ß=-.44) and more symptom distress (ß=.53) reported more negative appraisal of the cancer. Patients with more negative appraisal of their cancer reported using more avoidant coping strategies (ß= .57). Furthermore, patients with more self-efficacy (ß=.26), more cancer-related communication (ß=.24), less symptom distress (ß=-.31), and less use of avoidant coping (ß= -.38) had higher QOL. Patients also reported a better QOL if their partners reported a higher QOL (ß=.16). No significant indirect effect was found between communication and appraisal of illness.

Partner Quality of Life

Three partner models were computed; the first model included all the partners' variables and two patients' variables (i.e. patients' QOL and patients' symptom distress) as seen in Figure 4.1. The initial model was a fair fit (χ^2 = 13.437, p = .266, df = 11, RMSEA = .055, 90% CI = .000 - .140, GFI = .94, CFI = .98). Two antecedents, (communication and patients' QOL) had no significant direct or indirect effect on partners' QOL so they were removed individually from the model. However, results indicated a less than adequate fit when communication was removed (χ^2 = 524.76, p = .000, df = 12, RMSEA = .76, 90% CI = .705 - .816, GFI = .91, CFI = .00), and when patients' QOL was removed (χ^2 = 533.97, p = .000, df = 11, RMSEA = .802, 90% CI = .744 - .860, GFI = .92, CFI = .00). Therefore, both antecedents were retained in the model. Next, the variance explained by active coping was low (ß=.08) so active coping and its corresponding paths were removed from the model. The model was rerun and the removal of active coping significantly improved the model fit (χ^2 = 6.9, p = .33, df = 6,

RMSEA = .045, 90% CI = .000 -.163, GFI = .97, CFI = .99). Finally, modification indices did not indicate the addition of any additional paths.

It is evident from the final model (Figure 4.3) that a small number of factors accounted for the variance in partners' QOL; however, these few factors contributed a large amount to the explained variance. Overall, the final model accounted for 37% of the variance in partners' appraisal of caregiving, 33% of the variance in avoidant coping and 74% of the variance in partners' QOL. Partners with less self-efficacy (*ß*=-.55) reported more negative appraisal of their role as caregiver. Additionally, partners who perceived patients as having more symptom distress (*ß*=.30) reported more negative appraisal of the illness. Partners with more negative appraisal of the patients' cancer used more avoidant coping strategies (*ß*=.60). Partners who used less avoidant coping had a better QOL (*ß*=-.57). No significant indirect effect was found between communication and partners' appraisal of caregiving. There were no significant direct effects for partners' self-efficacy and communication and patients' symptom distress and QOL on partners QOL.

DISCUSSION

Results of this study are important and contribute to the growing body of theory-driven knowledge regarding family-based psycho-social oncology research and provides support for the Modified Stress-Coping model examined in this study. The data is a good fit for the model, therefore, provided support for the study's hypotheses. The effects of specific antecedents on the QOL of advanced prostate cancer patients and partners were partially mediated by appraisal and coping. Results of this study indicate that, for patients, antecedents (self-efficacy, symptom distress, communication and partners' QOL) had both direct and indirect effects on their QOL (Figure 4.2). Self-efficacy,

patients' symptom distress, communication and partners' QOL all had a direct effect on patients' QOL. Self-efficacy and symptom distress also had in indirect effect on patients' QOL. Furthermore, patients with less self-efficacy, more symptom distress, more negative appraisal and greater use of avoidant coping had overall poorer QOL.

Results of SEM for the partners' model (Figure 4.3) indicated that two of the antecedents (i.e. self-efficacy and symptom distress) had an indirect effect on QOL, while communication and patients' QOL had no significant effect (direct or indirect) on partners' QOL. However, the paths for communication and patients' QOL were retained in the model for two reasons (1) the paths, though nonsignificant, are strongly supported in the literature (Hodges, Humphris, & Macfarlane, 2005; Ko et al., 2005; Kornblith et al., 1994; Manne et al., 2010) and (2) SEM indicated that the fit of the model, without these paths, is worse (i.e. decreased from .74 to .65). The significant pathways in the model indicated that partners who reported less self-efficacy, more negative appraisal of caregiving and utilized more avoidant coping reported poorer overall QOL.

The models examined in this study predicted a large percentage of the variance in the QOL of advanced prostate cancer patients and their partners (89% and 74%, respectively [see Appendix for further explanation]). Similar variances were found in a QOL study of women with recurrent breast cancer and their family caregivers (Northouse et al., 2002). QOL variances in the Northouse et al study ranged from 72% to 81%. Additionally, the Northouse et al study and the current study utilized a number of the same antecedent and mediator variables (e.g. self-efficacy, symptom distress, and appraisal of illness/caregiving). Results of the current study would suggest that the antecedents and

mediators identified are important variables when examining the complex nature of QOL in patients and partners.

In both patients' and partners' model self-efficacy was a very strong predictor, directly and/or indirectly, of QOL. Patients and partners with less self-efficacy experienced more negative appraisal and patients with less self-efficacy had lower QOL. These finding are consistent with the research of others who have found that patients and partners reporting less self-efficacy report poorer QOL and those reporting more self-efficacy report better QOL (Campbell et al., 2004; Eton, Lepore & Helgeson, 2001; Keefe et al., 2003; Weber et al., 2004). According to Peterson and colleagues (1993) when individuals are exposed to uncontrolled events they project this sense of lack of control onto other situations (e.g. appraisal of illness or caregiving) and appraise these situations in a more negative light. This results in a more negative outcome (e.g. QOL). Results of this study may point toward a subset of advanced prostate cancer patients and their partners who experience a poor sense of overall or cancer specific self-efficacy, possibly related to past negative general or cancer-related experiences, which results in a more negative appraisal and ultimately a poorer QOL.

Exploratory analysis suggests that patients' self-efficacy was significantly correlated with patients' symptoms (Table 4.3). As patients' symptom distress increased their self-efficacy or confidence in their ability to manage the illness also decreased. Similar findings were found in a study by Campbell and colleagues (2004).

Patients' symptom distress was also found to be a strong predictor of QOL in both models; however, it was stronger in the patients' model than the partners' model. Additionally, symptom distress had a direct and indirect effect in the patients' model

while only an indirect effect in the partners' model. The additional direct path between patients' symptom distress and patients' QOL suggests patients' symptom distress has more of a direct effect on patients' QOL than partners' QOL. This direct path may represent the actual physical side effects experienced by patients which are not experienced by partners. This is supported by a study of breast cancer patients and their spouses (Northouse, Mood & Kershaw, 2002); patients' symptoms had both direct and indirect effect on patients' QOL while patients' symptom only had an indirect effect on partners' QOL. In their analysis Northouse and colleagues also included partners' symptoms and results indicated that partners' symptoms had a direct effect on partners' QOL but no direct effect on patients' QOL. Consistent with other studies of cancer patients (including prostate cancer) symptom distress is an important antecedent factor in the Modified Stress-Coping Model (Campbell et al., 2004; Dacal, Sereika, & Greenspan 2006; Herr & O'Sullivan, 2000; Northouse, Mood & Kershaw, 2002) and it underscores the significance of the symptoms experienced by advanced prostate cancer patients treated with ADT and the impact of the symptoms directly and/or indirectly on the QOL of both patients and partners. Furthermore, these findings suggest that healthcare providers must assess how patients and partners are managing and controlling symptoms.

Patients' level of perceived open cancer-related communication with their partner had a significant direct effect on patients' QOL. Patients with higher levels of communication had better QOL. However, for partners there was no significant effect (direct or indirect), of their perceived level of cancer-related communication with the patient, on their own QOL. Emerging research suggests that dyads which participate in open cancer-related communication report better QOL (Manne et al., 2010; Song et al., 2011). Furthermore,

some studies suggest that partners (typically women) of prostate cancer patients are often disturbed by the lack of cancer communication (Harrison, MaGuire, & Pitceathly, 1995). An explanation for this may be that partners, in this study, were reluctant to discuss the cancer with the patients for fear of upsetting them. This is consistent with reports of others that have found that partners, even though they may desire a higher level of communication, often avoid cancer-related communication to protect and shield patients from negative thoughts and feelings (Boehmer & Clark, 2001; Badr & Taylor, 2009). It may be beneficial to investigate specific patterns of communication, for example, Badr and Taylor (2009) found that mutually constructive communication, among dyads with prostate cancer, was associated with better marital satisfaction. While Manne and colleagues (2010) reported that prostate cancer patients and partners who avoided cancer-related communication experienced more distress. A final possibility is that specific types of communication (i.e. avoidance, aggressive) may serve as a mediator or moderator between antecedents and outcomes. Fried and colleagues (2005) investigated the adequacy of caregiver-patient communication in the seriously ill population and found that the amount of communication modified caregiver burden.

This study was unable to ascertain the relationship between patients' variables and partners' variables in one model secondary to the small sample size, however, patients' and partners' QOL were regressed on each other and it was found that partners' QOL accounted for a significant amount of variance in patients' QOL. This is an important finding as it indicates that advanced prostate cancer patients are not only affected by their own disease, but also by the QOL of their partners. Thus, healthcare providers should be cognizant of the health and healthcare needs of partners since partners are typically the

primary source of patients' daily physical and emotional support. Based on the research of others (Hodges, Humphris, & Macfarlane, 2005; Phillips et al., 2000) it was surprising that patients' QOL did not account for a significant amount of variance in partners' QOL, however, this may suggest that partners own appraisal of caregiving and use of avoidant coping are stronger determinants of their own QOL than patients' QOL. Finally, this finding may also have been related to the small sample size, as the relationship was approaching significance ($ß$=.23, p = .06) and it is possible that with an increased sample size significance would have been seen.

Findings from this study support the important mediating role of appraisal and avoidant coping which is consistent with the theoretical perspectives. As seen in both the patients' and partners' models (Figures 4.2 and 4.3) appraisal (illness/caregiving) and avoidant coping serve as mediators between the antecedent variables and the outcome variable, QOL. Results of this study indicate that patients who appraise the cancer more negatively and partners who appraise caregiving more negatively utilize more avoidant coping strategies to manage the stress of the disease and its treatments. One explanation for this finding may be that patients and partners who appraise the illness or caregiving more negatively are overwhelmed and feel that they cannot change the demands associated with the cancer, and subsequently use maladaptive coping strategies, such as avoidant coping, thus avoid dealing with the stress. Of significance may be the fact that all of the patients in this study had had a recent diagnosis ($\leq$ 6 months) of advance cancer (i.e. metastatic disease or biochemical recurrence, post-primary treatment), therefore, they were likely facing questions and concerns of life and death, treatment changes and potential treatment side effects that influenced their negative appraisal. Studies indicate

that avoidant coping strategies are frequently utilized when individuals feel that they are unable to manage a stressful situation (Folkman & Greer, 2000; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986). Furthermore, as found in this study and supported in the literature, a consequence of using avoidant coping strategies appears to be an increased psychological risk for worse QOL outcomes for both patients and partners (Green et al., 2002; Kershaw et al., 2008; Ko et al., 2005; Malcarane et al., 2002). In total, the results of the analysis in this study of mediators would suggest that it is important for healthcare providers to assess how patients are managing the stress of the cancer and how their partners are managing the stress of caregiving. Moreover, interventions to reframe negative appraisal and decrease utilization of maladaptive coping might serve to enhance the QOL of patients and/or partners who are identified as struggling with the illness.

LIMITATIONS

This study was a cross-sectional design; therefore, causality cannot be determined. Future research should examine QOL in advanced prostate cancer patients and their partners longitudinally, so that the trajectory of QOL and its predictors can be more thoroughly explored. The sample size is small (75 dyads) making it difficult to examine multiple interactions between variables. Future studies should include a larger sample size which would increase statistical power allowing for the analysis of combined patients' and partners' models. The sample included only advanced prostate cancer patients treated with ADT and their partners, therefore, generalization of these results is limited to this population.

SUMMARY

Consistent with the models the specified antecedents (self-efficacy, symptom distress, communication and QOL [patients/partners]) and mediators (appraisal of illness/caregiving and coping) predicted a large amount of explained variance in the QOL of patients (89%) and partners (74%). These results underscore the importance of healthcare providers assessing patients and their partners for physical and mental changes that might put them at risk for poorer QOL. Furthermore, an awareness of the relevance of these variables will help guide future research specific to advanced prostate cancer patients and their partners.

PRACTICE IMPLICATIONS

Results of this study suggest that certain factors such as self-efficacy, symptom distress, communication, partners' QOL, appraisal (illness/caregiving) and coping strategies can affect the QOL of advanced prostate cancer patients treated with ADT and/or partners. Healthcare providers are in a position, during office visits with patients and partners, to assess, and if needed, address these factors with available interventions and/or resources. Providers may also be in a position whereby they can help patients and partners. For example, they can help to increase patients and partners perceived self-efficacy by reinforcing positive efficacious actions taken or expressed since the last visit or during the current visit. To elicit more conversation about symptoms which patients and/or partners may consider more personal nature, providers can inquire about symptoms, and when appropriate, reframe questions in a nonthreatening manner (e.g. Some men/partners/couples treated with ADT experience this… Have you had any difficulty with this?) Providers can encourage and teach open cancer-related

communication between patients and partners. Furthermore, healthcare providers can help patients and partners attain a better QOL by promoting positive re-appraisal of the disease and caregiving and decrease the utilization of avoidant coping strategies by teaching positive active strategies.

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Table 4.1

Demographic and Medical Characteristics (n = 75 dyads)

Variable	Patient	Partner	Dyad
Age, years (Mean, SD)	66.7 (9.5)	62.4 (9.8)	
Education, years (Mean, SD)	14.8 (2.7)	14.2 (2.7)	
Race, %			
Caucasian	82.7	82.7	
African American	17.3	17.3	
Family Income, %			
< $5,000			2.7
$5,000-$15,000			5.3
$15,001-$30,000			9.3
$30,001-$50,000			22.7
$50,001-$75,000			14.7
>$75,001			38.7
Length of Marriage, years (Mean, SD)			36.0 (15.1)
Employment Status, %			
Full/Part-time	36		39
Retired	64		40
Homemaker			21
Other Health Problems, %			
No health problems	0.0		22.7
1 health problem	100.0		77.3
2 health problems	76.0		53.3
3 health problems	52.0		22.7
4 or more health problems	32.0		4.0

Table 4.2

Bootstrap Results for Indirect Effects

	Indirect Effect	Standarized Indirect Effect	SE	LL 95 CI[a]	UL 95 CI[b]	Two-tailed Significance
Patient						
	Self-Efficacy on QOL	.096	.048	.029	.232	*
	Symptom Distress on QOL	-.113	.045	-.219	-.043	*
	Communication on QOL	-.001	.027	-.053	.056	.97
	Partner QOL on patient QOL	.154	.077	-.030	.303	.09
Partner						
	Self-Efficacy on QOL	-.186	.073	-.534	-.114	*
	Symptom Distress on QOL	-.102	.051	-.220	-.018	*
	Communication on QOL	-.012	.055	-.130	.093	.82
	Patient QOL on partner QOL	.249	.163	-.099	.567	.13

[a] Lower limits 95% confidence interval

[b] Upper limits 95% confidence interval

** P < .05*

Table 4.3

Correlations of Variables

	1	2	3	4	5	6	7	8	9	10	11	12
1. Self-efficacy (pt)	-											
2. Self-efficacy (prt)	.289 *	-										
3. Symptoms (pt)	-.360 *	-.019	-									
4. Symptoms (prt)	-.221	-.191	.220	-								
5. Communication (pt)	.420 *	-.031	-.272 *	-.322 *	-							
6. Communication (prt)	.028	.550 *	-.077	-.294 *	.338 *	-						
7. Appraisal (pt)	-.624 *	-.061	.555 *	.230 *	-.332 *	.047	-					
8. Appraisal (prt)	-.261 *	-.479 *	.240 *	.260 *	-.096	-.273 *	.321 *	-				
9. Avoidant cope (pt)	-.398 *	.042	.254 *	.228 *	-.246 *	.042	.444 *	.184	-			
10. Avoidant cope (prt)	-.046	-.328 *	.056	.389 *	-.024	-.230 *	.051	.482 *	.256 *	-		
11. Quality of life (pt)	.664 *	.111	-.542 *	-.448 *	.538 *	.103	-.716 *	-.279 *	-.582 *	-.189	-	
12. Quality of life (prt)	.261 *	.450 *	-.323 *	-.538 *	.178	.392 *	-.302 *	-.429 *	-.237 *	-.618 *	.452 *	-

* $P < .05$

pt = patient, prt = partner

Figure 4.1

The Modified Stress-Coping Model

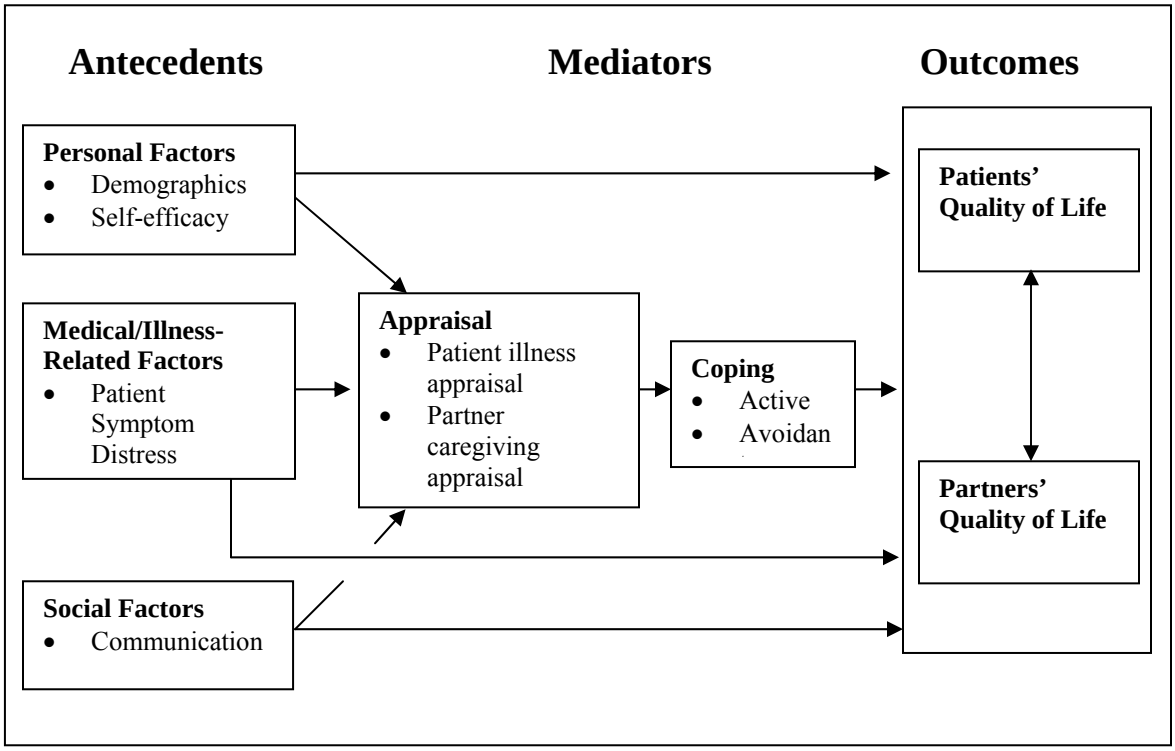
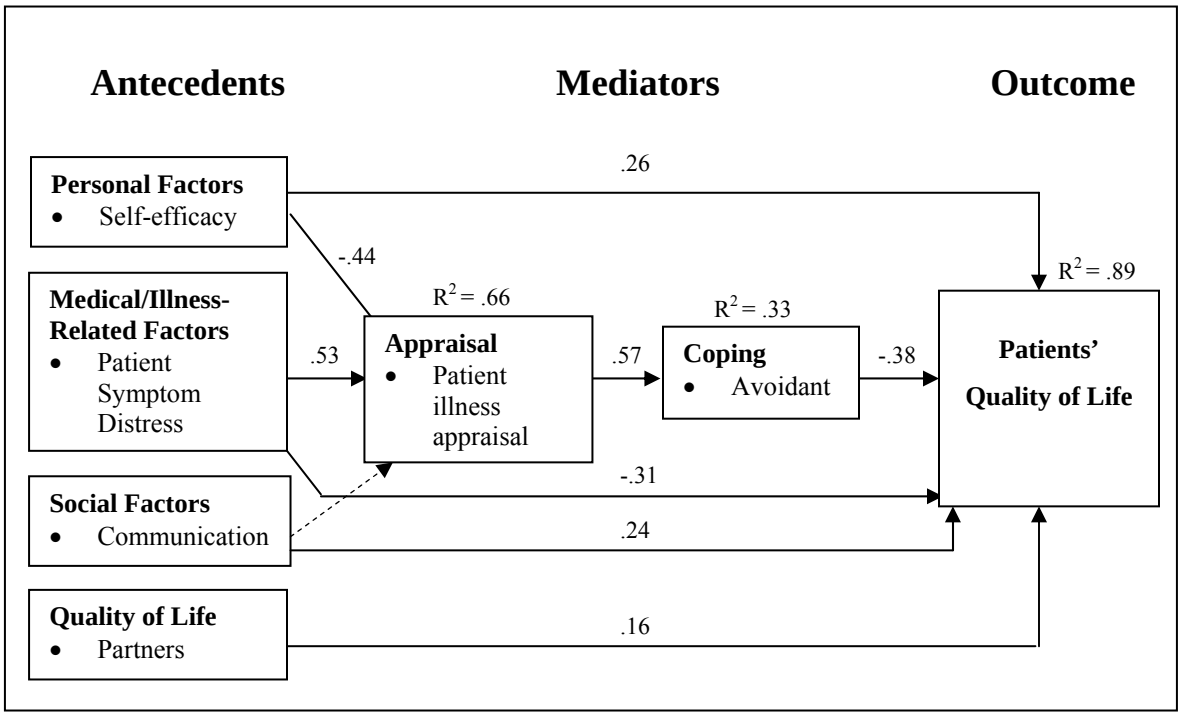


Figure 4.2

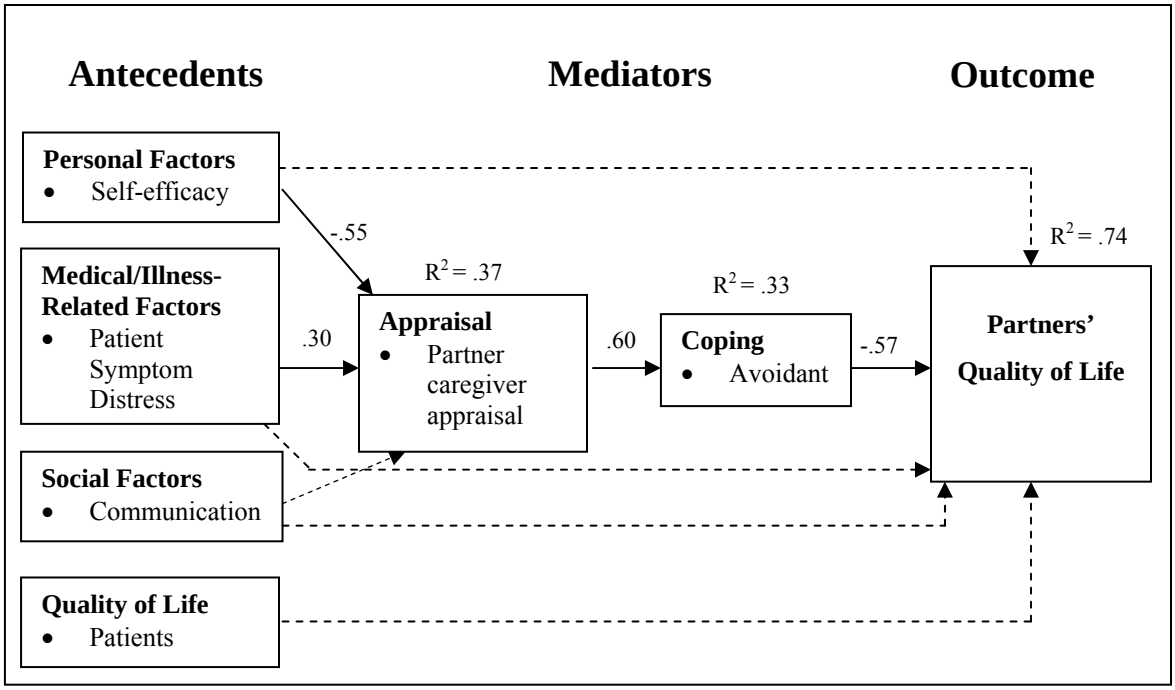
Patients' Model



Solid lines represent significant paths ($p < .05$). *Dashed lines* represent nonsignificant paths.

Figure 4.3

Partners' Model



Solid lines represent significant paths ($p < .05$). *Dashed lines* represent nonsignificant paths.

APPENDIX

Details of Procedure Used to Verify Outcome Variances

This appendix details the procedure used to verify the high outcome variances found in the

Patients' Model (Figure 4.2) and the Partners' Model (Figure 4.3).

1) Descriptive statistics were re-computed on all data.
2) Histograms for all data were computed and examined, no incongruent or erroneous data were found.
3) Verified that the importation of data from SPSS to AMOS was correct.
4) Re-computed and verified correlations for all variables

CHAPTER V

CONCLUSIONS

The purposes of this dissertation were to: 1) compare the levels of QOL and specific antecedents and mediators of advanced prostate cancer patients receiving ADT and their partners, and 2) test if the Modified Stress-Coping Model can predict the QOL of advanced prostate cancer patients treated with ADT and their partners. The following section summarizes the research results, practice implications, and directions for future research.

RESEARCH RESULTS

Comparisons of Prostate Cancer Patients and their Partners on Study Variables

Results indicated that patients when compared to partners, were significantly older, more educated and had more co-morbidities. There were no significant differences found between patients' and partners' levels of self-efficacy, symptom distress, communication, and appraisal. No differences were also found in the mean levels of active and avoidant coping strategies utilized, however, results indicated that both patients and partners used significantly more active coping than avoidant coping. Patients and partners had similar mean scores for total QOL and three of four subscales (i.e. physical, functional and social). Partners reported significantly worse emotional QOL when compared to patients. When prostate cancer patients and their partners QOL scores were compared to a normative sample of men and women without cancer there were no significant

differences in total QOL mean scores for patents or partners. Comparison of subscales indicated that patients had significantly lower emotional QOL but higher social QOL then the normative sample. Partners, when compared to the normative sample, had significantly higher physical and social QOL but lower emotional QOL.

Predictors of Quality of Life in Patients and Their Partners

Results of SEM indicated that antecedent factors and mediators predicted a large amount of the variance in the QOL of patients (89%) and partners (74%). There were a number of significant direct effects found for patients. Specifically, patients who had higher self-efficacy, less symptom distress, more cancer-related communication and who had partners with higher QOL, reported higher overall QOL. Furthermore, appraisal of illness and avoidant coping partially mediated the relationship between patients' self-efficacy and symptom distress and their QOL. Additionally, patients who reported more negative appraisal of their illness and greater use of avoidant coping strategies also reported poorer overall QOL.

For partners, there were no significant direct effects of the antecedent variables on QOL. However, there were significant indirect effects through the mediators. Partners' appraisal of caregiving and avoidant coping partially mediated the relationship between partners' self-efficacy and symptom distress and their QOL. Additionally, partners who reported more negative appraisal of caregiving and greater use of avoidant coping strategies also reported poorer overall QOL. Findings of this study provided support for most of the hypothesized relationships tested in the stress-coping model that was tested in these analyses.

PRACTICE IMPLICATIONS

Results of this study identified a number of factors that had direct and indirect effect on the QOL of advanced prostate cancer patients and their partners. These findings have a number of practice implications. First, though patients and partners were found to have poorer emotional QOL when compared to a normative sample, partners emotional QOL was also worse than patients. This would suggest that healthcare providers should not only assess the patients' emotional needs but also those of their partners.

Second, partners' QOL was found to be a significant predicator of patients' QOL. This underscores the importance of the psychological and physiological well-being of partners, and would indicate that not only should healthcare providers assess the QOL of patients but partners too. Furthermore, interventions to help improve QOL should not only be limited to patients but should be extended to partners since improving partners' QOL could also have a direct benefit for the patients QOL.

Third, this study suggests that there are a number of specific antecedent and mediating factors that are predictors of the QOL of patients and partners. For patients self-efficacy, symptom distress, communication, partners' QOL, appraisal of illness and avoidant coping were identified as significant predictors of their QOL. For partners self-efficacy, patients' symptom distress, appraisal of caregiving and avoidant coping were identified as significant predictors of their QOL. Healthcare providers are in a position to assess these QOL predictors and intercede if needed. Appropriate interventions to address predictors could include programs designed to build self-confidence, reduce symptom distress, reframe negative appraisal and decrease the utilization of avoidant coping

strategies. Open cancer-related communication was found to be a predictor of patients' QOL, therefore, if warranted, healthcare providers should initiate interventions to promote more open dyadic cancer-related communication.

Fourth, a number of potential areas for patient and partner interventions were identified in this study including specific antecedent and mediating QOL predictors. Research has identified a few promising intervention formats that could be utilized in the practice setting, for example, Campbell and colleagues (2007) developed a telephone-based intervention to improve the coping skills of prostate cancer patients and their partners. Preliminary results indicated that the intervention had a moderate to large effect and was a feasible intervention approach for patients and partners. The feasibility and acceptability of group sessions to improve the QOL of for men with recurrence prostate cancer was the focus of a pilot study by Ames et al. (2011). Preliminary results indicated that this intervention format was feasible and furthermore, acceptable to the study participants. Another intervention approach that might be feasible in a practice setting is the utilization of social network via software application (e.g. Skype).

DIRECTIONS FOR FUTURE RESEARCH

Based on the findings of this study there are a number of areas that warrant future research. First, replication of this study using a larger sample would provide adequate power to combine predictors in both the patients' model and partners' model into one model. Structural equation modeling of a combined model would more realistically assess the relationships between patient and partner variables and their QOL. Second, future studies should use longitudinal designs, thus providing a more accurate picture of how antecedent and mediator variables predict QOL and how they evolve over time.

Third, many of the side effects associated with ADT are unique to the treatment. Therefore, future studies in this population should include a prostate-specific scale that could more accurately assess the side effects often experienced by men receiving hormonal therapy. Fourth, there is a need to study populations that are diverse with respect to race and sexual orientation. In this study, the racial makeup was more diverse, with regard to Caucasians (83%) and African Americans (17%) than many studies. However, the sample was devoid of other races such as Asian Americans, American Indians, Hispanic or Latinos. A more diverse sample would allow for greater generalization to the diversity of the U.S. population (Siegel, Ward, Brawley, & Jemal, 2011). Currently there is dearth of research examining gay and bisexual prostate cancer patients and their partner even though it is estimated that approximately 5,000 gay or bisexual men are diagnosed with prostate cancer each year yet few if any studies have included or focused on this population (Blank, 2005). Future studies should endeavor to sample this underserved population. Finally, results of this study also create new areas of inquiry that could be addressed with future research, For example, it is apparent from existing research that advanced prostate cancer patients treated with ADT and their partners can experience a large number of psychological and physiological changes (Higano, 2006; Kershaw et al., 2008). Other factors such as resiliency may be important to assess. Some studies have shown that with age comes a sense of resiliency (Holland et al., 2009). Future studies of the advanced prostate cancer population may be enhanced by considering additional variables such as resiliency.

In summary, this study compared prostate cancer patients and their partners on a number of important variables and identified factors associated with their QOL. Findings

indicate that both patients' and partners' QOL was effects by the illness and that both may benefit from psychosocial care.

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