# COUPLES' COMMUNICATION AND QUALITY OF LIFE DURING PROSTATE CANCER SURVIVORSHIP

By

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# CHAPTER I

# INTRODUCTION

### STATEMENT OF PROBLEM

Prostate cancer is the most frequently diagnosed cancer and the second leading cause of cancer-related deaths in men in the U.S. (SEER, 2006). While prostate cancer can occur in men of all ages, it is more prevalent among those 65 years of age and older (American Cancer Society, 2007). With the 5-year survival rate above 99% for all races, an increasing number of prostate cancer patients are living longer; there are over 2 million prostate cancer survivors in the U.S. (SEER, 2006). The illness and the treatments for it often cause considerable difficulties for patients and their partners (e.g., urinary incontinence, erectile dysfunction, and psychological distress) that negatively affect their quality of life (QOL) (Eton & Lepore, 2002; Northouse, et al., 2007a) and intimate relationships over an extended period of time (Eton & Lepore, 2002; NCI, 2005).

Couples' communication under these circumstances, i.e., the exchange of cancer-related information and concerns between patients and their partners, has been shown to significantly interfere with the life of couples coping with cancer (Manne, et al., 2006; Porter, Keefe, Hurwitz, & Faber, 2005). Prostate cancer patients and their partners, in particular, often encounter a variety of communication problems such as avoidance of communication and protectiveness (Arrington, 2005; Boehmer & Clark, 2001a, 2001b; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000a). Yet there has been little research on the relationships between communication and QOL in couples coping with prostate cancer. Of the studies conducted in the prostate cancer population, most

have been qualitative or quantitative studies with small sample sizes (Arrington, 2005; Boehmer & Clark, 2001a); few have concurrently examined the perspectives of both patients and their partners as it relates to their communication about the illness and their QOL (Edwards & Clarke, 2004; Gotcher, 1995). In addition, although cancer survivorship extends over months and years, there is an absence of longitudinal research that have examined how the patterns of communication change over time, and how communication between patients and partners affects their QOL. Finally, few studies have been theory-based.

The purposes of this dissertation are to describe the patterns of change in couples' communication over time, taking into consideration of the effects of selected bio-psychosocial factors, as well as to examine whether communication mediates the effects of these bio-psychosocial factors on QOL of prostate cancer patients and their partners over time. The specific aims are as follows:

**Aim 1**: To compare patterns of change in levels of dyadic communication by role (patient versus partner) and by phase of illness (i.e., localized, biochemical recurrence, and advanced) over time

Aim 2: To examine whether personal, family, and cancer-related factors are associated with the levels of dyadic communication between patients and partners over time

**Aim 3**: To examine the relationships between personal-, family-, and cancerrelated factors and QOL in patients and partners over time

**Aim 4**: To determine if levels of dyadic communication reported by patients and their partners mediates the relationships between selected bio-psychosocial factors and couples' QOL over time

To address the gaps and achieve the aims, this dissertation will examine the theoretical issues pertaining to the communication between prostate cancer patients and

their partners and provide an overview of couples' communication and QOL during prostate cancer survivorship. Next, the dissertation will present two longitudinal studies using multilevel models. The first study, focusing on couples' communication during cancer survivorship, will address specific aims 1 and 2. The second research will describe the relationships between couples' QOL and selected bio-psychosocial factors, as well as to examine the mediation effects of communication on the relationships between these factors and couples' QOL during prostate cancer survivorship (research aims 3 and 4). The conclusions will be drawn based on the literature review and the two longitudinal studies. Finally, implications for research and clinical practice as well as future directions will be discussed.

## CONCEPTUAL FRAMEWORK

The following section will examine the theoretical issues related to couples' communication: (a) examine the effects of prostate cancer on patients' and their partners' QOL to provide background information; (b) critique the theoretical frameworks that are relevant to research in cancer patients and their family members; (c) present a new Couple's Cancer-Related Communication Model; and (d) discuss the implications of this new model in communication research among cancer patients and their families.

## Impact of Prostate Cancer on the QOL of Patients and Their Partners

Although prostate cancer is increasingly diagnosed at an early stage with longer survival times, the illness and its treatments often introduce significant symptoms and difficulties (e.g., incontinence, impotence, fatigue, and distress) that affect different aspects of QOL in men (Lintz, et al., 2003; Northouse, et al., 2007a). In addition, prostate cancer also lowers QOL in patients' close family members, especially their partners (Eton, Lepore, & Helgeson, 2005; Kornblith, Herr, Ofman, Scher, & Holland, 1994; Northouse, et al., 2007a; Rees, et al., 2005). These effects may be temporary or

sustained over time, differing across phase/stage of the illness, time since diagnosis, and types of treatment patients receive (Eton & Lepore, 2002).

#### **QOL in Prostate Cancer Patients**

Prostate cancer patients often suffer considerable deterioration in their urinary, sexual, and bowel functions as well as hormonal symptoms that are caused by the illness and treatments for it (Litwin, *et al.*, 1995; Wei, Dunn, Litwin, Sandler, & Sanda, 2000). Compared to men of the same age without the disease, prostate cancer patients usually have more problems with their urinary, bowel and sexual functions, irrespective of the type of treatment used (Litwin, et al., 1995). Although patients undergoing observation, surgery, radiotherapy, or hormonal therapy all have continuous decrements in sexual function (Lubeck, et al., 1999), incontinence and impotence are most prevalent among men with advanced (Eton & Lepore, 2002; Northouse, et al., 2007a) or with localized prostate cancer treated with surgery and/or radiotherapy (Helgason, et al., 1997; Helgason, et al., 1996; Miller, et al., 2005). Hormonal symptoms such as hot flashes are also very common among prostate cancer patients (Clark, Wray, & Ashton, 2001), especially among advanced patients (Northouse, et al., 2007a).

Prostate cancer patients' QOL declines with time since diagnosis as the disease progresses (Schag, Ganz, Wing, Sim, & Lee, 1994). A recent study (Northouse, et al., 2007a) reported that, among patients in different phases of prostate cancer, those with advanced disease had more emotional distress and significantly lower physical QOL than others. Patients with biochemical recurrence had worse emotional distress than those with newly diagnosed prostate cancer. Newly diagnosed patients had the highest scores in emotional and physical QOL of all patients.

Prostate cancer patients' QOL is affected by different medical factors (e.g., phase of illness and types of treatment). Early cross-sectional studies showed that the decline in general QOL was similar for men with localized prostate cancer treated with

different regimens (Litwin, et al., 1995). Longitudinal studies further revealed that men treated with radical prostatectomy for early stage prostate cancer experienced problems in some domains of general QOL (i.e., physical, mental, and social functioning), but these problems sharply improved over time (Litwin, McGuigan, Shpall, & Dhanani, 1999; Lubeck, et al., 1999). A comprehensive review of literature corroborated that effects of prostate cancer and its treatments on men's QOL differ across stages of disease and types of treatment (Eton & Lepore, 2002).

When compared to survivors with other types of cancer (e.g., colorectal and lung cancer), QOL of prostate cancer survivors often declines with time (Schag, et al., 1994). A longitudinal study showed that men dying of prostate cancer had more rapid decrease in their physical functions than those dying of other cancers or benign causes (Litwin, et al., 2001). However, such conclusions would have been stronger if researchers had reported that they controlled for the major covariates (e.g., patients' age and comorbidities) in constructing the models including time trends, cause and place of patients' death, and patients' health related quality of life. Nonetheless, these findings indicate that prostate cancer patients' general QOL deteriorates significantly as a result of disease progression and aging.

#### **QOL in Partners of Prostate Cancer Patients**

In addition to lowering the QOL in patients, prostate cancer and its treatments also negatively affect the QOL of partners (Northouse, et al., 2007a). Research has shown consistently that prostate cancer is indeed a "couple's illness" (Gunby, 1997; Harden, Northouse, & Mood, 2006; Soloway, Soloway, Kim, & Kava, 2005).

The decreases in partners' QOL are highly correlated with prostate cancer patients' QOL. Partners' QOL, especially their emotional QOL, is often lower than patients'. For example, compared to patients with newly diagnosed localized prostate cancer, their partners have significantly higher mean scores on the depression and

distress measures(Soloway, et al., 2005). For men receiving primary treatments for their early stage prostate cancer, their spouses have more cancer-specific distress than patients, in particular, spouses' distress is highly predicted by patients' bowel function and mental health (Eton, et al., 2005). For patients with advanced prostate cancer, Kornblith and colleagues (1994) found that their partners were significantly more distressed than their ill husbands. This finding is supported by a recent study, which found that, although dyads with advanced prostate cancer had significantly poorer QOL than those newly diagnosed, their partners reported worse emotional well-being than the patients (Northouse, et al., 2007a). Moreover, partners' decreased QOL often persists for a long time. A recent study reported that partners of men with advanced prostate cancer had persistently greater psychological morbidity than patients six months after the diagnosis (Rees, et al., 2005).

# THEORETICAL FRAMEWORKS TO GUIDE RESEARCH ON COMMUNICATION BETWEEN CANCER PATIENTS AND PARTNERS

In this section, conceptual frameworks that have been used to study how cancer patients and their family members communicate about cancer will be briefly reviewed to lay a foundation for the development of the Couple's Cancer-Related Communication Model. The relevance, strengths, and limitations of each theory also will be discussed.

## The Systems Theory

#### Review of Systems Theory

Systems theorists consider a system as a dynamically interacting and interdependent group of components and their attributes; all living systems (e.g., dyadic family systems) are viewed as open systems which are composed of environment, input, throughput (transformation of resources), and output (Kuhn, 1974). According to family systems theory, each member affects other members in the family system (*interdependence*) and the whole of a system is greater than the sum of its parts (*non-*

*summarativity*). A family system has a strong tendency to reach and to maintain a balance (*homeostasis*). Yet, it constantly exchanges and interacts with its environment and restructures its internal operations so as to function more effectively in response to the changes in the environment (*morphogenesis*). Although the optimum family functioning can be attained through multiple routes and means (*equifinality*), the primary means occur through the dynamic interactions or communication of family members and their feedbacks to one another (Bavelas & Segal, 1982; Minuchin, 1974). In other words, communication between members in a family system helps them establish and maintain their relationships with one another (Bavelas & Segal, 1982).

#### Systems Theory in Interpersonal Communication

Similar to a system, communication is a transactional process (Penman, 1980) which involves a transfer of information using a set of common rules between a source and a receiver (Northouse & Northouse, 1998). The expression of information (a person's activity) becomes communication (a characteristic of the group) when the other family members interact (Montgomery & Fewer, 1988). Communication consists of basic components that are consistent with an open system. These include: (1) the context or environment, (2) information/message, (3) the source of the stimulus: encoder or sender, (4) the channel that carries the message, (5) the responder, decoder or recipient, and (6) the feedback (Smith & Bass, 1979). Just as systems are constantly interacting and changing, human communication is an ongoing dynamic process that goes on and on with the original source transmitting a message and receiving a response (or series of responses) from the recipient (Northouse & Northouse, 1998). Communication process involves a variety of forms and channels such as face-to-face, phone, and notes and letters (Chelune, 1987). Yet, the development and enhancement of the dyadic relationship between partners depend primarily on oral communication, with a combination of facial expressions, postures, gestures, words, tone of voice, and

other cues that carry meaning (Smith & Bass, 1979). As an important and basic attribute in interpersonal relationships, communication defines and regulates most of the human interactional systems (Bavelas & Segal, 1982).

## Relevance of Systems Theory

In coping with prostate cancer, a systems theory perspective switches researchers' attention from individuals or coexistence to the interactions between cancer patients and their partners, which is a key component in the communication model presented later in the paper. Conceptualizing the family as an emotional unit or a field influencing the functioning of each person (Bowen, 1978), systems theory places an individual in the context of an interpersonal, interdependent environment. Focusing on what goes on at the family level, rather than merely examining an individual family member, systems theory provides valuable insight into the patient-partner dyadic relationship as well as their communication. The exchange of information between family members regulates their capacities for emotional bonding and develops their interdependent relationship (Galvin & Brommel, 1986).

#### Strengths and Limitations of Systems Theory in Interpersonal Communication

Serving as an essential conceptual tool in studying human social interactions (Bowen, 1978), systems theory has the strengths that are integral to interpersonal communication research during cancer survivorship. One of the strengths of systems theory is that it holds a view of mutual influence, i.e., interdependence. According to systems theory, all subsystems (e.g., the partners in a dyadic relationship) are interrelated and connected and no system operates without being influenced by other subsystems. Communication between partners, a dynamic transactional process between two persons, also possesses similar characteristics (Fisher, 1982). Specifically, during dyadic communication both partners actively and simultaneously interact as sources and receivers of information (Northouse & Northouse, 1998). Through certain

channels, partners encode and decode both what is said and why the message is sent. As a result, the encoder and the decoder construct and define the event he/she experiences in his/her own ways. Thus, each person affects the other individual in the communication process immediately and over time and both people are affected by factors in the surrounding environment (Chelune, 1987).

Because members are interrelated with each other, when individual family members function poorly, family interaction is negatively affected (Montgomery & Fewer, 1988). Manne and colleagues (2006) found that mutual constructive communication was associated with less distress and more relationship satisfaction for breast cancer patients and partners. Mutual avoidance, on the other hand, was associated with more distress for both people. For a couple, if one person wanted to communicate more openly but the other person withdrew, the couple had higher distress and lower relationship satisfaction.

Another strength of systems theory is its proposition of openness, which is highly related to dyadic communication. Systems theorists consider all human systems as open systems that continuously interact with the environment to maintain their state. Although open systems contrast with closed systems, human systems are rarely ever totally open or closed, but rather open to some and closed to other influences (Bowen, 1978). Similarly, interpersonal communication is often on a continuum between open and closed communication (Galvin & Brommel, 1986). Relatively open communication involves a great deal of freedom to share thoughts, feelings, and opinions among the members. Openness also involves the freedom to communicate congruently, completely, and honestly. Relatively closed communication, on the other hand, involves blocking, distorting, or denying thoughts, feelings, opinions, and truth. Family members may also use silencing to block specific communication or communication in a specific area (Galvin & Brommel, 1986).

Communication between prostate cancer patients and their partners tends to be more closed. Although couples have identified managing and sharing feelings as an important factor in coping with prostate cancer (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000b), many men tend to be reticent about sharing their illness symptoms, treatment side effects, and the impact of the illness on their emotional well-being (Boehmer & Clark, 2001a; Steginga, et al., 2001). Most men with prostate cancer usually avoid the discussion of their illness except on a "need to know" basis (Gray, et al., 2000a). Partners of prostate cancer patients have identified patients' lack of communication as one of the most common problems (Hawes, et al., 2006). Closed communication, which is associated with a closed family system may limit family members from sharing perceptions and feelings in ways that can open or change the system. Thus, closed communication hinders effective relationship building among family members at a time when supportive relationships are needed the most (Northouse & Northouse, 1998).

Despite the strengths, systems theory has limitations. Systems theory concepts are abstract and can be difficult to operationalize for research purposes. Systems theory provides universal explanations and a general understanding of family interactions (Bowen, 1978) and communication (Chelune, 1987), but not the particulars that are necessary for empirical testing. Another weakness is that research using family systems theory often relies heavily on case studies of individual families (Rothbaum, Rosen, Ujiie, & Uchida, 2002). While providing in-depth information about family functioning and differences in perspectives of individuals or individual families, generalizability of such findings can be limited. Thus, the principles of systems theory may serve as a meta-theory that helps researchers with logic and analytic reasoning rather than as a middle-range theory useful for model testing in family communication research.

### The Transactional Model of Stress and Coping

## Review of the Stress-Coping Model

The Transactional Model of Stress and Coping, originally developed by Lazarus and Folkman (1984), is a framework for evaluating the processes of individual adaptation, i.e., coping with stressful events such as cancer. Its basic assumption is that the impact of an external stressor is mediated by people's appraisal of the stressor and by the psychological and social resources at their disposal. When confronted with a stressor, people evaluate the potential threat of the stressor as well as their abilities to alter the situation and to manage negative emotional reactions (i.e., appraisals). Thus, appraisal is more than a mere intellectual exercise in spotting all the challenges and options. It is a complex evaluative process (Lazarus & Folkman, 1984).

Coping, that is, any effort to manage external demands and/or the emotional reactions to the event, serves as a stabilizing factor that can help individuals' psychosocial adaptation during stressful periods. Coping encompasses cognitive and behavioral efforts that reduce or eliminate stressful conditions and associated emotional distress (Lazarus & Folkman, 1984). Two forms of coping have been identified by Lazarus and colleagues, namely problem-focused coping (e.g., information seeking and problem solving) and emotion-focused coping (e.g., venting feelings and avoidance). Problem-focused coping strategies are most adaptive for stressors that are changeable, whereas emotion-focused strategies are most adaptive when the stressor is appraised as uncontrollable or when all problem-focused coping attempts have been made (Lazarus & Folkman, 1984; Wenzel, Glanz, & Lerman, 2002). Coping strategies may vary greatly over time and from person to person (Lazarus, 1984). The coping process can result in complex consequences and outcomes (e.g., psychological distress or compromised QOL) (Wenzel, et al., 2002).

#### Relevance of the Model

The Stress-Coping Model has provided a conceptual tool for evaluating and understanding an individual's adaptation process in responding to a stressor, e.g., a cancer diagnosis. Cancer survivors continuously balance the demands of the illness and treatment-related side effects and the available resources. In facing such adversity, coping is essential for patients' adaptation. When demands are great and when resources are limited, cancer patients may have a negative stress reaction, manifested by deteriorating emotional or physical health.

#### Strengths and Limitations

A number of strengths of the Stress-Coping Model are related to cancer research. First, the model indicates the importance of the appraisal process. According to Stress-Coping theory, individuals' emotional and behavioral responses to health threats are influenced to a large degree by their subjective interpretations, i.e., appraisals. Generally, two appraisal processes are involved: primary and secondary appraisals. Primary appraisal refers to the evaluation of the significance of a stressor or a threatening event. Secondary appraisal is the evaluation of the controllability of the stressor and a person's coping resources. The perception of an individual's ability to change the situation, manage one's emotional reaction, or cope effectively can lead to successful coping and adaptation (Lazarus & Folkman, 1984). On the other hand, when a stressor is perceived as highly threatening and uncontrollable, an individual may be more likely to use disengaging coping strategies such as distancing, avoidance, and denial. The concept of appraisal helps to explain why some people are threatened by a stressor while others are not (Lazarus & Folkman, 1984).

Another strength of the Stress-Coping Model is that it contends that stress and emotion are best understood as processes rather than static events (Lazarus, 1984). Therefore, stress needs to be studied as it changes over time and across encounters.

Consistent with Lazarus's theory, coping with a life-threatening disease such as prostate cancer is a process, rather than a transient event. Research has shown that couples often face different challenges at different phases of the illness (i.e., before diagnosis, during and after treatment, and remission), which forces them to master various practical and informational tasks (Gray, et al., 2000b). Thus, the Stress-Coping Model provides a theoretical basis for studying dynamic coping process over time and helps to facilitate an understanding of the characteristics of cancer survivorship at different phases.

The Stress-Coping Model also has some limitations that may constrain its utility in studying the interpersonal communication phenomenon in cancer populations. First, the Stress-Coping Model is a frame of reference rather than a model that can guide empirical research. It fails to incorporate concepts regarding common and specific aspects of illnesses such as cancer. Second, although Lazarus and Folkman indicate that person-situation transactions are important, the situation dimension is poorly represented in the model.

Third, a major limitation of the model is its highly individualistic perspective which is originated from its strong psychological focus. The model focuses on how a stressor shapes an individual's appraisal and coping behaviors, and minimizes an individual's interactions with the context, or the influence that others may have on an individual's coping. Individuals are portrayed as functioning independently in appraising a stressor and in mobilizing resources necessary to manage or eliminate the stressor. According to the theory, individuals independently choose coping strategies and devote coping efforts to manage the stressors in their lives (Lazarus, 1984; Wenzel, et al., 2002). Such an individualistic perspective has masked individuals' need for social integration and for interdependence, and thus, has given insufficient attention to the importance of other social environmental factors affecting coping and adjustment (Lyons, Mickelson, Sullivan, & Coyne, 1998).

This limitation is especially critical in the area of managing prostate cancer. Cancer patients do not cope with their illness in a vacuum; their family members (e.g., partners) are affected by illness-related stressors and play an integral role in patients' coping with the illness-related stress (e.g., providing care and assistance in illness management). Cancer patients and their partners are usually interdependent with one another, especially in terms of their communication. In fact, maintaining good relationships and communicating openly have been identified by both prostate cancer patients and their partners as the major issues during their survivorship experiences (Gray, et al., 2000b). A common communication problem experienced by patients and their partners is that they try to "deal with" the illness alone by concealing feelings in order to protect one another (Gray, et al., 2000a; Vess, Moreland, Schwebel, & Kraut, 1988). As described previously, the effects of prostate cancer and the treatment for it extend far beyond the patient. Patients' daily interactions with their partners may directly affect (i.e., improve or exacerbate) their physical and psychological conditions. Evidence from an epidemiological study indicated that prostate cancer patients who were married had significantly longer median survival and lower risk of mortality than those who were divorced, single, separated or widowed (Krongrad, Lai, Burke, Goodkin, & Lai, 1996). Even the appraisal process is beyond an individual perspective: prostate cancer patients have reported that supportive social relationships help them cognitively process their cancer experiences and improve their mental functioning (Roberts, Lepore, & Helgeson, 2006). When facing prostate cancer, patients often turn to their partners for emotional support to reduce fear and depression (Arrington, 2005; Boehmer & Clark, 2001b). Thus, what superficially appears to be the achievement of an individual patient in coping with the illness may actually depend on the efforts of the partners and on couples' ability to work together as a team.

In an attempt to utilize Lazarus' Model to guide clinical research, Northouse and colleagues (2005) have modified the Transactional Model of Stress and Coping to examine the coping efforts and outcomes of both cancer patients and their family caregivers. Three major changes have been made in the Stress-Coping Model to address the above limitations. First, systems theory is integrated to reflect that patients' coping experiences are interdependent with their social environmental context. From the systems' perspective, family members' view of and experience with the cancer are included in the model. Second, the modified model is depicted as a mid-range theory that guides empirical research on cancer patients' and their families' responses and adaptation to cancer. Third, the modified model includes illness-related factors that may influence how patients and their family members appraise and cope with an illness, which in turn affects their QOL. Communication is considered as one of the coping strategies.

A series of longitudinal randomized clinical trials guided by the modified Stress-Coping Model have been conducted in patients with cancers of the breast, colon, and prostate and their family caregivers (primarily the spouses) (Kershaw, et al., 2008; Northouse, et al., 2005; Northouse, Mood, Templin, Mellon, & George, 2000; Northouse, Templin, & Mood, 2001). These studies have shown that the model predicts a sizeable amount of variance in patients' and spouses' QOL and adjustment to the diagnosis of colon cancer (variance explained ranges from 54% to 68%) (Northouse, et al., 2000), breast cancer at one year (71% to 81%) (Northouse, et al., 2001), and prostate cancer in different phases of illness at 8 months follow-up (40% to 43%) (Kershaw, et al., 2008). All these findings have provided strong evidence that the modified Stress-Coping model is conceptually sound and clinically relevant in guiding research on appraisal, coping, and QOL for patients and families dealing with different types of cancer and at different phases of survivorship.

# Resiliency Model of Family Stress, Adjustment and Adaptation (Resiliency Model) Review of the Resiliency Model

Another theory that is relevant for studying cancer experiences is the Resiliency Model of Family Stress, Adjustment and Adaptation. From the family perspective, this theory explains why families react in certain ways in the face of stressors. According to the model, a family system is a host of interrelated environmental influences which can and does have a profound impact upon the individual family member and particularly his or her physical and psychological health status (McCubbin & McCubbin, 1991b).

The fundamental assumptions of this theory are that (1) families face hardships and changes as a natural and predicable aspect of life; (2) families develop basic strengths and capabilities to foster the growth and development of family members and to protect the family from major disruptions in the face of family transitions and changes; (3) families develop basic and unique strengths and capabilities to protect the family from unexpected stressors and strains and to foster the family's adaptation following a family crisis; and (4) families benefit from and contribute to the network of relationships and resources in the community, particularly during periods of family stress and crises (McCubbin & McCubbin, 1991a).

Stressors in this model refer to biological, economic, social, or psychosocial events, hardships, or transitions that disrupt the family system. Stressors precipitate changes in the family's patterns of functioning and can increase the likelihood that a negative outcome may occur in the family. According to McCubbin and McCubbin, families engage in two distinguishable but related family processes in response to life changes and catastrophes over their life cycle. The first process is *adjustment*, which facilitates the family's ability and efforts to maintain its integrity and functioning, and to fulfill developmental tasks in facing a stressor. The second process is *adaptation*, which promotes the family's ability to "bounce back" and to move on. Adjustment and

adaptation processes are influenced by a family's appraisals or perceptions of the stressor or the situation and available family resources to deal with the stressor (McCubbin & McCubbin, 1996; McCubbin & McCubbin, 1991b).

According to the Resiliency Model, a family's resources or strengths enable the family to resist a crisis or disruption and to adjust and meet the demands associated with stressful events and hardships. There are three potential sources of family resources: individual family members, the family unit, and the community. Yet, a family crisis is resolved most often by the family using its own resources (McCubbin & McCubbin, 1991b).

Family researchers have identified a variety of family resources that are characterized by healthy families such as communication. Communication plays an important role in buffering the impact of a stressor on family life and in promoting adjustment (McCubbin & McCubbin, 1991b; Olson, Lavee, McCubbin, Klein, & Aldous, 1988). In the face of life changing events, communication is the means through which families create a shared sense of meaning, develop coping strategies, and maintain harmony and balance. Communication is key for families through different developmental stages, especially for those families in the empty nest and retirement years (McCubbin & McCubbin, 1996).

Similar to the Stress-Coping Model, the Resiliency Model also contends the family's appraisal process is critical during times of stress (McCubbin & McCubbin, 1991b). Appraisal is the family's subjective definition of the stressor, which reflects the family's values and previous experiences in dealing with changes and crises. When facing adversity, a family's situational appraisals are called into action by the demands of the crisis situation. Changes in the functioning of the family unit may be needed: routines may be altered; roles may be readjusted. Newly instituted patterns and accompanying roles and expectations emerge (McCubbin, et al., 1998). Families face stress, appraisal,

and changes throughout the family life cycle and over time (McCubbin & McCubbin, 1991b).

According to the Resiliency Model, coping helps strengthen the organization of the family unit, maintain emotional stability and well-being of family members, and utilize family resources to manage the situation (McCubbin & McCubbin, 1991b). A family may employ at least three basic coping strategies, avoidance, elimination, and assimilation, to bring about family adjustment. <u>Avoidance</u> is a family's efforts to deny or ignore the stressors and other demands in the belief and hope that they will go away or resolve themselves. <u>Elimination</u> is a family's active efforts to rid itself of all demands by changing or removing the stressor, or altering the definition of the stressor. <u>Assimilation</u> is the efforts to accept the demands created by the stressor and add them into the existing structure and patterns of family interaction. Both avoidance and elimination serve to minimize the threat or protect the family unit from making modifications. Yet, by adopting assimilation strategies, the family absorbs the demands by making only minor changes within the family unit.

## Strengths and Limitations

The Family Resiliency Model provides guidance on how to address the complex issues of family adjustment and adaptation in coping with a specific stressor. It highlights the importance of family strengths and resources (e.g., quality marital communication) that play a critical role in buffering the negative impacts of unexpected life events and fostering family adaptation in a crisis. The Family Resiliency Model has been used extensively in health promotion research on families, especially those with children and adolescents, coping with substance abuse or changing health behaviors (Fergus & Zimmerman, 2005). It has been used less commonly in cancer populations, especially in adult cancer patients and their families (Andersen, Shapiro, Farrar, Crespin, & Wells-Digregorio, 2005; Carver, 2005; Stommel, Given, & Given, 2002).

Despite its significant strengths, the Resiliency Model has limitations that have limited its utility. There is a lack of common language in the research using this framework. The theoretical and operational definitions of the concepts (e.g., family resiliency) are either lacking or too abstract, inconsistent across studies (Andersen, et al., 2005; Carver, 2005; Stommel, et al., 2002), or inconsistent with the Resiliency Theory (Fergus & Zimmerman, 2005).

The Resiliency Model also places similar or related concepts under different constructs. For example, in the model, communication is categorized as part of family resources, but avoidance, elimination, and assimilation are identified as the basic coping strategies (McCubbin & McCubbin, 1996). Although these coping strategies are defined as different efforts to bring about family adjustment, they share common characteristics with the act of communication. In fact, avoidance and elimination are the most commonly reported communication problems in cancer patients and their partners (Badr & Acitelli, 2005; Hagedoorn, et al., 2000; Langer, Rudd, & Syrjala, 2007; Manne, et al., 2007; Zhang & Siminoff, 2003).

Another limitation of the model is that communication is conceptualized as one of the trait-based family resources and strengths (McCubbin & McCubbin, 1996). As described in the systems theory section, communication is inherently influenced by social and environmental contexts. Communication is not a static trait or a "quality" that people always possess, rather, it is a dynamic transactional process that is defined by factors such as the context, the source and the recipient of the information, and the communication channels used. Treating communication as a trait raises concerns that it may place blame on couples for failing to communicate under highly stressful circumstances. It also raises questions about the usefulness of intervention efforts because trait-based characteristics may not be amenable to change.

To summarize, a serious illness (e.g., prostate cancer) affects the lives of the ill individual and the partner. The set of added demands and strains may increase couples' vulnerability to the development of secondary problems in their relationships or adaptation, which may cause their QOL to deteriorate. Because there appeared to be a lack of theory to guide empirical research on communication in cancer patients and their partners, this paper reviewed the strengths and limitations of three theories that are relevant to family research to guide the development of a feasible theoretical model for future research. The newly developed model will be detailed in the following section.

# THE COUPLE'S CANCER-RELATED COMMUNICATION MODEL

The Couple's Cancer-related Communication Model (Figure 1.1) was developed based on the modified Stress-Coping Model developed by Northouse and colleagues. It is a predictive model that maintains the structure and most of the key components of the modified Stress-Coping Model which has integrated systems theory (Northouse, et al., 2005; Northouse, et al., 2000; Northouse, et al., 2001).

## Insert Figure 1.1 Here

#### Couple's Cancer-Related Communication Model

#### **Review of the Model**

Consisting of three categories of variables: predictors, mediators, and outcomes, this model hypothesizes that (1) patients' and their partners' predictor variables (i.e., personal, social/family, and cancer-related factors) have a direct effect on couples' communication about the illness (i.e., levels of dyadic communication); (2) the predictor factors at baseline have a direct effect on patients' and partners' QOL; (3) dyadic communication between patients and partners partially mediates the relationships between predictor variables and outcomes, and (4) patients' QOL and partners' QOL are correlated. (1). Predictor variables: In the Couple's Cancer-Related Communication Model, predictors include personal, social/ family, and cancer-related factors that may influence how patients and their partners respond to the illness. These factors are the characteristics of patients/their partners, the family/couple, and the illness.

First, <u>personal factors</u> refer to demographics (i.e., age, race, and education). Couples who are older and/or retired report being reticent to talk with each other about cancer (Hilton, 1994). Younger age has been linked to greater disease disclosure in patients with early stage breast cancer (Henderson, Davison, Pennebaker, Gatchel, & Baum, 2002), and older age is associated with lower levels of communication in patients undergoing chemotherapy (Ward, Leventhal, Easterling, Luchterhand, & Love, 1991). With regard to race, white spouses have higher levels of disclosure than African-American spouses (Porter, et al., 2005).

Regarding the relationship between personal factors and QOL of prostate cancer patients and their partners, patients' demographics (e.g., age, education, and race) are reported to explain significant amount of variance in their functional well-being (Litwin, et al., 2007). Younger prostate cancer patients have better physical QOL outcomes than patients who are older than 65 years (Hu, et al., 2004). While younger patients themselves also experience worsening overall QOL as a result of prostate cancer, they are more likely than older patients to return to their baseline physical QOL one year after radical prostatectomy. However, the mental QOL for younger patients often remains low (Hu, et al., 2004; Lintz, et al., 2003). The QOL of married and white patients is more likely to improve postoperatively. According to some research, patients' education level is inversely associated with the improvement in their QOL after prostatectomy (Litwin, et al., 1999).

For partners of prostate cancer patients, being younger is associated with better physical QOL at 8-month follow-up (Kershaw, et al., 2008). Overall, there has been

limited research on the role of personal factors in explaining couples' communication and the partners' QOL while coping with prostate cancer.

The second category of predictors is <u>family factors</u>, which includes the *length of relationship, family income*, and *social support*. The longer the relationship or marriage, the less likely it is that patients disclose and that couples talk about cancer-related information (Hilton, 1994; Porter, et al., 2005). When coping with breast cancer, couples with shorter relationships or marriages reported more discrepancy in their preference for communication, i.e., one partner may want to talk more than s/he is afforded in a couple's relationship (Hilton, 1994; Lichtman, Taylor, & Wood, 1987). Higher household income has been related to better QOL in prostate cancer patients (Hu, et al., 2004).

Social support, the network of family, friends, neighbors, and community members that is available in times of need has been related to active coping in both cancer patients and families (Bloom, Petersen, & Kang, 2007; Jones, et al., 2008; Lethborg, Aranda, Cox, & Kissane, 2007). There has been limited research exploring the relationships between social support perceived by patients and families and their communication. However, perceived *social support* from friends and other relatives has been identified as one of the psychosocial factors that are associated with higher QOL in prostate cancer patients in cross-sectional studies (Rondorf-Klym & Colling, 2003). Social support also was identified as one of the factors affecting QOL of partners of patients undergoing hematopoietic stem-cell transplant (Bishop, et al., 2007). However, a recent study did not find the association between baseline social support and later QOL in the partners of prostate cancer patients (Kershaw, et al., 2008).

The last category of predictors is <u>cancer-related factors</u>, which include time since *diagnosis, phase of illness, uncertainty about the illness,* and *symptom distress*. It has been reported that *time since diagnosis* is negatively associated with couples' communication about cancer-related information. Regardless of communication

patterns, couples decrease their talking about cancer and related issues over time after surgery (Gray, et al., 2000a). For most couples, once the treatments are completed and side effects have abated, communication about cancer lessens (Hilton, 1994). As for the relationship between *phase of illness* and couples' communication, Northouse and colleagues (2007a) have found that couples with biochemical recurrent prostate cancer have significantly less communication about the illness than couples in the newly diagnosed or advanced/metastatic phases of the illness.

*Uncertainty* about the illness is common among cancer patients and partners (Northouse, et al., 2007a). It has been used extensively as one of the outcomes in a series of psychoeducational intervention studies aimed to promote the QOL in cancer patients and their families (Clark, et al., 2001; Kershaw, et al., 2008; Mishel, et al., 2003; Northouse, et al., 2007b). Yet, there is little research on how uncertainty about the illness affects the levels of dyadic communication between cancer patients and their families.

*Symptom distress* is the physical or mental anguish or suffering that results from the experience of symptom occurrence (Rhodes, Watson, & Hanson, 1988). Although the most common and debilitating symptoms (e.g., pain and fatigue) are found to be underreported in cancer patients (Glajchen, Fitzmartin, Blum, & Swanton, 1995; Passik, et al., 2002), the relationship between symptom distress and couple's communication has rarely been examined in cancer research.

Nonetheless, there is consistent evidence in the literature about the relationships between cancer-related factors and the QOL of prostate cancer patients and their partners. *Time since diagnosis* has been negatively associated with the QOL in patients (Lintz, et al., 2003) and their partners (Couper, et al., 2006). Yet, aging and comorbidities may have confounded the findings. Regarding *phases of illness*, couples coping with advanced/metastatic prostate cancer have significantly poorer physical,

emotional, functional, and overall OQL than dyads with newly diagnosed illness. Couples with biochemical recurrence (rising PSA) have poorer emotional QOL than newly diagnosed dyads, but better QOL than dyads with advanced/metastatic illness (Northouse, et al., 2007a).

*Uncertainty about the illness* has been associated with lower emotional QOL (Wallace, 2003) and higher psychological distress in patients and family caregivers (Germino, et al., 1998; Wallace, 2003). Yet, a recent study did not find uncertainty reported by prostate cancer patients and their spouses at baseline predict their QOL measured at 8-month follow-up (Kershaw, et al., 2008), suggesting that uncertainty, measured one time at baseline, may be resolved as couples adapt to their survivorship. Lastly, *symptom distress* affects the QOL in cancer patients and their partners (Kershaw, et al., 2008; Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004).

(2). Mediators: In the Couple's Cancer-Related Communication Model, the mediators are the perceived levels of dyadic communication between patients and their partners, specifically, the perception of the extent to which patients and their partners exchange cancer-related information and concerns. Couples coping with other types of cancer who are able to share information about the illness, its consequences, and their thoughts and feelings have demonstrated enhanced intimacy, empathy, and marital satisfaction, all of which have been associated with better individual QOL (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000; Gotcher, 1992, 1995; Pistrang & Barker, 1995). Studies also have shown the significant association between insufficient communication (e.g., hiding feelings) and higher levels of psychological distress and lower QOL in cancer patients and their families (Ko, et al., 2005; Manne, Ostroff, Winkel, Grana, & Fox, 2005; Northouse, et al., 2001; Reiche, Morimoto, & Nunes, 2005; Schultzel, et al., 2006). Despite the recognized contribution of couple's communication,

there is limited research on how it is directly associated with the QOL in prostate cancer patients and their partners.

(3). Outcomes: The outcomes in the model are the individual patient's and partner's QOL assessments, which have been detailed earlier in the section on the impacts of prostate cancer. Quality of life, defined by the National Cancer Institute as the overall enjoyment of life, is a multidimensional construct that includes physical, emotional, functional, and social health (Aaronson, 1990). The QOL of prostate cancer patients has been reported to directly affect the QOL of their partners and vice versa (Northouse, et al., 2007a).

#### Strengths and Limitations

The Couples' Cancer-Related Communication Model has multiple strengths. First, it conceives the family (i.e., the couple) as a unit and a whole, clearly holding the belief that coping with cancer is a task for both individual patients and their families (i.e., partners). Second, it depicts how couples' communication may mediate their QOL in response to the stress and demands of cancer. This theoretical framework can provide guidance for designing communication interventions to promote QOL for patients and their families. Third, variables are well defined and can be examined with existing instruments. In addition, there is often more than one measure that can be used to test each concept.

On the negative side, the Communication Model also possesses the following limitations. First, for pragmatic reason, the model shows the relationship and influences between/among factors (e.g., QOL and mediators) as unidirectional instead of bidirectional or reciprocal (Lazarus, 1984). The mutual impact that the factors may have on each other is simplified to keep the model parsimonious. Another limitation is that some variables that are critical for the parent Modified Stress-Coping Model (e.g., appraisal) are not included in the initial version of the Couple's Cancer-Related

Communication Model to eliminate multiple mediators. Nonetheless, this model will lay the foundation for developing a more comprehensive model in the future.

#### Significance of the Couple's Cancer-Related Communication Model

The proposed model will provide a framework for assessing the factors that may affect the communication between prostate cancer patients and their partners. It also will provide an alternative approach to explain the role of communication in maintaining couples' QOL. It is hoped that future research guided by this model will use a more holistic, comprehensive approach toward optimizing QOL among couples coping with prostate cancer. The efforts of developing this Couple's Cancer-Related Communication Model address important research priorities, i.e., to enhance cancer survivorship experiences for patients and their families as recognized by the National Cancer Institute (NCI, 2006), the Institute of Medicine (IOM, 2003), and the Oncology Nursing Society (Berry, 2007). The model-developing endeavor also supports the effort of the National Institute of Nursing Research (NINR) in extending research to address problems encountered by patients' families and caregivers to improve QOL through self-management and caregiving (NINR, 2006).

In summary, the relational context has been acknowledged as important for prostate cancer patients' and their partners' adjustment to the illness (Harden, et al., 2006; Krongrad, et al., 1996). This paper briefly examined three conceptual models that are relevant to cancer survivorship research in patients and families. After comparing and contrasting the strengths and limitations of these theories, a new Couples' Cancer-Related Communication Model was formulated as an attempt to guide future research. Research guided by this Model will provide understanding on the interactional dynamics of patients and their partners, as well as evidence on how to improve couples' communication about the illness, and ultimately, their QOL.



Figure 1.1. Couple's Cancer-Related Communication Model
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### CHAPTER II

# COMMUNICATION IN COUPLES COPING WITH PROSTATE CANCER

### INTRODUCTION

Communication between patients and their families plays an important role during cancer survivorship. Investigators have found that reciprocal, open communication between husbands and wives positively affects their psychosocial adjustment to cancer (Manne, et al., 2006; Manne, et al., 2004b; Walker, 1997). Yet communication problems (e.g., avoidance or overprotection) are common among cancer patients and their families (Figueiredo, Fries, & Ingram, 2004; Manne, et al., 2004b; Zhang & Siminoff, 2003), especially when they face prostate cancer (Arrington, 2005; Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). Lack of sufficient reciprocal communication is associated with negative cancer experiences in patients and families (Fried, Bradley, O'Leary, & Byers, 2005; Manne, et al., 2006; Manne, et al., 2004b; Zhang & Siminoff, 2003).

Despite the difficulties that couples may encounter, research on communication in prostate cancer patients and partners is limited. Most of the existing evidence has been cross-sectional and drawn from qualitative studies or quantitative studies with small sample sizes. There is little prospective research on how couples communicate about the illness over time and what factors influence their communication. The purpose of this paper is to provide an overview of couples' communication during prostate cancer survivorship. Design and methodological issues and challenges in communication

research in this population will be discussed. Finally, the directions for future research will be explored.

# **OVERVIEW OF COUPLES' COMMUNICATION DURING CANCER SURVIVORSHIP**

Communication is a complex and multidimensional social phenomenon. There is no single, explicit definition of communication in the cancer literature. Terms such as open communication, interaction, interpersonal communication, openness, disclosure, self-disclosure, confiding, emotional expression and sharing have been used interchangeably (Figueiredo, et al., 2004; Gray, et al., 2000; Harrison & Maguire, 1995; Harrison, Maguire, & Pitceathly, 1995; Hilton, 1994; Iwamitsu, et al., 2005; Pistrang & Barker, 1998). In this review, communication refers to the exchange of cancer-related information and personal experiences (e.g., concerns and feelings about the illness) that occurs between cancer patients and their partners.

In the following section, the importance of and the common problems in the communication between cancer patients and their partners will be discussed. Since there is a lack of research on prostate cancer (Table 2.1), studies on other types of cancer (e.g., breast, gastrointestinal, and lung) are used to supplement the discussion (Table 2.2). Meanwhile, although most of the literature related to prostate cancer identifies the partner as the "wife," this review acknowledges the interchangeable roles of "partners" or "significant others."

#### Insert Table 2.1 Here

Studies of Communication in Couples Coping with Prostate Cancer

#### Insert Table 2.2 Here

Studies of Communication in Couples Coping with Cancer

# Importance of Couples' Communication during Cancer Survivorship

Communication in a relationship plays an important role in the QOL of cancer patients and their partners. Cancer and its treatments often jeopardize the physical,

psychological, and relational aspects of couples' QOL. However, research suggests that couples who have effective communication may adjust better during cancer survivorship. To address the importance of couples' cancer-related communication during the cancer experience, this section will cover the following themes: (1) prostate cancer is a couple's disease; (2) communication is a source of support for couples; and (3) communication has positive outcomes in couples coping with cancer.

# Prostate Cancer Is a Couple's Illness

The first reason that communication between partners is important during cancer survivorship is because prostate cancer has significant effects on the lives of both patients and their partners. While coping with prostate cancer, especially the advanced illness, quality of life of a couple is often compromised due to the patient's symptoms (e.g., impotence, incontinence, fatigue, and pain), poor social and emotional well-being, and mortality issues (Eton & Lepore, 2002; Northouse, et al., 2007a). Additionally, these symptoms, whether temporary or persistent, often negatively affect the most intimate part of a couple's life (Harden, 2005; Harden, et al., 2002). Thus, it is not surprising that prostate cancer is known as a "couple's illness" (Gunby, 1997). Researchers have found that marriage seems to buffer the negative effects of the illness. Being married was associated with better urinary function (Litwin, Pasta, Yu, Stoddard, & Flanders, 2000; Stephens, et al., 2007) and with significantly longer survival than being divorced, single, separated, or widowed in prostate cancer patients (Krongrad, Lai, Burke, Goodkin, & Lai, 1996).

Communication is also an integral part of life for couples who spend most of their time with each other while coping with prostate cancer and age-related challenges. About 65% of all diagnosed prostate cancer cases and more than 90% of all prostate cancer deaths occur in men 65 years and older, who are in a later developmental stage (SEER, 2006). The social network of aging persons often shrinks considerably due to

retirement, the death and illness of acquaintances, and personal health status (Steverink, Westerhof, Bode, & Dittmann-Kohli, 2001). As elders interact more exclusively with their families, especially their spouses, their ability to maintain close relationships is positively related to their QOL (Nussbaum, Baringer, & Kundrat, 2003; Sparks, 2003). Prostate cancer survivors and their partners must deal with cancer and treatment-related complications, as well as other age-related chronic problems of health and living (Harden, 2005). Maintaining communication, i.e., the exchange of information and concerns, becomes especially important because opportunities for couples to interact physically or to engage in leisure activities may become limited due to the illness and aging process.

Communication is fundamental to caregiving during prostate cancer survivorship. Research suggests that the wife is viewed as a partner in managing prostate cancer and is expected to act on behalf of her husband in all phases of the illness trajectory (Heyman & Rosner, 1996). Although different sources of support are available to prostate cancer patients (Echlin & Rees, 2002; Feltwell & Rees, 2004), they are generally less likely to discuss their feelings in public settings (Arrington, Grant, & Vanderford, 2005; Voerman, et al., 2007). Neither do they identify other relatives (including adult children) as a major source of assistance because of the concern of "the extension of fear" (Arrington, 2005). In other words, patients worry that discussing the illness with family members may spread their own fears to others. Yet, prostate cancer patients identify their partners as their primary caregivers and the major source of support, especially emotional support. It is common that men with prostate cancer confide their concerns about their disease <u>only</u> to their wives (Arrington, et al., 2005).

However, the demands of providing care and support to prostate cancer patients can be overwhelming for the partners who are likely to be challenged by their own agerelated comorbidities and disabilities. As patients' disease progresses, the need for

restructuring family roles and responsibilities may force some partners to take over the traditional male tasks in the household or work extra hours out of the home, in addition to being the principal caregivers for the patient and other family members. Some partners also feel helpless seeing their husband in pain and distress. A recent survey of caregivers who provided care to patients with poor health conditions (e.g., cancer), have found that 52-70% of the caregivers (85% are females) have depression, stress and/or panic attacks as a result of their caregiver role (National Alliance for Caregiving, 2006). <u>Couples' Communication and Social Support</u>

Communication is also important because it facilitates social support (i.e., emotional, appraisal, and informational) and helps couples adjust during their cancer survivorship. This, in turn, improves quality of life for the patient and his partner. Research has revealed that support from the partner is of primary significance and represents the most important source of support to the patient (Revenson, 1994).

Communication can facilitate various types of support. First, communication can help the <u>emotional support</u> for couples. Prostate cancer survivors are challenged not only by the devastating physical symptoms but also by a variety of concerns such as sexual problems, masculine image, a sense of failure, and potential death from cancer (Clark, et al., 1997). These concerns create psychosocial distress such as fear, anxiety, and depression in men (Kunkel, Bakker, Myers, Oyesanmi, & Gomella, 2000; Lintz, et al., 2003). The need for support is one of the most common unmet care needs of prostate cancer patients (Lintz, et al., 2003) while dealing with patients' fears and depression are the major tasks for the partners (Hawes, et al., 2006). Partners are considered as the main and sometimes the only people to whom men with prostate cancer can turn for emotional support (Arrington, 2005; Boehmer & Clark, 2001a).

Communication also provides healthy spouses with needed emotional support. Prostate cancer often evokes negative feelings in partners, e.g., anger, sadness, and

even depression, about what is happening to the patient as well as concerns for the patient's future (Cliff & MacDonagh, 2000; Edwards & Clarke, 2004; Hawes, et al., 2006; Mishel, et al., 2003). Kornblith and colleagues (1994) found spouses of prostate cancer patients had frequent intrusive thoughts and images. While carrying out the major care and support for their husbands, spouses receive less information and support from health care professionals than do the patients (Heyman & Rosner, 1996). Rarely do they get sufficient help from support groups (Arrington, et al., 2005). The overwhelming role of caregiver and the emotional burden associated with it are likely to further strain the spouse's own age-related decline in physical health and limited psychosocial resources. Compared to spouses who are not caregivers, spousal caregivers report more fatigue, less energy, and more sleep difficulty (Teel & Press, 1999). Research also found that wives of prostate cancer patients often have a lower emotional QOL than patients (Kornblith, Herr, Ofman, Scher, & Holland, 1994; Northouse, et al., 2007a).

Communication between partners, i.e., sharing cancer-related information and concerns, provides them both with emotional benefits. For prostate cancer patients and their partners, their sense of belonging and control are often deprived by the illness (Kunkel, et al., 2000). The availability of companionship provides people the opportunity to share feelings, unload concerns, and distract them from persistently thinking about upsetting and negative events (Rimé, Phillips, Boca, & Mesquita, 1992). Emotional reassurance through an open expression of love, care, and sympathy helps to renew couples' commitment and reconnect with each other in the face of physical adversity, and thus, enhance mutual support (Collins & Miller, 1994; Derlega, Metts, Petronio, & Margulis, 1993).

Second, communication between partners is a source of <u>appraisal support</u>, which involves the provision of information that is useful for self-evaluation purposes, such as constructive feedback and affirmation (Heaney & Israel, 2002). A person tends to make

an appraisal of the threat, loss, or challenges posed by an event or stress, as well as the resources available to deal with it (Lazarus & Folkman, 1984). It is common for prostate cancer patients and their partners to experience a sense of loss of control over their bodies, schedules, lifestyles, and intimacy due to the illness and treatment-related side effects (Green, Pakenham, Headley, & Gardiner, 2002; Mishel, et al., 2003; Rosenfeld, Roth, Gandhi, & Penson, 2004). Some men may also feel the illness threatens their male identity and challenges their basic beliefs about the self and the world (Gray, et al., 2000; Green, et al., 2002), which causes a variety of psychological and emotional sequelae in patients (e.g., being profoundly fearful and uncertain) (Steginga, et al., 2001). In addition to patients in different phases of prostate cancer also had negative appraisal of caregiving, uncertainty, and hopelessness. Spouses also reported significantly more uncertainty about the illness than patients (Northouse, et al., 2007a).

On the other hand, communication, i.e., information exchange, can assist people to organize their thoughts, to develop self-understanding and insight about the situation, and to find meaning in their experiences, thus reducing negative feelings and appraisals (Rimé, Mesquita, Philippot, & Boca, 1991; Rimé, et al., 1992). Researchers have found that guidance, reassurance of worth, and emotional closeness can help prostate cancer patients cognitively process their cancer experiences and improve their mental functioning (Roberts, Lepore, & Helgeson, 2006). A longitudinal qualitative study conducted among 34 Canadian prostate cancer patients and their female partners also found that, patients' concrete gestures and verbal expressions of appreciation for the care they received increased the healthy spouses' knowledge of being loved and helped them appraised their caregiving efforts as worthwhile and less burdensome (Fergus, Gray, Fitch, Labrecque, & Phillips, 2003).

Lastly, effective communication between partners facilitates the process of <u>information support</u>. Information support involves the provision of information that a person can use to address problems (Heaney & Israel, 2002). During their encounters with health care providers, a significant proportion of cancer patients selectively share and disclose about their disease and treatment (Rosser & Maguire, 1982). The most common and debilitating symptoms (e.g., pain and fatigue) are often underreported (Glajchen, Fitzmartin, Blum, & Swanton, 1995; Passik, et al., 2002). Patients, especially those male patients with lower education, older age, and more severe disease (Benbassat, Pilpel, & Tidhar, 1998), are even more reticent to discuss the psychological problems associated with their cancer (Maguire, 1985). Researchers found that cancer patients withheld 60-80% of their concerns (e.g., energy loss, independence, and coping) from the nurse (Heaven & Maguire, 1997).

Spouses of prostate cancer patients, in addition to being the health care monitor and provider, often take on the roles of information-seeker, negotiator, and interpreter between physicians and their husbands throughout the survivorship (Arrington, 2005; Boehmer & Clark, 2001a). They search for information on their husbands' behalf and make sure the information is clear to the patient (Maliski, Heilemann, & McCorkle, 2002). Sharing cancer-related information with each other can help healthy spouses be more effective in carrying out these caregiving roles and enable them to be a conduit between health care providers and the patient. Such communication can better inform patients and partners to make appropriate treatment decisions (Boehmer & Clark, 2001a).

### Positive Outcomes of Couples' Communication

Couples' communication is also important because of the positive outcomes associated with it. First, effective communication can positively affect couples' relationships. In the cancer population, holding back concerns is associated with lower marital satisfaction among couples, especially when patients experience relatively high

levels of psychological distress or physical limitations (Hagedoorn, et al., 2000). On the contrary, better communication (e.g., sharing concerns and not being overprotective) between cancer patients and their partners has been associated with better marital satisfaction and better QOL in patients (Hagedoorn, et al., 2000). Avoidance or mismatched communication (demand-withdraw) are associated with higher distress and lower relationship satisfaction in patients and partners (Manne, et al., 2006). Mutually constructive communication (e.g., mutual discussion, expression of feelings, and understanding of one another's views) has been associated with less distress and more relationship satisfaction (Manne, et al., 2006).

Second, open communication between patients and families about cancerrelated information is related to their positive adjustment, increased cohesion, and lower mood disturbance (Oh, Meyerowitz, Perez, & Thornton, 2007). Couples coping with breast cancer report better adjustment to cancer survivorship when they are able to share information about the illness, its consequences, and their thoughts and feelings (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000; Pistrang & Barker, 1995), whereas cancer patients who hold back emotions and concerns report lower emotional well-being and more distress (Figueiredo, et al., 2004). Communication also has been associated with fewer regrets for grieving family members following the death of a cancer patient (Hinton, 1981, 1998). While the value of open communication is less documented in the prostate cancer population, the results of a cross-sectional study of patients with prostate, breast, and colorectal cancer and their families have indicated that communication within families with a prostate cancer patient is more important than it is for families facing breast and colorectal cancers (Edwards & Clarke, 2004). However, the relatively small sample size of prostate cancer in this study may have jeopardized the validity of the findings.

Less research has addressed the outcomes of effective communication on healthy spouses. The evidence from lung cancer research suggests that sharing information and concerns between partners helps partners gain a better understanding of the patient's physical and emotional needs, which subsequently decreases caregiver strain (Badr & Acitelli, 2005). A study of gastrointestinal cancer also has shown that, when patients and their spouses communicate and have similar perceptions of the patient's pain, patients report less mood disturbance and better quality of life, and spouses have lower levels of caregiver strain (Porter, Keefe, Hurwitz, & Faber, 2005). Yet, communication between partners facing prostate cancer may differ considerably from couples dealing with other types of cancers because of the illness's unique association with gender socialization and sensitive issues such as sexuality and incontinence.

It is noteworthy that findings from studies that have examined the relationships between couples' communication and their QOL have been inconsistent. For example, a study on communication between patients with terminal cancer and their relatives (89% were spouses) have reported somewhat controversial results (Hinton, 1998). Specifically, the correlations between patients' and relatives' emotions and their communication are generally weak (*r* ranged from .01 to .22, and 75% of the correlations are less than .15). Patients' openness about their feelings is associated with greater anxiety (r = .29, p< .05) rather than less anxiety. Nonetheless, the overall results of this study indicate that open communication has some advantages: relatives who had more open communication with patients had greater acceptance of the outcomes (e.g., cancer prognosis and dying), less regrets, and more satisfaction with the care (Hinton, 1998).

Another study also reported that communication between partners at baseline, although reduced hopelessness in prostate cancer patients and uncertainty about the illness in healthy partners at 4-months follow-up, did not affect their QOL 8 months later

(Kershaw, et al., 2008). These findings suggest that patients and partners may have different communication needs at different phases of illness.

#### Problems in Couples' Communication during Cancer Survivorship

Although communication is important and potentially beneficial during cancer survivorship, couples often experience a variety of communication problems such as insensitivity, avoidance of communication, and protective buffering. Insensitivity, i.e., saying things too bluntly or hurtfully, giving too much advice, or trying to fix a situation instead of listening to the feelings of the other person, is a communication problem that is frequently experienced by cancer patients and their partners. A qualitative study reported that some lung cancer patients felt their families did not want to listen even when they expressed a desire to share more feelings about the cancer (Zhang & Siminoff, 2003). Breast cancer patients have reported unhelpful conversations with their healthy spouses, such as lack of empathy, changing topics, and attempts by the spouse to encourage the patient to be optimistic (Pistrang, Barker, & Rutter, 1997). They also report that it is unhelpful when partners are blunt and hurtful to one another or bring up unresolved issues in arguments (Hilton, 1994). Breast cancer patients describe helpful communication with partners as communication that is characterized by high empathy and low withdrawal rather than by criticism and changing the focus of a conversation (Manne, et al., 2006; Manne, et al., 2004b; Manne, et al., 2007). Although there has been limited research on the relevant topics in prostate cancer, insensitivity such as turning topics away from emotional content to problem-solving has been reported in the communication between prostate cancer patients and their partners (Arrington, 2005).

Next, <u>avoidance of communication</u> is the most commonly reported problem among couples facing cancer. Although families want to be compassionate and understanding, they are often inclined to avoid discussion of cancer-related topics due to their own fears of cancer (Northouse & Northouse 1987). When spouses are unable or

afraid to express feelings of intense sadness, helplessness, and anger, they may choose to avoid discussion altogether (Wortman & Dunkel-Schetter, 1979). In general, frequent and open communication about cancer seldom takes place within the family unit; avoidance of communication between patients and their families is a widespread phenomenon (Walsh, Manuel, & Avis, 2005; Zhang & Siminoff, 2003).

Prostate cancer patients, in particular, avoid discussing the illness except on a "need to know" basis (Gray, et al., 2000). Researchers have found that, although most men are capable of speaking about the factual physical changes of their illness, they withhold symptoms from their wives (Boehmer & Clark, 2001a). Although some prostate cancer patients complain that their wives do not know how they feel about the illness (Heyman & Rosner, 1996; Mason, 2005), men themselves also are reticent about discussing their symptoms, side effects, and the impacts of these concerns on their emotional well-being (Boehmer & Clark, 2001b; Steginga, et al., 2001). Some prostate cancer patients even expect their partners to keep their concerns to themselves (Arrington, 2005). Even well-adjusted patients, who have more frequent and open communication with their partners, still have a need to have more open discussions about unpleasant topics, such as fears, recurrence, and death (Gotcher, 1995).

Avoidance of communication also occurs among family members, including healthy spouses. In a sense, they become part of the "conspiracy of silence" (Zhang & Siminoff, 2003). Spouses have reported that verbal exchanges about feelings generally do not occur with their husbands, which results in uncertainty about each other's feelings or thoughts (Boehmer & Clark, 2001b). Yet, partners are reluctant to discuss cancer or cancer-related issues with patients because they fear it may stir up feelings in their husbands or create problems that are nonexistent for their husbands (Arrington, 2005). Spouses themselves not only hold back feelings from the patient (Hawes, et al., 2006), some also expect their husbands to hide their feelings to preserve spouses' mental well-

being (Arrington, 2005). However, when couples attempt to protect one another by not sharing information and feelings, they, in fact, limit their ability to support one another to work as a team through the distress.

Another common communication problem is <u>protective buffering</u>, i.e., the efforts to protect one's partner from being upset and being burdened by concealing worries, hiding concerns, and yielding to the partner to avoid disagreements (Coyne & Smith, 1991). Patients or spouses are reluctant to disclose their emotions in order to protect their loved ones from the despair, hopelessness, fears and frustrations they may experience, or to protect themselves from the reactions the other persons may have (Arrington, 2005; Lintz, et al., 2003). Protective buffering, marital satisfaction, and emotional distress are interrelated in cancer patients and partners (Hagedoorn, et al., 2000; Langer, Rudd, & Syrjala, 2007; Manne, et al., 2007). When cancer patients do not openly share their concerns or emotions, they report lower emotional well-being and more emotional distress (Figueiredo, et al., 2004).

To summarize, communication has been recognized as a major source of support that helps couples cope with prostate cancer. Research has shown that, despite the availability of other support resources, partners are often the major or sole confidant for prostate cancer patients. Yet little is known about how communication between partners changes overtime, and how it may affect their survivorship experiences.

### DESIGN AND METHODOLOGICAL ISSUES

### **Design Issues**

An increasing number of studies have provided important information on communication patterns in cancer populations. However, some design and methodological issues warrant examination. First, there is a lack of research on couples' communication in the prostate cancer literature; most studies pertaining to communication have been conducted in the breast cancer population. The significant

gender and role differences associated with prostate and breast cancer may result in major differences in how couples share information and concerns during their survivorship. Women are traditionally socialized to be open and more emotionally expressive; it is acceptable for breast cancer patients to openly talk about how the illness affects their lives. However, men, especially those holding more traditional conceptions of masculinity, often repress their emotions to show strength and invulnerability. The norms that "men don't cry" and "men need to be strong and tough" are the essential aspect of most masculine ideologies, which makes the communication between prostate cancer patients and partners difficult and at times impossible. Thus, the physical as well as cultural contexts need to be considered when we explain how prostate cancer affects different aspects of couples' life, including their communication.

Next, few studies have concurrently examined the perspectives of both patient and family members, especially the spouses, regarding communication (Boehmer & Clark, 2001b, 2001a; Northouse, et al., 2007a; Oh, et al., 2007). There are limitations when research includes only one partner, often the prostate cancer patient, to report on the communication between partners. The perception of one partner may be quite different from that of the other partner. As noted by researchers, spouses often have lower emotional quality of life, less confidence in their ability to manage the illness, and perceive less support than prostate cancer patients (Northouse, et al., 2007a). One partner reporting for the other is not a reliable or valid source of information about the other partner. Yet, little analysis has been done regarding the communication dynamics between prostate cancer patients and their wives. In order to understand couples' "real experience" during prostate cancer survivorship and to determine the optimal focus for interventions, it is necessary to assess simultaneously both the patient and the partner in future research.

Third, most research on communication between partners has been retrospective and cross-sectional. There is a lack of longitudinal research on how couples' communication patterns change over time in relation to the cancer diagnosis, treatment, and remission or recurrence trajectory (Gray, et al., 2000; Quartana, Schmaus, & Zakowski, 2005; Weber, et al., 2004). The few longitudinal studies that have been conducted have only a short follow-up period (i.e., 4 or 8 weeks) (Quartana, et al., 2005; Weber, et al., 2004). Longitudinal design with a longer period of follow-up will help determine the different challenges couples face at different phases of prostate cancer (i.e., waiting for the diagnosis, during active treatment, recurrence, etc), and thus, provide valuable information for designing "phase-appropriate" interventions tailored to couples' needs.

A fourth issue with many studies on communication in cancer populations is the lack of theoretical orientation to guide the study. As most of the research has been qualitative, grounded theory is often used to explore communication phenomena (Boehmer & Clark, 2001b, 2001a; Gray, et al., 2000). In a handful of quantitative research studies, stress-coping theory (Northouse, et al., 2007a) and transactional theory (Perczek, Burke, Carver, Krongrad, & Terris, 2002) have been used. There is a need for more theory-driven research to study couples' communication in a more systematic manner.

Finally, most of the empirical research on communication in the prostate cancer literature has used small sample sizes (Arrington, 2005; Boehmer & Clark, 2001b, 2001a; Edwards & Clarke, 2004; Weber, et al., 2004), which has plagued the power and generalizability of these studies. Moreover, although African-American men have the highest prostate cancer incidence and mortality rates, the samples of most studies are predominantly white. The homogeneous participant population limits the generalizability

of the results because culture is a critical factor that can have a major impact on communication (Northouse & Northouse, 1998).

#### Methodological Issues

In the literature on communication of couples/families coping with cancer, a variety of methods (e.g., observational techniques, self-report measures, and conversational analysis) have been used. In the following section, the strengths and limitations associated with these methods will be discussed.

<u>Self-report</u> such as narratives, interviews, and questionnaires, has been the most commonly used assessment techniques in studying communication between partners in the context of prostate cancer (Arrington, 2005; Boehmer & Clark, 2001b, 2001a; Northouse, et al., 2007a) (Table1). These self-report methods have used either qualitative or quantitative approaches.

Narrative analysis and interviews are qualitative, self-report methods. Openended questions and probes are used to elicit survivors' stories verbally (Arrington, 2005) or in writing (Salander & Hamberg, 2005). The narratives and interviews are transcribed, lists of the most prevalent elements/themes are compiled, and the stories are compared and contrasted in terms of the elements (Arrington, 2005). Although reflecting survivors' experiences and perspectives, these methods can be influenced by the motives and needs of both participants and observers. Social desirability and the intense emotional involvement of cancer patients and their families may increase their tendency to distort their perceptions of the actual interactions. Observers/researchers may also predetermine what is meaningful in the data and dismiss the "irrelevant" content.

The quantitative self-report method such as questionnaires has been widely used in communication research in cancer populations (Edwards & Clarke, 2004; Oh, et al., 2007; Quartana, et al., 2005) (Table 2.1). Questionnaires and scales, e.g., Lewis Mutuality and Interpersonal Sensitivity Scale (MIS) (Lewis, 1996), are used to assess

communication concerns, frequency, honesty, encouragement, and discussion of unpleasant topics in couples facing prostate cancer (Fried, et al., 2005; Gotcher, 1995; Northouse, et al., 2007a). Objective measurements assess different aspects of communication and often reflect the researcher's perspectives. Thus, investigators have greater control over the data. As very specific and highly structured operational definitions of communication are often required, only a limited spectrum of communication behaviors about cancer experiences may be examined, e.g., avoidance and self-disclosure (Fried, et al., 2005; Jakobsson, Hallberg, & Loven, 1997; Manne, et al., 2006; Porter, et al., 2005) (Table 2.2). This may hamper the generalizability across studies. In addition, self-reports offer only general depictions of detailed and contingently organized interactions (Atkinson & Heritage, 1984). Yet the self-report measures are easily scored and administered to large groups of subjects. They do not require equipment, observers, or laboratory space. With a few modifications and/or additions, their efficiency can be increased substantially.

Observational and objective scoring techniques (e.g., observer rating system and field studies) also have been developed to studying communication interactions (Arrington, et al., 2005; Pistrang & Barker, 1998). The objective data are obtained in an exchange procedure by having the subjects choose a question to answer or a topic to discuss. Thus, the data are often situation-specific, that is, unique to the experimental conditions employed to obtain the data. While the presence of the observer tends to distort people's behaviors substantially and disrupts the normal flow of interpersonal exchange, only few researchers have elaborated on how the protocols are administered to reduce such an impact.

Since subjective evaluation is required, the transcription and ratings of audio or video tapes of the interviews need to be conducted by trained raters (Heaven & Maguire, 1997; Manne, et al., 2004b) or the patients themselves (Pistrang & Barker, 1998). Thus,

the assessment of observation studies is often complex. In addition, communication might not occur in a turn-by-turn sequence. As some people need to wait to respond, there may be a lag time where other information is communicated before the "desired" interaction takes place. Thus, there are concerns embedded in observation techniques, such as the rating reflecting the perspective of participant versus that of the observer/researcher, stereotyped expectations of the observers, and the interaction between observer and subject characteristics (Beach & Anderson, 2003a).

Finally, <u>conversational analysis</u> has been introduced to study the process of communication. It involves the direct examination of recordings and transcriptions of naturally occurring communication activities (Beach & Anderson, 2003b) (Table 2.2). It captures moment-by-moment interactions of medical encounters of cancer patients, family members, and health professionals. Conversational analysis can examine both single cases (e.g., a single conversation or a single response within a conversation) and large collections of recurring phenomena (Schegloff, 1996). This method has only been used in a few communication studies in patients and families coping with breast cancer (Beach & Anderson, 2003b; Pistrang, et al., 1997) (Table 2.2). The goal for conversation analysis is to provide understanding of a particular case and to generate hypotheses, rather than to test hypotheses or to achieve prediction and generalization.

In summary, there are a variety of techniques and methods for studying communication. Researchers need to carefully consider the advantages and disadvantages of each approach. Both objective and subjective assessment schemes need to be incorporated to obtain better understanding about couples' communication behaviors.

### DIRECTIONS FOR FUTURE RESEARCH

This paper has reviewed the importance of dyadic communication and communication problems that couples encounter during cancer survivorship, with a

focus on couples facing prostate cancer. The research design and methodological issues also are discussed. The following section will address a number of ideas and suggestions for future research, which include the need for (1) concurrently examining the experiences of both patients and their family members (e.g., spouses), (2) conducting longitudinal studies, (3) including a diverse population, (4) developing testable hypotheses from theoretical frameworks, and (5) adopting a variety of research methods.

First, there is a pressing need for more research to concurrently examine the experiences of prostate cancer patients and their partners. It is necessary to determine how open communication can benefit one or both partners (e.g., communication that strengthens their relationships and promotes a sense of bonding and trust) and what kind of communication may cause distress. Inclusion of both patients and their partners simultaneously in research helps explore the different perspectives on communicative interactions and information transactions of each partner as well as examine their concordance and discrepancies in communication preferences and behaviors. Such information is critical for clinical practice and interventions to strengthen couples' relationships and facilitate adaptive coping.

Second, future research needs to include more prospective longitudinal studies because coping with prostate cancer often is a chronic process, rather than a transient event. The improvements in early detection and treatment for prostate cancer have led to a 5-year survival rate of 100% for men with localized cancer (American Cancer Society, 2007; SEER, 2006); there are more patients and families whose life may be negatively affected by prostate cancer and its treatment over an extended period of time. Thus, there is a need for studying the communication dynamics between cancer patients and their families over time so as to understand the characteristics of their coping and caregiving patterns at different phases of illness.

Third, future research needs to include populations with diverse etho-cultural background (e.g., couples from different ethnic groups, socioeconomic backgrounds, and sexual orientations). Although the incidence and mortality rates of prostate cancer are racially disparate (American Cancer Society, 2007), evidence of how people share their cancer-related information, feelings, and concerns in the face of physical adversity has been obtained mainly from homogeneous populations (e.g., white, middle to higher social class). Yet, communication is heavily culture-laden: social and cultural backgrounds are intricately related to how people perceive the illness, its treatment, and how they talk/share cancer-related information (Northouse & Northouse, 1998). There is a need to devote great efforts in exploring the communication phenomenon in the context of illness management in diverse populations. Such research will provide evidence for culturally-sensitive cancer care.

Next, future research needs to incorporate theories in studying communication between prostate cancer patients and their families. A clear conceptual and operational definition of communication is often lacking in current studies. Researchers need to explore theories across disciplines to address the complexity of communication issues in couples who strive to manage the illness. Such efforts will help understand the mechanisms of couples' communication and adjustment, and provide evidence regarding the pros and cons of dyadic communication, as well as factors that may improve or deteriorate their communication. Theory-based research will systematically advance evidence-based psycho-behavioral oncology care for patients and their families.

Finally, future research needs to adopt a variety of research methods (i.e., quantitative and qualitative population and laboratory studies) to gain insight into the operation of cancer-related communication during survivorship. Communication is more multidimensional than it is often operationalized (Hummert, Nussbaum, & Wiemann, 1994). Triangulation of qualitative and quantitative methods may compensate for the

limitations of different research techniques, yield more comprehensive insights about cancer-related communication between cancer patients and their families, and offer direct clinical applications.

In conclusion, these ideas about future direction are largely theory-based. The process of implementing these ideas to empirical research can be complex. The information that results, however, will enrich our understanding of the basic processes of communication in close relationships and the health-promoting properties of communication. The information will also provide evidence for clinicians to better facilitate both patients and their partners reap the maximum possible benefits from their most important relationship while managing chronic, sometimes life-threatening illnesses.

Study	Sample	Phase of Illness	Method	Communication Measurement	Outcome
(Arrington, 2005)	16 patients	Not specified	Qualitative (interview)	N/A	<ol> <li>Partners were the main or only person to whom survivors turn to for emotional support against fear and depression.</li> <li>Survivors characterized their partners either as not having concerns about themselves or as keeping those concerns to themselves rather than expressing them.</li> </ol>
(Arrington, et al., 2005)	20 Man to Man group meetings (patients) 14 monthly side- by-side meetings (wives)	Not specified	Qualitative (observation & field note)	N/A	<ol> <li>Men with cancer were less likely to discuss their feelings in public; they are more likely to confide disease-related concerns to their wives</li> <li>Wives spoke little about themselves at support group. Their major concerns were issues related to their husbands' illness.</li> </ol>
(Boehmer & Clark, 2001b)	20 married men 7 wives	Patients treated with orchiectomy and hormone ablation therapy	Qualitative (focus group, retrospective)	N/A	1. There was little spousal communication about the implications of prostate cancer on their lives, especially emotions, worries, and fears.
(Boehmer & Clark, 2001a)	7 married men 7 wives	Metastatic cancer	Qualitative (focus group)	N/A	1. Many men did not share their prostate cancer- related health problems with their wives.
(Edwards & Clarke, 2004)	8 prostate ca patients among 48 patients) 48 family members (59% females)	Patients with surgery, chemotherapy, and radiation therapy	Descriptive Quantitative Cross-sectional	Family relationships index Family environment scale	<ol> <li>Cancer affected the whole family.</li> <li>Act openly and express feelings directly were associated with lower levels of depression</li> <li>Communication among families with a prostate cancer patient was more important than for other families.</li> </ol>

# Table 2.1 Studies of Communication in Couples Coping with Prostate Cancer

Study	Sample	Phase of Illness	Method	Communication Measurement	Outcome
(Gray, et al., 2000)	34 couples with prostate cancer	Not specified	Longitudinal Qualitative (Pre-surgery, 8- 10 wks and 11-13 months)	N/A	<ol> <li>Men avoided telling anyone other than their spouses about prostate cancer.</li> <li>Men's disclosure about illness decreased overtime after surgery</li> </ol>
(Hawes, et al., 2006)	66 partners of prostate cancer patients	Mainly stage I & II	Descriptive (cross-sectional, part of RCT)	NA	<ol> <li>Lack of communication or dysfunctional communication with her husband or partner was one of the most frequently reported problems.</li> </ol>
(Northouse, et al., 2007b)	235 patients 235 partners	All phases	Longitudinal RCT (baseline, 4, 8 and 12 months)	Lewis MIS Scale	1. Couples who participated in the family-based psycho-behavioral intervention were able to communicate more effectively about the illness than those in controls.
(Northouse, et al., 2007a)	263 patients 263 spouses	Advanced, biochemical recurrent, and newly diagnosed	Descriptive (cross-sectional, part of RCT)	Lewis MIS Scale	<ol> <li>Biochemical recurrence dyads had significantly less communication about the illness than newly diagnosed and advanced dyads.</li> </ol>
(Oh, et al., 2007)	106 patients 106 partners	Early stage (before radical prostatectomy)	Descriptive (cross-sectional)	10-item communication within patient- partner dyad	<ol> <li>Patients with high need for cognition who were partnered with high need for cognition partners reported better dyadic communication than others.</li> </ol>
(Fergus, et al., 2003)	34 patients 34 female partners	Not specified (Before radical prostatectomy, 8-10 weeks, and 1 year post-surgery)	Qualitative, longitudinal (Separate semi- structured interviews for patients & partners)	N/A	<ol> <li>Women found their partner's protective efforts to be antagonistic to their own and the patient's coping, esp. when attempts to hide negative feelings were unsuccessful</li> <li>Patients' verbal expressions of appreciation positively influenced their partners' perception of themselves and their caregiver role.</li> </ol>

# Table 2.1 Studies of Communication in Couples Coping with Prostate Cancer (Cont'd)
Study	Sample	Phase of Illness	Method	Communication Measurement	Outcome
(Gotcher, 1995)	Among 102 subjects, 55 prostate cancer patients	Not specified (Undergoing radiation therapy)	Descriptive (Triangulation: qualitative and quantitative)	Researcher- developed communication scale measuring frequency, honesty, encouragement, discussion of unpleasant topics	<ol> <li>Well-adjusted patients and maladjusted patients differed in the frequency of communication, level of honesty in the communicative environment, amount of encouragement received from relational partners, and the way unpleasant topics were handled.</li> <li>Well-adjusted patients reported talking significantly more often about the illness and its consequences than maladjusted patients.</li> </ol>
(Quartana, et al., 2005)	75 Pca patients (Total: 120 subjects)	All phases (within 5 years since first diagnose)	Descriptive Longitudinal Quantitative	Social Constraint Scale-Spouse	1.Men tended to reveal less emotion to others than women.
(Kershaw, et al., 2008)	134 patient- partner dyads	All phases	Longitudinal study (baseline predictors, 4-month appraisals, 8-month coping variables, and 8- month outcomes)	Lewis MIS Scale	<ol> <li>Patients with less communication at baseline reported more hopelessness at 4-month follow-up.</li> <li>Patients had higher hopelessness when their spouses reported more communication.</li> <li>Spouses with less communication at baseline had more uncertainty at 4-month follow-up.</li> </ol>
(Manne, Babb, Pinover, Horwitz, & Ebbert, 2004a)	60 wives of prostate cancer patients	Not specified	Longitudinal Randomized clinical trail	Cancer-specific marital interactions	<ol> <li>No significant differences in the cancer-specific marital interaction scores between wives in the psychoeducational intervention group and those in the control group.</li> </ol>

# Table 2.1 Studies of Communication in Couples Coping with Prostate Cancer (Cont'd)

Study	Sample	Illness	Method	Outcome
(Badr & Acitelli, 2005)	13 patients 12 spouses	Lung cancer	Qualitative (Semi-structured interview)	<ol> <li>A variety of social constraints hindered open spousal communication.</li> <li>Patients and spouses reported trouble discussing continued tobacco use, cancer-related symptoms, prognosis, and emotional offacts of the illness on the anguage</li> </ol>
(Figueiredo, et al., 2004)	66 patients	Breast cancer	Descriptive Quantitative Cross-sectional	<ol> <li>Failure to disclose concerns was associated with low social support, high unsupportive social interactions, and low emotional well-being.</li> </ol>
(Fried, et al., 2005)	193 patients 193 caregivers	Cancer (not specified) Heart failure COPD	Descriptive Quantitative Cross-sectional	<ol> <li>A large proportion of caregivers and seriously ill older persons had an unmet desire for increased communication.</li> <li>Caregivers and patients frequently disagreed with each other about their desire for more communication.</li> <li>Caregivers' desire for more communication is highly related to caregiver burden.</li> </ol>
(Glajchen, et al., 1995)	191 patients	Cancer (Not specified)	Descriptive Cross-sectional	1. Family communication and other psychological, demographics, and medical factors could complicate cancer pain assessment and treatment of cancer pain.
(Gotcher, 1992)	102 patients	Cancer patients receiving radiation therapy	Descriptive Cross-sectional	<ol> <li>Communicating with significant others about cancer in an emotionally supportive environment was conducive to patients' effective adjustment.</li> </ol>
(Hagedoorn, et al., 2000)	68 patients	Cancers of breast, intestine, skin, larynx, and bone	Descriptive Cross-sectional Quantitative	<ol> <li>Protective buffering and overprotection were negatively associated with marital satisfaction only when patients experienced relatively high levels of psychological distress or physical limitations.</li> </ol>
(Harrison, et al., 1995)	520 patients	breast, colon, female reproductive tract, testicle or lymphoma	Descriptive Cross-sectional	<ol> <li>Men were as likely as women to have confided their main concerns in others.</li> <li>Men were more likely to use only one confidant while women used more confidants.</li> </ol>

# Table 2.2 Studies of Communication in Couples Coping with Cancer

Study	Sample	Illness	Method	Outcome
(Henderson, Davison, Pennebaker, Gatchel, & Baum, 2002)	299 patients	Breast cancer	Descriptive Cross-sectional	<ol> <li>Patients discussed their cancer more often to their spouses and doctors in the month following their diagnosis.</li> <li>Greater disease disclosure was predicted by younger participant age, greater disease severity, optimism, stress-related growth, and disclosure-oriented attitudes.</li> </ol>
(Hilton, 1994)	41 patients 41 partners	Breast cancer	Qualitative and quantitative	<ol> <li>There are different types of communication between partners.</li> <li>The congruence and discrepancy of communication depended on spouses' perception of the importance of sharing their fears and concerns.</li> <li>The diagnosis of cancer didn't change the communication pattern for "talkers."</li> <li>"Nontalkers" were usually older, with no children or with grown children.</li> </ol>
(Hinton, 1998)	76 patients 76 family caregivers	Terminal cancer (not specified)	Quantitative Longitudinal (8 wks before and after patients passed away)	<ol> <li>Patients had more open communication about feelings and conditions with their spouses and children than with Health Care Providers.</li> <li>Caregivers' satisfaction and acceptance of the situation were associated with patients' open communication about prognosis, feelings and dying.</li> <li>Caregivers later felt more regrets if they themselves had less communication with patients about the condition or situation</li> </ol>
(Iwamitsu, et al., 2005)	14 patients	Breast cancer	Longitudinal (1st visit, post diagnosis & operation, 3 months after discharge)	<ol> <li>Patients with emotional suppression tended to report more emotional distress at visit, after diagnosis &amp; discharge.</li> <li>Patients suppressed anger &amp; anxiety felt strong psychological distress</li> </ol>
(Manne, et al., 2006)	147 patients 127 partners	Breast cancer	Descriptive Quantitative Longitudinal (During cancer treatment & 9 months later)	<ol> <li>Mutual constructive communication was associated with less distress and more relationship satisfaction for both patients and partners.</li> <li>Demand–withdraw communication was associated with higher distress and lower relationship satisfaction for both patients and partners.</li> <li>Mutual avoidance was associated with more distress but was not associated with relationship satisfaction for patients and partners.</li> </ol>
(Manne, et al., 2004b)	148 patients 148 partners	Breast cancer	Descriptive Cross-sectional	<ol> <li>Partners' responses played a role in women's adaptation to breast cancer and psychological distress.</li> </ol>

# Table 2.2 Studies of Communication in Couples Coping with Cancer (Cont'd)

Study	Sample	Illness	Method	Outcome
(Pistrang & Barker, 1995)	113 patients	Breast cancer	Descriptive Cross-sectional	<ol> <li>Good communication with the partner was characterized by high empathy and low withdrawal.</li> </ol>
(Pistrang, et al., 1997)	3 patients 3 partners	Breast cancer	Descriptive Qualitative Conversation analysis	<ol> <li>Communication between couples served positive purposes.</li> <li>The effectiveness of communication on support depended largely on the personal meanings of the interactions and the context of the couple's relationship.</li> </ol>
(Pistrang & Barker, 1998)	26 patients 26 partners	Breast cancer	Descriptive Cross-sectional Conversation analysis	<ol> <li>Helpful couples' conversation was negatively correlated with criticism.</li> <li>The partners who were lower in marital adjustment scores tended to use less exploration and more criticism.</li> </ol>
(Porter, et al., 2005)	47 patients 45 partners	Gastrointestinal cancer	Descriptive Cross-sectional	<ol> <li>Patients and their spouses varied in how much they discuss their cancer-related concerns with each other.</li> <li>Spouses reported lower levels of disclosure than patients and engaged in protective buffering to a greater degree than patients.</li> <li>Both patients and partners' high levels of holding back was related to less perceived intimacy, and more negative responses from the other partner.</li> </ol>
(Quartana, et al., 2005)	75 Pca patients (Total: 120 subjects)	All phases (within 5 years since first diagnose)	Descriptive Longitudinal Quantitative	<ol> <li>Female pts who experienced and expressed significant levels of distress tended to foster the greatest constraints from their male spouses.</li> <li>Men tended to reveal less emotion to others than women.</li> </ol>
(Salander & Hamberg, 2005)	83 narratives by cancer patients	Testicular/prost ate respiratory, Ear, nose and throat, bowel, lymphoma, lung, et al	Descriptive Qualitative	<ol> <li>Female patients wrote longer, more personally, and more emotionally than the males.</li> <li>Female patients complained more about bad connections and negative experiences.</li> </ol>
(Walker, 1989)	60 patients 60 husbands	Breast cancer	Descriptive Cross-sectional Quantitative	<ol> <li>Increased communication about the treatment was associated with an increase in both measures of adjustment for wives and fear of recurrence for husbands.</li> <li>Reciprocity of support predicted husbands' general emotional adjustment.</li> </ol>

# Table 2.2 Studies of Communication in Couples Coping with Cancer (Cont'd)

Study	Sample	Illness	Method	Outcome
(Walker, 1997)	58 patients 58 husbands	Breast cancer	Descriptive Cross-sectional	<ol> <li>The amount of communication about the illness explained the most variance in adjustment for both patients and partners.</li> </ol>
(Walsh- Burke, 1992)	7/14 patients completed 7/13 spouses completed	Mainly breast cancer	Longitudinal Intervention (1 wk pre-, 1wk and 3-mon post- intervention)	<ol> <li>Families with more open communication had less difficulties coping with cancer.</li> <li>The psychosocial educational intervention improved open communication.</li> </ol>
(Ward, Leventhal, Easterling, Luchterhand, & Love, 1991)	Study 1: 81 patients Study 2: 99 patients	Cancer patients receiving chemotherapy (Not specified)	Study 1: Descriptive Cross-sectional Study 2: Interventional	<ul> <li>Study 1:</li> <li>1. Communication with significant others about the disease might damage a patient's self-esteem even when the others are perceived as supportive.</li> <li>Study 2:</li> <li>1. Higher levels of communication—sharing information were associated with greater self-esteem.</li> </ul>
(Zhang & Siminoff, 2003)	37 patients 40 caregivers (Total: 26 families)	Lung cancer	Qualitative	<ol> <li>The avoidance of family communication was common.</li> <li>The avoidance of communication was to avoid psychological distress, to achieve mutual protection, and to engage in positive thinking.</li> </ol>

# Table 2.2 Studies of Communication in Couples Coping with Cancer (Cont'd)

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#### CHAPTER III

# CANCER TALK: A LONGITUDINAL STUDY OF COUPLES' COMMUNICATION DURING CANCER SURVIVORSHIP USING MULTILEVEL MODELS

## INTRODUCTION

Communication is an integral part of day-to-day life while patients and their partners cope with cancer and the side effects associated with its treatments. Couples' communication, i.e., the exchange of cancer-related information and concerns between patients and their partners, is not only a function of informal caregiving, but also an important source of mutual support for patients and partners. Communication has been shown to affect quality of life (QOL) of cancer survivors and their families.<sup>1,2,3</sup> Knowing the patterns of couples' communication will provide valuable information that can help develop intervention strategies to assist couples to communicate effectively and to support one another as they face the challenges during cancer survivorship. The purpose of this longitudinal study is to examine the patterns of change in communication and factors associated with communication over time in couples when the husband has prostate cancer. The research aims are two-fold: 1) to compare patterns of change in levels of dyadic communication by role (patient versus partner) and by phase of illness (i.e., localized, biochemical recurrence, and advanced) over time, and 2) to examine whether personal (age and education), social/familial (length of relationship and social support), and cancer-related factors (prostate cancer-specific symptoms, general symptoms, and uncertainty about the illness) are associated with the dyadic communication between patients and partners over time.

#### LITERATURE REVIEW

#### Communication

Communication is a complex process and a multidimensional social phenomenon. It involves the exchange of information between a source and a receiver.<sup>4</sup> The information that is exchanged via messages can be factual in nature or involve feelings or attitudes; the expression of information by a person becomes communication when others (e.g., family members) interact.<sup>5</sup> During the course of cancer survivorship, communication is often concerned with the coping process that affects the patients and their families.<sup>6</sup> In this paper, communication refers to the exchange of information about cancer and personal experiences (such as concerns and feelings about the illness) that occurs between cancer patients and their partners.<sup>7,8</sup>

Two underlying assumptions that are drawn from a Systems Theory perspective are of particular relevance to studying interpersonal communication. First, communication is dynamic rather than static or linear in nature.<sup>4</sup> Second, communication is a transactional process involving a bidirectional transfer of information; both individuals in an interaction simultaneously influence and are influenced by one another. Viewing communication as a reciprocal transactional process shifts the focus from the individual to the dynamic relationship between individuals.

## Communication between Patients and Partners during Cancer Survivorship

Communication between partners plays an important role during cancer survivorship. It provides cancer patients and families with distraction and companionship as well as with opportunities to exchange information and share feelings and concerns.<sup>9,</sup> <sup>10, 11, 12</sup> This sharing helps couples to stop persistently thinking about upsetting events, to develop insight into each others' perspectives about the situation, and to clarify the meanings of their feelings.<sup>12, 13</sup>

However, prostate cancer patients and their partners often report inadequate communication.<sup>14, 15, 16, 17</sup> Qualitative studies have shown that men with prostate cancer often identify their partners as their major (sometimes their only) source of support, especially emotional support.<sup>15, 17</sup> Yet wives report that verbal exchanges with their husbands about the cancer and illness-related feelings often do not occur.<sup>16</sup> Most men avoid discussing their cancer except on a "need to know" basis.<sup>14</sup> Striving to return to their "normal life," prostate cancer patients often are reticent about their symptoms and treatment side effects (e.g., urinary, bowel, and sexual dysfunction), and the effects of these concerns on their emotional well-being.<sup>16, 18, 19</sup> On the other hand, partners themselves also play a role in the "conspiracy of silence" as they often hold back feelings from patients as well.<sup>20</sup> Both prostate cancer patients and their partners.<sup>17, 21</sup> Yet, the failure to communicate effectively with each other can make informal caregiving more difficult, which in turn may have a deteriorating effect on the QOL of both patients and caregivers.

#### Factors That May Influence Couples' Communication

The factors that may affect couples' communication during cancer experiences can be categorized into personal, social/familial, and cancer-related factors. First, <u>personal factors</u> such as *age, gender, race,* and *education* may influence how couples communicate while coping with cancer. *Age* plays an important role in communication between partners. Specifically, couples who are older and/or retired tend to discuss cancer less than younger couples.<sup>22</sup> Younger age is linked to greater disease disclosure in patients with early stage breast cancer,<sup>23</sup> and older age is associated with a lower level of dyadic communication in patients undergoing chemotherapy.<sup>24</sup> There have been no studies on age and its relation to communication in prostate cancer.

Gender is another important variable that may affect couples' communication. In general, men do not reveal their emotions to others as much as women.<sup>16, 25</sup> Another study found that, while patients' disclosure was not related to their gender, race, or education level, female spouses tended to share more personal information than the male spouses.<sup>3</sup>

<u>Social/Familial factors</u> have been found to affect couples' communication during cancer survivorship. Specifically, the *length of relationship* is negatively related to patients' disclosure and couples' sharing cancer-related information,<sup>3, 22</sup> suggesting that couples in longer relationships are less likely to discuss or share cancer-related information. *Social support*, the network of family, friends, neighbors, and community members that is available in times of need, has been related to active coping in both cancer patients and families.<sup>26, 27, 28</sup> Yet, there has been limited research exploring the relationships between social support as perceived by patients and families and their patterns of communication.

Finally, <u>cancer-related factors</u> may affect how couples communicate. The number of *months since diagnosis* affects whether couples share cancer-related information with each other. Hilton<sup>25</sup> reported that, regardless of communication patterns, couples decreased their discussion of the cancer and its related issues over time.<sup>22</sup> For most couples, once the treatments were completed and side effects had abated, their communication about cancer phased out. Porter and colleagues<sup>3</sup> found that the longer the gastrointestinal cancer patients of both genders had been dealing with the illness, the less likely they were to talk about their illness-related concerns with their spouses.<sup>3</sup> However, healthy spouses' disclosure was not found to be associated with months since diagnosis, indicating some discrepancy in couples' communication also seems to decrease as months since diagnosis and/or treatment elapse.<sup>14</sup>

Regarding the relationship between the *phase of illness* and couples' communication, findings are inconsistent. Some researchers report that patients with more advanced cancer tend to have higher levels of disclosure,<sup>23</sup> but data from other research have not supported this relationship.<sup>3</sup> For prostate cancer in particular, couples in the biochemical recurrence phase of illness report significantly less communication about the illness than couples in the newly diagnosed localized and advanced phases of illness.<sup>29</sup>

*Uncertainty about the illness* is common among cancer patients and partners.<sup>29</sup> It also has been used as one of the outcomes in a series of psychoeducational intervention studies to promote quality of life in cancer patients and their families.<sup>1, 30, 31, 32</sup> However, there has been little research on how uncertainty about the illness affects the levels of dyadic communication between cancer patients and their families.

Finally, there has been limited information on how cancer symptom distress affects couples' communication. In general, cancer patients and spouses frequently have trouble discussing cancer-related symptoms, prognosis, and the emotional effects of cancer.<sup>33</sup> Among couples facing prostate cancer, men are capable of communicating the factual physical changes to their wives, but are less willing or unable to share their feelings regarding the changes.<sup>16</sup>

## Methodological Limitations of Previous Studies

There have been some methodological limitations in previous studies of communication in the context of cancer. First, only a few studies have concurrently examined the perspectives of both patient and their family members regarding communication.<sup>15, 16, 29, 34, 35</sup> There are limitations when research relies on only one partner, often the cancer survivor, to report on the communication between partners. The perception of one partner may be quite different from that of the other partner. Thus, one partner reporting for the other is not a valid and reliable source of information about

the dyadic communication. Little analysis has been done regarding the relational dynamics that exist between prostate cancer patients and their wives.

Second, most research on communication between partners has been retrospective and/or cross-sectional. There is a lack of prospective longitudinal research on how couples' communication patterns change over time in relation to a cancer diagnosis and its treatment.<sup>14, 25, 36</sup> The few longitudinal studies that have been conducted have only a short follow-up period (e.g., 4 or 8 weeks between baseline and follow-up assessments)<sup>25, 36</sup> and/or use small samples.<sup>36</sup> Adequately designed longitudinal research will provide a better understanding of how communication patterns change over time as couples face different challenges at various phases of survivorship.

Last, there are dilemmas in family research, especially in analyzing family/couple data. For research that involves multiple family members, a common practice that researchers have used is to aggregate the measurements and assessments of different people to obtain one single score by averaging summing, differencing, or maximizing across family members.<sup>37</sup> This practice, although is convenient, can cause aggregation bias and generate inaccurate results and interpretation that are different from the reality.

#### METHODS

#### Study Design

This research was a secondary analysis of the longitudinal data obtained from a randomized clinical trial (RCT) testing a family-based supportive nursing intervention to improve quality of life for patients with prostate cancer and their partners (parent study). After informed consent was obtained, research participants completed the baseline measurement, were stratified by phase of illness (i.e., localized, biochemical recurrence, and advanced/metastatic) and risk for distress, and then randomized to one of three arms, extensive intervention, brief intervention, or control (standard care). Follow-up measurements were obtained at 4-, 8-, and 12-month post-baseline.

## Participants and Procedures

*Sample:* The participants of the current study included only patients and their partners from the control group (usual care condition) of the RCT to eliminate any possible effect of the experimental condition (i.e., family-based intervention) on the study variables. The sample and sampling method for the RCT have been reported previously. <sup>29, 32, 38</sup> Patients were 30 years of age or older, had a life expectancy of at least 12 months, lived within a 75 mile radius of one of the participating research sites, and had a spouse or live-in partner (male or female) who also was willing to be in the study. The partners were eligible for the study if they were 21 years of age or older and identified by the patient as his partner or spouse. Patients were excluded if they had a second primary cancer, and partners were excluded if they themselves had been diagnosed with cancer within the previous year or were receiving active treatment for cancer. The dyad was excluded if either member was ineligible or unwilling to participate.

*Measurements:* The measurements used to assess study variables and their psychometric properties are summarized in Table 3.1. All measures were assessed at baseline, and 4-, 8-, and 12-month follow-ups unless otherwise noted. The outcome variables are the patient's and partner's perceived levels of dyadic communication about the illness. The predictor variables included personal (i.e., age, education, and income), familial (i.e., length of relationship and social support), and cancer-related factors (i.e., months since diagnosis, phase of illness, uncertainty about the illness, and symptom distress). All measures were completed independently by the patient and the spouse.

## Insert Table 3.1 Here

## The variables and the measurements

<u>Dependent variables</u>: The 23-item Lewis Mutuality and Interpersonal Sensitivity Scale (MIS) <sup>39</sup> was used to independently assess the perceptions of dyadic communication for patients and for their partners. All items are worded using the

pronoun "we" to obtain each participant's perception of the extent to which he/she communicates with the partner about the information and feelings related to cancer. With a 5-point Likert scale with response choices ranging from 1 (never true) to 5 (always true), higher scores indicate more open dyadic communication about the illness with one another. Examples of the items of this instrument include "We keep the communication open between us about the cancer" and "We spend a lot of time talking about how things are going with the cancer." In the original study, factor analysis of the scale yielded three factors: talking a lot, sharing feelings, and keeping positive. Subscales to total scale correlations are sufficiently high<sup>41</sup> to warrant using only the total scores in this study. Evidence of construct and criterion validity have been reported.<sup>39</sup> The internal consistency reliabilities ( $\alpha$ ) for prostate cancer patients and partners were .90 and .91 in the parent study.<sup>29</sup>

Independent variables: Personal factors (i.e., age, and education) were evaluated at baseline using the demographic section of the Risk for Distress (RFD, originally known as Omega Screening Questionnaire).<sup>40</sup> The RFD has been used to assess the risk for distress in over 1500 radiation therapy patients,<sup>42</sup> and more recently in patients with breast and prostate cancer and their family members.<sup>29, 41</sup> RFD has been shown to possess sound concurrent, predictive, and construct validity and test-retest reliability.<sup>40</sup>

Social/family factors included the *length of relationship* and *social support. The length of marriage/relationship* was measured using a question in the demographic section of the RFD. *Social support* was assessed with the Personal Resource Questionnaire (PRQ) developed by Brandt and Weinert.<sup>42</sup> This 25-item Likert scale measures the amount of general social support people perceive from others (e.g., friends and relatives). Adequate internal consistency and evidence of predictive and

construct validity have been established.<sup>42</sup> The Cronbach's alphas were .89 for both prostate cancer patients and partners in the parent study.<sup>29</sup>

Cancer-related factors include *months since diagnosis, phase of illness, uncertainty about the illness,* and *symptom distress. Months since diagnosis* and *phase of illness* (localized, biochemical recurrent, and advanced) were obtained from patients' medical history questionnaire. *Uncertainty about the illness* was assessed using the 28item Mishel Uncertainty in Illness Scale.<sup>43</sup> Validity and reliability of this scale have been well established in patients with breast and prostate cancer.<sup>34, 43</sup> The Cronbach alphas were .91 for both prostate cancer patients and partners in the parent study.<sup>29</sup>

Symptom distress consists of prostate cancer-specific symptoms and general symptoms. Prostate cancer-specific symptoms in patients (i.e., bowel, hormonal, sexual, or urinary symptoms) were measured using the 50-item Expanded Prostate Cancer Index Composite (EPIC).<sup>44</sup> Concurrent validity of the EPIC has been previously reported by Wei *et al.*<sup>44</sup> The partners completed a four-item EPIC spousal version which assessed how much of a problem their husbands' bowel, hormonal, sexual, or urinary symptoms was for the spouses. Higher scores in the EPIC indicate fewer prostate cancer specific symptoms. The Cronbach alphas ranged from .77 to .93 for the EPIC subscales in the parent study.<sup>29</sup> General symptom distress (e.g., fatigue, pain, and sleep disturbance) was measured with the 16-item Symptom Scale, which is a part of the RFD.<sup>40</sup> Patients and partners independently rated their own symptoms on a 3-point scale (no trouble, some, and a lot), with higher total scores indicating more general symptom distress. The satisfactory reliability and validity of this scale have been reported previously in patients and family caregivers with different types of cancer.<sup>29, 40, 41</sup> Its reliability alphas were .82 and .81 for prostate cancer patients and their partners, respectively, in the parent study.<sup>29</sup>

## DATA ANALYSIS

Preliminary analyses described demographic and medical characteristics of patients and spouses. Examination of histograms and analyses of skewness identified non-normally distributed data. Chi-square analyses and Student t-tests were conducted to assess any differences between patients and partners at baseline.

To achieve the research aims, a series of multilevel models (MLM) for the longitudinal measures of communication (i.e., separate models for prostate cancer patients and their partners, and combined models for couples) were fitted. Maximum likelihood (ML) estimation was employed in the linear mixed models procedure in SPSS 16.0 to fit all the models except the crude model, which was fitted using restricted maximum likelihood (REML).<sup>45</sup> According to the multilevel model specification, the repeated measures of the outcome variable (levels of dyadic communication) and time-varying predictors (i.e., social support, uncertainty about the illness, prostate cancer specific symptoms, and general symptoms) were conceptualized as being nested within individuals were conceptualized as being nested within couples.

In order to guide the specification of the combined model for couples, separate models for patients and partners were first fitted so that variables significantly related to levels of dyadic communication could be identified. While the separate models had two levels (i.e., estimating the variance at intra-personal and inter-person levels in changes in the levels of dyadic communication across time) (Figure 3.1), the combined model had three levels as indicated in Figure 3.2: intra-personal variation (level-1), intra-couple (level-2), and inter-couple variability in levels of dyadic communication (level-3). The separate models for patients and partners were fitted in two steps: crude, including only linear and quadratic effects of time, and adjusted models which expanded the crude model to include all other variables of interest. The combined models for couples were created in a similar fashion. The adjusted combined model the was reduced to a final

parsimonious combined model to isolate significant predictors of the changes in levels of dyadic communication in couples across time.

#### Insert Figure 3.1 Here

## Data Structure for the Separate Models

#### Insert Figure 3.2 Here

## Data Structure for the Combine Multilevel Models for Couples

These models also included random intercepts and random linear and quadratic time effects. However, it was observed that the random time effects were not significant, suggesting patterns in communication over time do not vary significantly among patients and spouses, thus the random time effects were dropped from the models. Subject-specific group centering of predictors was used for ease of interpreting the results.<sup>46</sup> Specifically, the continuous predictor variables were scaled by subtracting the mean of an individual person (patient or partner) across time from each observed score. EPIC for patients and spouses were standardized within individuals because of the major scoring differences between the patient (50 items) and partner (4 items) versions.

In this study, the "time" predictor was treated as a continuous variable. Referring to the month since the prostate cancer diagnosis, the time variable was calculated as the months since diagnosis at baseline (which varied for different individuals) plus the months since baseline of the follow-up interviews (i.e., 0, 4, 8, and 12, respectively). Since the exploratory plots suggested that trends in levels of dyadic communication were non-linear in nature, the linear and quadratic fixed effects of time were included in the models to capture the potentially curvilinear effect of time on communication. These models allowed for assessment of whether the perceived levels of dyadic communication reported by patients and/or partners changed over time and whether the changes were at a constant rate (linear time effect) or at a rate that accelerated (or decelerated) over time (squared time effect).

Competing models were compared to each other via (1) the likelihood ratio test (LRT)—a statistical test comparing the fit of a larger model to a more parsimonious nested model with fewer parameters,<sup>45</sup> and (2) the effect size—the percentage of change in the three variance components between the final parsimonious and fully unconditional models. The results from the final combined model would provide evidence on whether the patterns of change in levels of dyadic communication over time (a) varied by role, (b) varied by phases of illness, and (c) were related to personal, social/familial, and cancer-related factors.

## RESULTS

## **Descriptive Findings**

Of the 134 dyads who were in the control group in the RCT and completed the baseline assessment, 124 completed the 4-month assessment, 123 completed the 8-month assessment, and 114 completed the final follow-up assessments at 12 months. Participants' characteristics are listed in Table 3.2. Patients were diagnosed with localized (n=87; 65%), biochemical recurrent (n=16; 12%), or advanced cancer (n=31; 23%). In general, patients were older and with higher education than their partners. For all the participants, the mean *years of marriage* was 31.74 (SD=14.26) and no significant differences were found across phases of illness. Patients' mean *months since diagnosis* at recruitment was 28.96 (SD=39.66) months. Couples coping with localized cancer had more recent diagnosis (mean=7.90 months, SD=4.19) than those coping with biochemical recurrent (mean=85.44 months, SD=42.21) and advanced cancer (mean=58.92 months, SD=45.99), F(2, 131)= 83.91, p<.001.

## Insert Table 3.2 Here

## Descriptive Statistics for Research Participants at Baseline

## Model Building Results for Patients

In the <u>crude model</u>, there was no evidence of a linear or quadratic change in communication over time. After adjusting for other important patient variables, time remained non-significantly related to levels of dyadic communication. Higher levels of uncertainty about the illness were negatively related to the levels of dyadic communication. Higher social support was positively related to levels of dyadic communication in patients. Patients' age, education, phases of illness, prostate cancer specific symptoms and general symptoms were not significantly related to patients' perception of levels of dyadic communication.

#### Insert Table 3.3 Here

## Summary of Parameter Estimates

of the Mixed Model of Levels of dyadic communication for Patients

## Model Building Results for Spouses

In the crude model (Table 3.4), the linear and quadratic effects of time were significant, suggesting that partners experienced changes in their levels of dyadic communication over time. After controlling for all other predictors, the linear effect of time continued to have a significant negative effect on dyadic communication. Yet the quadratic effect of time became insignificant. This suggests that levels of dyadic communication decreased over time at a constant rate for partners when controlling for the other covariates. The factors that were significantly related to partners' perception of levels of dyadic communication included social support, uncertainty about the illness, patients' phase of illness, and prostate cancer-related hormonal symptoms. Consequently, these factors were kept in the combined model for further investigation. Partners who reported higher social support, less uncertainty about the illness, and fewer hormonal symptoms in patients tended to report higher levels of dyadic communication. In addition, partners of patients with localized prostate cancer perceived

significantly lower dyadic communication. The perceived levels of dyadic communication did not differ between partners of patients with advanced cancer and those with biochemical recurrence. Partners' age, education, general symptoms, and other prostate cancer specific symptoms in patients were not related to partners' perceived levels of dyadic communication.

### Insert Table 3.4 Here

## Summary of Parameter Estimates

#### of The Mixed Model of Levels of dyadic communication for Partners

## **Combined Model Fitting for Couples**

In the <u>crude (fully unconditional) combined model</u>, the variance in the outcome variable (i.e., levels of dyadic communication) was statistically significant across the three different levels: intra-personal, intra-couple, and inter-couple, suggesting a three-level analysis was justified. Next, the <u>full multilevel model</u> (Table 3.5) was fitted with all the predictors that were significant in the separate adjusted models for patient or partner, and the interaction terms among the major variables of interest (i.e., time, role, and phase of illness). The following variables and interactions were significantly related to couples' levels of dyadic communication in the full model: time (linear), time-squared (curvilinear), phase of illness, social support, uncertainty about illness, prostate cancerspecific hormonal symptoms, and interactions between role and time (linear and curvilinear effects). The interaction between role and phase of illness and the interaction between time and phase of illness were insignificant, and thus, excluded from the final model.

#### Insert Table 3.5 Here

# Summary of Parameter Estimates of the Mixed Model of Levels of dyadic communication for Couples

The <u>final parsimonious model</u> was fitted with all predictors and interaction terms that were significant in the full model. In the final model, time and time-squared terms were significant, indicating couples' *levels of dyadic communication* decreased over time and the rate of decline increased over time. The interaction between time and role was significant and the interaction between role and time-squared was marginally significant, suggesting that the rates of change in levels of dyadic communication over time differed by role. The main effect of the "role" variable negatively related to levels of dyadic communication but did not reach statistical significance. This indicates that perceived levels of dyadic communication <u>at diagnosis</u> were similar between cancer patients and their partners who had mean scores on social support, uncertainty about the illness, and prostate cancer-specific hormonal symptoms.

Phase of illness was negatively related to levels of dyadic communication, suggesting couples' levels of dyadic communication varied by phases of illness at diagnosis. Compared with couples facing advanced and biochemical recurrent cancer, those with localized cancer perceived the lowest levels of dyadic communication at diagnosis. The differences in levels of dyadic communication between couples in advanced phase and biochemical recurrence phase did not reach statistical significance. The insignificant interaction between phase of illness and time indicated that patterns of change in patients' perceived levels of dyadic communication over time did not vary by phase of illness. The interaction between phase of illness and role suggested spouses' perceived levels of dyadic communication were similar to patients' at baseline.

The results of the final model also showed that social support and hormonal symptoms were positively related to levels of dyadic communication, suggesting that higher levels of social support from other people and fewer hormonal symptoms in patients increased communication in couples. Uncertainty about the illness was

negatively related to levels of dyadic communication, indicating feeling more uncertainty about the illness reduced levels of dyadic communication in couples.

The significant random effects in the final model, after controlling for all fixed effects, indicated that the total variability in couples' levels of dyadic communication was partitioned into three parts: intra-personal at level one approximately 26% of the variation; intra-couple at level two, 31%; and inter-couple at level three, 43%.

The result of model integrity evaluation using the likelihood ratio test was in favor of the final parsimonious model (chi-sq=9.86, df=7, p=.80, number of observations=888), suggesting the final model was as good as the full model but with fewer predictor variables. By adding the subject-specific variables (role and phase of illness) and time-varying predictors (i.e., months since diagnosis, social support, uncertainty about the illness, and prostate cancer-specific hormonal symptoms) to the fully unconditional model, the final model reduced the variance in couples' levels of dyadic communication by 10.84% at the intra-personal level, 25.33% at the intra-couple level, and 23.89% at the inter-couple level. These results suggest that the parsimonious model also had improved variance estimates. Thus, the final parsimonious model was used to the address the research aims.

#### Primary Results Addressing Research Aims

Aim 1. To compare the patterns of change in perceived levels of dyadic communication by role (patient versus partner) and phase of illness (i.e., localized, biochemical recurrence, and advanced) over time. The final model for couples showed that, when holding all the other predictors constant, 1) there was no significant difference in perceived levels of dyadic communication between patients and their partners at the time of diagnosis; 2) perceived levels of dyadic communication decreased over time in a curvilinear pattern for both patients and their partners, and 3) the patterns of change in the perceived levels of dyadic communication varied by role with partners' perceived

levels of dyadic communication decreasing more rapidly over time than that of patients. (Figure 3.3)

## Insert Figure 3.3 Here

## The Predicted Patterns of Change over Time in

#### Perceived Levels of Dyadic Communication between Patients and Partners

Regarding the phase of illness, the results of the final combined model indicated 1) patients' perceived levels of dyadic communication at the time of diagnosis varied by phase of illness: patients with localized illness reported significantly lower levels of dyadic communication than patients in the advanced and biochemical recurrent illness (Figure 3.4); 2) spouses' perception of levels of couples' communication were similar to patients'; and 3) patterns of change in couples' perceived levels of dyadic communication over time did not vary by phase of illness.

#### Insert Figure 3.4 Here

The Predicted Patterns of Change over Time in Perceived Levels of

Dyadic Communication among Couples Facing Different Phases of Illness

Aim 2. To examine whether person- (sociodemographics), family- (length of relationship and social support), and cancer-related factors (prostate cancer specific symptoms, general symptoms, and uncertainty about the illness) are associated with couples' levels of dyadic communication over time. Some time-varying social/familial and cancer-related factors were associated with couples' levels of dyadic communication over time. Some time-varying social/familial and cancer-related factors were associated with couples' levels of dyadic communication over time. Specifically, higher perceived social support, lower uncertainty about the illness, and lower spouses' or patients' rating of patients' hormonal symptoms were associated with increased perceived dyadic communication for both patients and partners. Couples' age, education, and length of relationship, patients' prostate cancer-specific bowel, sexual, and urinary symptoms, and couples' general symptom scores were not significantly related to couples' levels of dyadic communication.

#### DISCUSSION

This study used multilevel modeling to conduct a longitudinal assessment of patterns of change in levels of dyadic communication between patients with prostate cancer and their partners over time. Results showed that, patients' and partners' levels of dyadic communication were similar at diagnosis and then decreased over time in a somewhat curvilinear pattern. This research also found the rates of change in levels of dyadic communication varied by role. Specifically, the rate of decrease in levels of dyadic communication over time was greater for partners than that of the patients', when both had mean scores in selected physical and psychosocial factors (e.g., social support, uncertainty about the illness, and hormonal symptoms). These findings corroborate the findings of previous gualitative research.<sup>47, 48</sup> In those studies, communication between prostate cancer patients and their spouses was found to decrease over time. Researchers reported that, once the surgery was over, prostate cancer patients and their wives were ready to return to the "normal life." When approaching the first year anniversary of surgery, couples continued to have concerns about long-term effects of treatment and possible spread of disease. But these concerns were typically pushed to the background and rarely addressed in depth.<sup>47</sup> Further, the decline in levels of dyadic communication over time may also indicate that couples' need for communication decreases and they talk about cancer-related issues on a need-to-know basis. At the time of the cancer diagnosis, patients and partners need to deal with a lot of illnessrelated information, which may have motivated them to talk to each other to adjust to the "new situation" and make decisions. As months since diagnosis pass, couples gradually switch their focus from cancer and its treatment to other parts of their lives. Indeed, researchers have found some couples deliberately avoid talking too much about the prostate cancer situation, especially the emotions, as a way of avoiding preoccupation with the illness.47

It is also interesting to note the differences in the patterns of change in levels of dyadic communication between patients and their partners over time. This research showed that partners' perception of dyadic communication decreased at a rate more rapidly than the patients' as months since diagnosis increased although levels of dyadic communication decreased for both persons. It seems that men may have a need to move on and have less desire to talk about the illness. A qualitative study of prostate cancer patients and their wives indicated that couples in general, but particularly the men, had strong desire to get their lives back together and move beyond prostate cancer, which may undercut their communication about fears and their feelings.<sup>16</sup> Research conducted by Gray et al also reported that men sometimes have a tendency to withdraw and they appreciate it when their wives respect their need for retreat.<sup>47</sup> In response to patients' reticence, the partners reciprocate and talk less over time even though they may want more communication.<sup>16</sup> Partners often believe that "it does more damage than good to push them (patients) to talk".<sup>47</sup> The overall downward trend in communication in both patients and spouses over time provides empirical evidence for the assumption that communication is a dynamic transactional process in which the persons in the process mutually influence each other.<sup>49</sup> As one person persistently conceals feelings and thoughts and holds back cancer related information, it may in turn make the other partner give up the effort to communicate, which eventually leads to the "conspiracy of silence."

This study also found the significant effect of the phase of illness on couples' levels of dyadic communication. At the time of diagnosis, couples with localized illness perceived significantly lower levels of dyadic communication than couples in the biochemical recurrent and advanced phases. But the patterns of change in levels of dyadic communication over time did not vary by phases of illness. These findings indicate that couples' levels of dyadic communication at baseline may be affected more
by the phase of illness, whereas the patterns of change of levels of dyadic communication over time are affected more by their role of patient or spouse. Prostate cancer (especially localized cancer) is often considered a "good cancer" that could be cured.<sup>48</sup> Thus, once treatment is over, couples may be ready to move on back to their "normal lives," and thus, they stopping talking about the illness and its impacts on their lives. On the other hand, the biochemical recurrent and advanced phases are often associated with more ongoing threats and bothersome symptoms, which may consequently increase couples' need to share feelings and thoughts about cancerrelated issues, yet not to the same level as observed at baseline.

This longitudinal study found that couples with localized cancer had the lowest levels of dyadic communication, which is different from the findings of the cross-sectional study by Northouse et al.<sup>29</sup> In that study, couples with biochemical reoccurrence prostate cancer had the lowest levels of dyadic communication. Such a difference may be due to the unbalanced sample sizes of couples with different phases of illness in the current study, especially, the sample sizes of participants at biochemical recurrence and advanced phases (N=16 and 31, respectively) were significantly smaller than that of the localized group (N=87). The observed trend in levels of dyadic communication in this study among couples coping with different phases of illness were primarily from couples facing newly diagnosed cancer (i.e., about 68% and 71% of these couples were within one and two years of diagnosis, respectively), especially those with localized cancer who typically were within 1.5 years of diagnosis. Future research needs to include couples at different phases of illness and at different times of survivorship to provide more rigorous evidence.

This study also examined the factors that may be associated with couples' levels of dyadic communication. Among the selected variables, patients and partners who perceived more social support from others (e.g., family, friends, and relatives) and less

uncertainty about the illness had more communication with one another. Social support plays an important role in the coping process during cancer survivorship.<sup>1, 19, 50</sup> Findings from this current study suggest that the more social support cancer survivors and families receive from other sources, the more they communicate. It is possible that sharing their experiences with others in their social network helps both partners normalize their feelings and experiences, which may help them talk to each other, especially those private feelings and thoughts that they do not want to share with others. Meanwhile, partners often report larger social support networks than prostate cancer patients;<sup>16</sup> these networks may help partners adjust to the cancer situation better,<sup>1</sup> which in turn can make the partner more resourceful and supportive to the patients.

Uncertainty about the illness was negatively associated with the levels of dyadic communication in both patients and their partners in this study. As uncertainty increased, communication about cancer and related issues reported by patients and their partners decreased. Mishel indicated in her early work that uncertainty reduces the person's sense of personal resources to manage the situation.<sup>51, 52</sup> Findings from this present study indicate that uncertainty decreases not only personal resources as noted by Mishel, but also couples' coping resources, or their ability to communicate with one another about the illness. Prostate cancer patients and their partners often find themselves in a situation dominated by uncertainty in regard to duration of symptoms associated with treatment and the possibility of a dire prognosis.<sup>12, 20, 47, 48, 53</sup> Because of a lack of certainty or knowledge about the situation, prostate cancer patients and their partners are unsure of how to initiate a discussion about the illness.<sup>47</sup> They also may be uncertain about how the illness affects the other person, and thus, do not know what to say to one another that is helpful.<sup>16, 47</sup> As a result, many couples avoid talking to each other about the cancer for fear of distressing themselves or each other in the face of their uncertainty.

Another interesting finding of this study was that, among all the prostate cancerspecific and general symptoms, only the elevated hormonal symptoms in men (e.g., hot flashes, breast tenderness, and decreased libido) were associated with lower dyadic communication between partners. Boehmer and Clark<sup>16</sup> found that men had a hard time adjusting to their physical changes, were not comfortable disclosing their feelings about these changes to their wives, and often withheld them. Women, on the other hand, want to make sure that they respect the patient's fragility and do not encroach on the patient's territory.<sup>47</sup> They usually do not ask about how their husbands are doing because of a fear they may "stir things up" in their husbands or create problems that are nonexistent for their husbands.<sup>16</sup> Engaging in the "don't talk, don't ask" strategy allows patients and partners to protect themselves and their loved ones by downplaying discouragement or embarrassment associated with certain symptoms.

Researchers also found that men who are faced with ongoing symptoms typically try to minimize the impact.<sup>47</sup> Couples in general believe that there is no use spending a lot of time thinking or talking about the symptoms. They usually prefer to wait and deal with problems when and if they arose.<sup>47</sup> Concealing symptoms, however, makes couples less likely to obtain help and support from other people, and consequently, this behavior may negatively affect couples' communication about the illness.

Unlike previous research,<sup>3, 22</sup> this study did not find any significant relationships between couple's levels of dyadic communication and age, education or length of relationship. This may be because study participants were fairly homogeneous in their age, education, and mean years of marriage (Table 3.2). Future research needs to include participants with more diverse sociodemographic background.

Finally, the study has provided interesting empirical support to the assumption that communication is a multidimensional, interactional process between patients and their partners. Results of the combined model showed that the partition of total variability

in couples' levels of dyadic communication was distributed across intra-personal, intracouple, and inter-couple levels (about 26%, 31%, and 43%, respectively), indicating that couples' communication is affected by personal as well as couple level variables. Further studies need to take into consideration of factors at different levels when explaining the complexity of communication between patients and their families coping with cancer.

#### The Benefits of Using Multilevel Modeling

It is worth noting that one major contribution of this study is the use of multilevel modeling to improve the statistical analysis techniques available to communication researchers. Communication is a complex and interactive process between people, and more advanced statistical modeling methods are needed to detect the variances at different levels (i.e., intra-personal, intra-couple, and inter-couple). Some of the results might otherwise have gone undetected if traditional quantitative methods are used. <sup>45, 46</sup> time effects on patients' levels of dyadic communication were not significant in the separate model for patients but became significant in the final combined model after taking the couple-level variance into consideration. Such findings not only validate the assumption that communication needs to be considered as an interpersonal process (rather than one person activity) but also assert the need of including both cancer patients and their partners when studying the effects of cancer.

The use of multilevel modeling also made it possible to model variance in patterns of change in communication over time (as opposed to assuming the same patterns for all individuals). Further, the multilevel models estimated the variances of individual and couple changes in levels of dyadic communication across time as a function of a set of time-varying variables and the interactions.

#### Limitations

Although the analyses in the present study yield important findings, this study has limitations. First, the sample consisted of primarily Caucasian and African American,

well educated couples with a long marital or relationship history, limiting the gerneralizability of the findings. Future research needs to be conducted with a more diverse sample in regard to race and socio-economic status in order to obtain an indepth understanding on how social and cultural contexts affect couples' communication during cancer survivorship. Second, the inclusion of all male patients and their female partners in the study limited the investigation of how gender affects couples' communication. Another limitation is related to the MIS measurement. Because the MIS focuses on persons going through cancer experiences (either their own or their spouses'), it may not tap into other topics of communication (e.g., their communication needs and their overall communication about other aspects of their lives). Finally, due to the nature of a secondary analysis of data, only a limited number of variables at personal and couple levels were assessed in this study.

#### CONCLUSIONS

The important contribution of this study is that it described patterns of dyadic communication of cancer patients and their partners over an extended (one year) period of time, using prospective data and multiple measurement time points. Evidence from this study showed that perceived dyadic communication decreases over time for patients and partners. The phases of illness and role have significant effects on couples' levels of dyadic communication at the time of diagnosis and over the course of the illness. Some time-varying bio-psycho-social factors (i.e., social support, prostate cancer specific hormonal symptoms, uncertainty about the illness) also contribute to patients' and partners' dyadic communication. Future research on communication between patients and families coping with non-gender specific cancers in a more diverse population may further illuminate the dynamic interaction process during cancer survivorship.

Variable	Instrument	Cronbach's Alpha		
		Patient	Partner	
Outcome variable				
Level of dyadic	Lewis Mutuality and Interpersonal	.90	.91	
communication	Sensitivity Scale (MIS)			
Predictors				
Age*	Risk for Distress Scale (RFD) <sup>#</sup>	na*	na*	
Education*	RFD	na*	na*	
Role (Patient vs Partner)*	RFD	na*	na*	
Length of Relationship*	RFD	na*	na*	
Phase of Illness*	Medical History questionnaire	na*	na*	
Months since diagnosis	Medical History Questionnaire	na*	na*	
Social Support	Personal Resource Questionnaire	.89	.90	
Uncertainty about the Illness	Mishel Uncertainty In Illness Scale	.91	.91	
Prostate Cancer-Specific	EPIC (Expanded Prostate Cancer			
Symptoms:	Index Composite)			
Bowel	<b>1</b>	.84	na†	
Hormonal		.74	na†	
Sexual		.90	na†	
Urinary		.80	na†	
General Symptoms	RFD_Symptom Subscale	.80	.76	

# Table 3.1. Variables and Measurements Used in the Combined DyadicCommunication Model

<sup>#</sup> Formerly named Omega Screening Questionnaire (OSQ)

\*Assessed at <u>baseline</u> only Reproducibility <.90 (test-retest reliability)

<sup>†</sup> Partner version of EPIC consists of a single item for each symptom

Characteristic		Patient	Spouse		Р	
		(N=134)	(N=134)	t		
Mean Age (Year)		62.57	58.92	20.54	< 001	
(SD, Range)		(9.22, 42-90)	(9.65, 34-84)	30.54	<.001	
Mean Education (Y	′ear)	16.13	14.68	12 30	< 001	
(SD, Range)		(3.63, 8-29)	(2.68, 8-22)	12.59	<.001	
Mean Years of Marriage		31 75 (14 26 33-65)				
(SD, Range)		51.75 (14.2	20, .33-03)	-		
		Patient*	Spouse*			
Characteristic		(%)	(%)	Chi-sq (ar)	ρ	
Phases of Illness	Localized	64.9	-			
	Advanced	23.1	-	62.70 (df=2)	<.001	
	Recurrent	11.9	-			
Self-reported Family Income < \$30,000		6.5	8.1			
\$30,001 - \$50,000		22.0	18.7	62 (df-2)	80	
\$50,001 - \$75,000		18.7	20.3	.03 (01–3)	.89	
> \$75, 001		52.8	52.8			
Presently Working No		54.5	42.5	2 02 (df-1)	05	
Yes		45.5	57.5	3.82 (ul=1)	.05	
Having Other Heal No	aving Other Health Problems No		50.7		. 004	
Yes		64.9	49.3	5.94 (at=1)	<.001	
Race						
White		85.1	82.8			
African Ame	rican	13.4	13.4	-	-	
Other (e.g., I	Multiracial)	1.5	3.8			

### Table 3.2. Descriptive Statistics for Research Participants at Baseline

\* Based on non-missing cases

Table 3.3. Summary of Parameter Estimates for Two-Level Mixed Model of Perceived Levels of Dyadic Communication for Patient

	Crude Model: Model with Time Effects Only			Adjusted Model:			
Parameter	Parameter Estimate	SE	P	Parameter Estimate	SE	P	
Intercept	3.80	.08	<.001	4.27	.48	<.001	
Fixed Effects							
Months since diagnosis	006	.004	.11	01	.01	.47	
Months since diagnosis_Squared	2.41x10⁻⁵	2.58x10⁻⁵	.35	1.45 x10⁻⁵	3.97 x10⁻⁵	.72	
Phase of Illness: Localized				19	.23	.40	
Phase of Illness: Biochemical Recurrence				02	.38	.96	
Age				003	.01	.69	
Education				02	.01	.18	
Length of Relationship				.006	.004	.14	
Social Support				.001	.002	.01	
Uncertainty about the Illness				01	.002	<.001	
Prostate Cancer-Specific Symptoms_Urinary				04	.03	.22	
Prostate Cancer-Specific Symptoms_Bowel				03	.03	.26	
Prostate Cancer-Specific Symptoms_Sexual				01	.01	.52	
Prostate Cancer-Specific Symptoms_Hormonal				.02	.03	.62	
General Symptom Score				01	.01	.34	
Phase of Illness * Months since diagnosis							
Localized * Months since diagnosis	001	.01	.94	01	.01	.40	
Biochemical Recurrence * Months since	0004	.004	.93	001	.004	.74	
diagnosis							
Random Effects							
Residual (Within Person)	.11	.01	<.001	.12	.01	<.001	
Intercept between Persons	.35	.05	<.001	.28	.04	<.001	

Table 3.4 Summary of Parameter Estimates for Two-Level Mixed Model of Perceived Levels of Dyadic Communication for Partners

	Crude Model: Model with Time Effects Only			Adjusted Model: Full Model with All Covariates			
Parameter	Parameter Estimate	SE	P	Parameter Estimate	SE	Ρ	
Intercept	3.91	.09	<.001	4.18	.48	<.001	
Fixed Effects							
Months since diagnosis	02	.004	<.001	02	.01	.01	
Months since diagnosis_Squared	.0001	2.70 x10⁻⁵	<.001	6.9 x10⁻⁵	3.9 x10⁻⁵	.08	
Phase of Illness: Localized				45	.23	.05	
Phase of Illness: Biochemical Recurrence				.20	.39	.61	
Age				.004	.01	.61	
Education				02	.02	.37	
Length of Relationship				.002	.01	.76	
Social Support				.01	.002	<.001	
Uncertainty about the Illness				01	.002	<.001	
Prostate Cancer-Specific Symptoms_Urinary				01	.02	.74	
Prostate Cancer-Specific Symptoms_Bowel				.02	.02	.45	
Prostate Cancer-Specific Symptoms_Sexual				.02	.02	.26	
Prostate Cancer-Specific				.07	.02	.004	
General Symptom Score				- 01	01	16	
Phase of Illness * Months since diagnosis				.01	.01	.10	
Localized * Months since diagnosis				- 003	006	65	
Biochemical Recurrence * Month since				- 002	004	66	
Diagnosis				.002		.00	
Random Effects							
Residual (Within Person)	.11	.01	<.001	.09	.01	<.001	
Intercept between Person	.42	.06	<.001	.30	.05	<.001	

Table 3.5 Summary of Parameter Estimates for Three-Level Mixed Model of Perceived Levels of Dyadic Communication for Couples\*

Parameter	Full Model			Final Parsimonious Model			
	Parameter Estimate	SE	р	Parameter Estimate	SE	р	
Intercept	4.26	.21	<.001	4.29	.14	<.001	
Fixed Effects							
Months since diagnosis	02	.01	.007	02	.003	<.001	
Months since diagnosis _Squared	7.5 x10⁻⁵	4.0 x10⁻⁵	.07	9.3 x10⁻⁵	2.4 x10⁻⁵	<.001	
Phase of Illness: Localized	49	.20	.02	52	.13	<.001	
Phase of Illness: Biochemical Recurrence	.19	.34	.59	03	.16	.86	
Role: Patient	27	.18	.14	02	.08	.80	
Social Support	.01	.001	<.001	.01	.001	<.001	
Uncertainty about the Illness	01	.001	<.001	01	.001	<.001	
Prostate Cancer-Specific Symptoms_Hormonal	.08	.02	.001	.05	.02	.005	
Prostate Cancer-Specific Symptoms_Hormonal*Patient	06	.03	.06				
Months since diagnosis*Patient	.01	.004	.006	.01	.004	.04	
Months since diagnosis _Squared* Patient	-6.0 x10⁻⁵	3.0 x10⁻⁵	.04	-5.0 x 10⁻⁵	2.9x10⁻⁵	.10	
Role*Phase of Illness: Patient*Localized	.24	.16	.12				
Role*Phase of Illness: Patient*Biochemical Reoccurrence	24	.19	.21				
Localized * Months since diagnosis	005	.01	.59				
Biochemical Recurrence * Months since diagnosis	004	.012	.75				
Localized * Months since diagnosis _Squared	1.9x10⁻⁵	6.8x10⁻⁵	.95				
Biochemical Recurrence * Months since diagnosis_squared	1.5x10⁻⁵	6.8x10⁻⁵	.83				
Random Effects							
Residual (Within Person)	.10	.01	<.001	.10	.01	<.001	
Intercept between Person	.14	.02	<.001	.14	.02	<.001	
Intercept between Couple	.16	.03	<.001	.17	.03	<.001	

\* Fully unconditional model is omitted from the table.



Figure 3.1 Data levels for Separate Models



Figure 3.2 Data Levels for the Combined Multilevel Models for Couples



Figure 3.3 The Predicted Patterns of Change over Time in Levels of Dyadic Communication between Patients and Their Partners.



**Figure 3.4** The Predicted Patterns of Change over Time in Levels of Dyadic Communication among Couples Coping with Different Phases of Illness.

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#### **CHAPTER IV**

## A LONGITUDINAL ANALYSIS OF COUPLE'S QUALITY OF LIFE AND RELATED FACTORS IN PROSTATE CANCER: A MULTILEVEL MODELING APPRAOCH

#### INTRODUCTION

Prostate cancer is the most frequently diagnosed cancer and a leading cause of cancer deaths in men.<sup>1</sup> The improvement in early detection and treatments in the past decade has resulted in an increasing number of prostate cancer patients diagnosed at early stages with longer survival. For patients who are married or in an intimate relationship, prostate cancer is known as a "couple's illness" because the illness and treatment-related side effects (e.g., sexual and urinary dysfunction) affect that relationship,<sup>2</sup> and cause major declines in both partners' quality of life (QOL) over time.<sup>3</sup> Surprisingly, few studies have concurrently examined the perspectives of both patients and their partners as it relates to their QOL.<sup>4, 5, 6</sup> There is also an absence of research examining prospectively how bio-psychosocial factors affect QOL for both patients and their spouses over time.

The purpose of this study is to describe how the trajectory of QOL of prostate cancer patients and their partners is affected by selected bio-psychosocial factors over time. The specific aims are two-fold: (1) to examine the relationships between personal-, family-, and cancer-related factors and QOL in patients and partners over time, and (2) to determine if levels of dyadic communication reported by patients and their partner mediate the relationships between these factors and their QOL over time.

#### THEORETICAL FRAMEWORK

This study was guided by Couples' Cancer-Related Communication Model, a modified Stress-Coping Model developed by Northouse and colleagues.<sup>7</sup> Integrating the Systems Theory, Northouse has transformed Lazarus' Stress-Coping Model <sup>8</sup> to a middle-range theory to guide cancer research and family-based intervention. Similar to the modified Stress-Coping Model, the CCCM conceptualizes the family (i.e., couple) as a unit and contends that coping with cancer is a task for both patients and their family members. It also suggests that some factors (e.g., couples' communication) may mediate the relationships between personal, family, and cancer-related factors and couples' QOL in response to the stress and demands of cancer.

The communication model consists of three categories of variables: predictors, mediator, and outcome (See Figure 4.1). It hypothesizes that (1) patients' and their partners' antecedent variables (i.e., personal-, family-, and cancer-related factors) have direct effects on couples' communication about the illness and indirect effects on their QOL; (2) the antecedent factors have direct effects on patients' and partners' QOL; and (3) dyadic communication between patients and their partners partially mediates the relationships between predictors and couples' QOL. This theoretical framework has the potential to provide guidance for designing interventions to promote QOL for patients and their families.

#### LITERATURE REVIEW: QOL AND FACTORS THAT AFFECT QOL

<u>QOL in Prostate Cancer Patients and Their Partners</u>: Defined by the National Cancer Institute as the overall enjoyment of life, QOL is a multidimensional construct that includes physical, emotional, functional, and social health.<sup>9</sup> Prostate cancer and its treatment often introduce symptoms and difficulties that affect different aspects of QOL in men and their spouses (e.g., impotence, incontinence, fatigue, and hot flashes).<sup>3, 5, 6, 10</sup> Patients' and their partners' report of their QOL are often significantly related, with some

partners reporting lower QOL than patients.<sup>6</sup> Research indicates that partners of men coping with newly diagnosed localized prostate cancer report significantly higher mean scores on depression and distress than patients.<sup>11</sup> Similarly, partners of men with advanced prostate cancer had lower emotional well-being than patients.<sup>6</sup> The decreased QOL in patients and partners often persists for an extended period of time.<sup>12</sup>

*Eactors Affecting QOL in Prostate Cancer Patients and Their Partners*: Researchers have identified a variety of bio-psychosocial factors that may affect QOL in cancer patients and their family members. Among patients' personal demographic factors, younger *age* has been associated with better physical QOL at baseline and in a long term,<sup>13</sup> but worsening mental well-being over time.<sup>10, 13</sup> Similarly, younger partners of prostate cancer patients report better physical QOL at the eight-month follow-up than those who are older.<sup>4</sup> Comparing to older couples, middle-aged couples often experience more distress related to the adjustment to the physical and emotional changes resulting from prostate cancer and its treatments, with depression identified as one of the serious problems in this age group.<sup>14</sup> Higher household income and education are related to better QOL in prostate cancer patients.<sup>13</sup>

Some psychosocial factors are associated with better QOL in cancer patients and their families. Perceived *social support* has been identified as one of the psychosocial factors that are associated with better QOL in prostate cancer patients in cross-sectional studies.<sup>15</sup> Social support was identified as one of the factors significantly affecting QOL of partners of patients undergoing hematopoietic stem-cell transplant,<sup>16</sup> however, a recent study did not find the association between baseline social support and later QOL in the partners of prostate cancer patients.<sup>4</sup>

*Communication*, the exchange of information and personal experiences (e.g., concerns and emotions about the illness) between patients and their partners, has been associated with QOL in cancer patients and their families. Couples facing different types

of cancer who are able to communicate more openly about the illness and share their thoughts and feelings report greater intimacy and higher marital satisfaction, all of which are associated with better individual QOL.<sup>17, 18, 19, 20</sup> Studies have indicated that inadequate communication (e.g., hiding feelings and protective buffering) is associated with higher levels of psychological distress, and subsequently, lower QOL in cancer patients and their families.<sup>21, 22, 23, 24, 25</sup>

Cancer-related factors also have been linked to QOL in patients and their families. The *phase of illness* or *stage of cancer* has been related to QOL of cancer patients. QOL of patients with localized prostate cancer often declines initially but improves over time; some may eventually recover to baseline.<sup>26, 27, 28</sup> A progressing, advanced stage of disease often negatively affects patients' QOL, especially in the emotional and social domains of QOL.<sup>10, 29, 30, 31</sup> A more recent study also found that couples coping with advanced/metastatic prostate cancer have significantly poorer physical, emotional, functional, and overall QOL than dyads with newly diagnosed illness.<sup>6</sup> However, it is noted that patients with metastatic prostate cancer in remission often report significantly better social and mental well-being than those not in remission.<sup>29</sup>

Findings regarding the effects of *time since diagnosis* on QOL have been inconsistent.<sup>32, 33</sup> A study showed, compared to QOL in patients with colorectal and lung cancers, QOL of prostate cancer survivors declined with time.<sup>34</sup> However, other crosssectional and longitudinal studies have reported that the negative effects of prostate cancer decreased over time (within six months to a year after treatments), independent of the phase of illness <sup>29, 30</sup> and/or the type of treatment patients received.<sup>10, 26, 27</sup> Research on QOL of patients' spouses, although sparse, has reported that time since diagnosis is negatively associated with their QOL.<sup>35</sup> However, these findings may have been confounded by aging or other age-related comorbidities.

Further, *uncertainty about the illness* has been associated with lower emotional QOL <sup>36</sup> and higher psychological distress in patients and family caregivers.<sup>36, 37</sup> Findings of a cross-sectional study of breast cancer patients suggested that women experienced worsening well-being (e.g., mood state) as uncertainty increased.<sup>38</sup> Yet, a recent study reported that uncertainty reported by prostate cancer patients and their spouses at baseline did not predict their QOL measured at 8-month follow-up,<sup>4</sup> suggesting that uncertainty, measured one time at baseline, may be resolved as couples adapt to their survivorship.

Finally, *prostate cancer-related symptoms* and *general symptoms* or *comorbidities* also have been associated with QOL in cancer patients and their partners.<sup>4</sup> Patients who report considerably greater pain, fatigue, urinary problems, and deteriorating physical functioning are more likely to experience problems in adaptation.<sup>5</sup> In contrast, a large scale study did not find that the patients' baseline urinary incontinence, bowel, and sexual dysfunctions affected their overall QOL at later followups.<sup>28</sup> Other researchers reported that men who had more comorbid illness at baseline often had lower QOL 6 and 12 months later;<sup>13, 39</sup> patients with psychiatric co-morbidities (e.g., anxiety or depression) had worse general QOL than patients with medical co-morbidities and than those with no co-morbidities.<sup>34, 40</sup> Among the few studies of spouses, distress is highly predicted by the bowel function and mental health of patients receiving primary treatments for their early stage prostate cancer.<sup>41</sup>

In summary, while most research has been retrospective and cross-sectional, there is a lack of longitudinal research on how couples' QOL change over time and how time-varying bio-psychosocial factors affect QOL over time. In addition, few studies have concurrently examined the perspectives of both patient and family members, especially the spouses, on these issues.

#### METHODS

#### Study Design

This research was a secondary analysis of the longitudinal data obtained from a randomized clinical trial (RCT) testing a family-based, nursing intervention to improve QOL for patients with prostate cancer and their partners (parent study). Research participants independently completed the measurements repeatedly at four points in time: at baseline upon recruitment, and at 4-, 8, and 12-month follow-ups.

#### Participants and Procedures

*Sample:* Participants in this study included dyads of patients and their partners from the control group of the RCT who were randomized to the usual care condition. Only the control group was used in order to eliminate any effects of the experimental condition (i.e., family-based intervention) on the study variables. The sampling and data collection procedures for the RCT have been described in earlier publications.<sup>4, 6, 42, 43, 44</sup>

*Measures:* The measures used to assess study variables, their assessment time points, and their reliability alphas are summarized in Table 4.1. The predictors include personal (i.e., age and education), family/social (i.e., family income and social support), and cancer-related factors (i.e., time since diagnosis, phase of cancer, uncertainty about the illness, and symptom distress). The mediators were the perceived levels of dyadic communication reported by patients and partners. The outcome variables were QOL of patients and their partners. All the instruments used to measure the predictors and outcome variables in this study have been previously used in prostate cancer patients and their partners.<sup>4, 6, 43</sup>

#### Insert Table 4.1 Here

#### Variables and Measurements

#### Distal Outcome Variables

The QOL was measured at baseline, 4-, 8-, and 12-month follow-ups using the

Functional Assessment of Chronic Illness Therapy (FACT; version 4) scales.<sup>45</sup> FACT has two parts: a 27-item FACT-G measuring general QOL in physical, social/family, emotional, and functional domains, and a 12-item FACT-P (i.e., prostate cancer subscale) measuring disease-specific symptoms and problems.<sup>46</sup> In this study, only the total score of FACT-G was used. Slight wording modification was made for spouses' version of FACT-G so that patients and partners reported on their own QOL. Evidence of satisfactory reliability and validity for the general FACT-G has been reported in initial psychometrics studies.<sup>45, 46</sup> The reliability of FACT-G was .89 and .90 for prostate cancer patients and their partners, respectively, in the parent study.<sup>6</sup>

#### The Proximal Outcome Variables (Mediators)

The mediators, i.e., *perceived levels of dyadic communication*, were measured independently for patients and for their partners using the Lewis Mutuality and Interpersonal Sensitivity Scale (MIS),<sup>51</sup> a 23-item scale that assesses the extent to which family members understand and communicate feelings related to the cancer. Higher scores indicate more open communication about the illness. Evidence of internal consistency reliability and construct and criterion-related validity have been reported in the initial study.<sup>51</sup> For prostate cancer patients and partners, Cronbach alphas were .90 and .91, respectively in the parent study.<sup>6</sup>

#### The Predictor Variables

Personal factors, i.e., *age* and *education*, were evaluated at baseline using the demographic section of the Risk for Distress scale (RFD, previously known as OSQ).<sup>47</sup> This section of the RFD has demonstrated satisfactory psychometrical quality (e.g., 98% predictability) in previous studies.<sup>7, 47</sup>

Family factors included *family income* and *social support*. The *family income* was measured using the demographic section of the RFD questionnaire. Because there was no significant difference in the incomes reported by prostate cancer patients and their

partners, only the income reported by patients was used in the study. *Social support* was assessed using the Personal Resource Questionnaire (PRQ).<sup>48</sup> This 25-item Likert scale measures the amount of general social support people perceive from others (e.g., friends and relatives). Higher scores indicate higher perceived support. Adequate internal consistency and predictive and constructive validity have been reported.<sup>48</sup> The Cronbach alphas were .89 for prostate cancer patients and spouses in the parent study.<sup>6</sup>

Cancer-related factors include *time since diagnosis*, *phase of illness*, *uncertainty about the illness*, and *symptom distress*. *Time since diagnosis* and *phase of illness* were taken from patients' medical history questionnaire, a researcher-designed survey completed by data collectors to obtain additional data on patients' medical characteristics from their medical record. *Uncertainty about the illness* was measured by the 28-item Mishel Uncertainty in Illness Scale.<sup>49</sup> Higher scores indicate more uncertainty about the illness. In the parent study, the reliability was .91 for prostate cancer patients and their spouse.<sup>6</sup>

Symptom distress consisted of prostate cancer-specific symptoms and general symptoms. Prostate cancer-specific symptoms in patients (i.e., bowel, hormonal, sexual, or urinary symptoms) were measured using the 50-item Expanded Prostate Cancer Index Composite (EPIC).<sup>50</sup> Their partners completed a four-item EPIC spousal version, which assessed how much of a problem their husbands' bowel, hormonal, sexual, or urinary symptoms was for the spouses. Concurrent validity of the spouse EPIC has been previously reported.<sup>50</sup> Higher scores on the EPIC indicate fewer prostate cancer-specific symptoms. The *general symptoms*, e.g., fatigue, pain, and sleep disturbance, were measured with the 16-item Symptom Scale, which is a part of the RFD.<sup>47</sup> Patients and partners separately rated their own symptoms on a three-point scale ("no trouble,"

#### DATA ANALYSIS

Multilevel Models (MLM) <sup>52</sup> were used to examine the longitudinal relationships between predictors (baseline and time-varying variables) and QOL of prostate cancer patients and their partners, as well as the possible mediating effects of communication, which is also a time-varying variable, on the relationships. Maximum likelihood (ML) estimation was employed in the linear mixed model procedure in SPSS 16.0 to fit all the models except the crude model, which was fitted using restricted maximum likelihood (REML).<sup>53</sup> The MLM method utilizes all available data and produces consistent, efficient estimates, unlike other conventional multivariate methods (e.g., Listwise deletion in repeated measures ANOVA).<sup>53</sup> (Table 4.2) In addition, MLM technique also allows the examination of patterns of change in QOL over time between patients and their partners and/or between couples in different phases of illness, while controlling for other time-varying bio-psychosocial factors.

#### Insert Table 4.2 Here

#### Comparison of Multilevel Modeling and Other Classic Methods

The continuous predictors were subject-specific group-centered before fitting the multilevel models for ease of interpretation and reducing potential multicollinearity.<sup>52</sup> Specifically, these continuous predictors were scaled by subtracting the group mean of an individual person (patient or partner) across time from each observed score. Due to the sizeable discrepancy between the EPIC scores for patients (ranged from 28 to 158) and the scores for spouses (ranged from 4-20), their EPIC measures were standardized within individuals across time.

To achieve the research aims, a series of multilevel models were fitted in two major steps: fitting multilevel models of couples' QOL and testing for mediation effects. Each model included two types of effects, i.e., fixed effects, which describe the constant marginal relationships between the dependent variable and the predictors, and the

random effects, which represent random deviations for a given subject or cluster from the overall fixed effects.<sup>53</sup>

<u>Step One: Fitting Multilevel Models of Couples' QOL</u>. The final model from this step was used to examine the relationships between predictors and QOL (Aim One). First, the crude model without any predictors was fitted using the REML estimation to detect the variability in QOL at three levels: intra-individual, intra-couple, and intercouple. Estimates of variance components from the crude model would inform whether it was necessary to include the couple-level variance when modeling patterns of change in QOL over time. <u>Second</u>, the adjusted model (with fixed effects of role: patient versus partner; time; interaction between time and role; and random effects of time) were used to decide whether there were significant variance between individuals within couples across time (i.e., time random effect), and thus provide evidence for whether to retain the random time effects in the model. The "time" predictor in this study was treated as a continuous variable, referring to the months since the prostate cancer diagnosis. Because the exploratory scatter plots suggested the trends in QOL were non-linear in nature, both the linear and quadratic fixed and random effects of time since diagnosis were included in the model to capture the possible curvilinear pattern of QOL over time. If there was no evidence of significant variances in the time effects between partners, the random effects of time would be excluded from later model specification steps. The interaction between role and time was included to compare the differences between the patterns of change in patients' QOL and that of the partners. Third, the full model was fitted by introducing to the adjusted model all the personal and couple-level variables in the modified Stress-Coping model (i.e., demographic, time-varying bio-psycho-social variables, and selected interaction terms between time, role, and phase of illness). Due to the consideration of power and the available sample size, only the interactions between time, role, and phase of illness were examined in the full model, eliminating the

interactions between role and other predictor variables. The results from this full model examined the relationships between the predictors and QOL, and laid foundation for the mediation testing as described in Step 2.

#### Step Two: Examine the Mediation Effects of Levels of dyadic communication.

This step aimed to examine whether levels of dyadic communication reported by patients and their partners mediate the relationships between predictors and QOL over time (Aim Two). The mediation effects were tested following Baron and Kenny's guidelines.<sup>54</sup> Three multilevel models with fixed effect parameter estimates were needed to establish the presence or absence of mediation between the predictors and the outcome variable (Figure 4.2).

#### Insert Figure 4.2 Here

#### Mediation Effect Testing Process Diagram

The first model (Path 1) estimated the fixed effects of the baseline and timevarying predictors on the time-varying outcome variable (i.e., QOL). Path 1 was a reduced form of the full model from Step 1. If the predictor did not have at least a marginally significant effect (*p*<.10) on the outcome variable, it would be excluded from the mediation testing process. Consequently, all the interaction terms were excluded from further analyses. The second model (Path 2) estimated the effects of predictors on the hypothesized mediating variable (i.e., levels of dyadic communication). Predictors in Path 2 included the baseline and time-varying variables that were statistically significant in Path 1. That is, the exact same predictors were considered in all steps of mediation testing, and only those significantly related to the outcome variable QOL in Path 1 and to the mediator in Path 2 were candidates for a mediation effect. The random effect of time became insignificant, and thus, was excluded from further model fitting. The final multilevel model (Path 3) examined the effects of the mediator (i.e., levels of dyadic communication) on the outcome (i.e., QOL) after adjusting for the effects of the baseline

and time-varying predictors. The results from Paths 1 and 3 would provide evidence for whether levels of dyadic communication mediated the relationships between predictors and the outcome variables (Aim Two). The magnitudes of the mediated effects were calculated by comparing the changes in the regression coefficients in Paths 1 and 3.

#### RESULTS

#### **Descriptive Findings**

Of the 134 patient-partner dyads who completed the baseline assessments, 124, 123, and 114 completed the assessments at 4-, 8-, and 12-month follow-ups, respectively. The characteristics of these participants are listed in Table 4.3. In general, patients were older, had higher education, and had more health problems than their partners. More spouses were currently working. There was a significant difference in the numbers of patients with different phases of illness: localized (n=87; 65%), biochemical recurrent (n=16; 12%), and advanced cancer (n=31; 23%) (*Chi-square*=62.70, *df*=2, p<.001). Patients' mean months since diagnosis at recruitment was 28.96 (SD=39.66) months. Patients with localized cancer had more recent diagnosis dates (Mean=7.90, SD=4.19, range 3-36) than those facing biochemical recurrent (mean=85.44, SD=42.21, range: 12-152) or advanced cancer (mean=58.92, SD=45.62, range: 2-150), *F* (2, 131)= 83.91, p<.001.

#### Insert Table 4.3 Here

#### Couples' Characteristics

During the 12-month follow-up period, 20 patients (15%) and 16 partners (12%) discontinued participation. The main reasons for attrition were patients' death (N=9), lost contacts (N=4), no time for follow-up (N=4), or other miscellaneous reasons (N=3). There was no statistical significance on the demographics and time since diagnosis between patients who remained in the study and those who were lost to follow-up. Yet, the percent of patients having advanced cancer was higher among drop-outs than among study

participants as a whole. For the partners, there were no significant differences in any of these variables between drop-outs and respondents.

The descriptive results (e.g., means and standard deviations) of each variable reported by patients and their partners at the four assessment points are presented in Table 4.4. At baseline, compared to prostate cancer patients, spouses reported similar QOL, less social support, and more uncertainty about the illness. The correlation coefficients between levels of dyadic communication and QOL across time were .46 and .47 for patients and partners, respectively.

#### Insert Table 4.4 Here

#### Descriptive Analysis Results

#### Preliminary Results of Model Building in Step 1 (Research Aim One)

The results of the crude model (Table 4.5) suggested that there were significant variances in the outcome variable (i.e., QOL) across three levels: intra-individual, intracouple, and inter-couple. Thus, a three-level analysis was justified. In the adjusted model of QOL with *time* (i.e., months since diagnosis) and *role* as independent variables, the fixed effects of time-linear were marginally significant and the fixed effects of time-squared were insignificant, indicating that QOL of patients and their partners tended to decrease over time in a linear fashion. The role effect and its interaction with time were not significant. However, in order to achieve research Aim One, the fixed effects of *time*, *role*, and the *interaction of time and role* were all kept in the model for further examination when controlling for other predictors.

#### Insert Table 4.5 Here

#### Models in Step 1: Model Fitting

Among the random effects, the variance components of the time-linear were marginally significant but time-squared random effects did not reach statistical significance, suggesting that study participants experienced changes in QOL over time in

a somewhat different manner, and the difference over time was in a linear trend. Thus, the linear random effects of time were kept, and the quadratic random effects of time associated with individuals were excluded to simplify the model specification.

The full model included all the predictors depicted in the Couples' Communication Model. The analysis results showed that QOL was significantly related to certain baseline predictors (i.e., *patient's education level, partner's age,* and *family income*) and time-varying variables (i.e., *social support, uncertainty, prostate cancerspecific hormonal symptoms,* and *general symptoms*). Specifically, less education in patients, older age in partners, higher family incomes at baseline were associated with better QOL for patients and their partners. Better QOL also was associated with the timevarying variables including higher levels of social support, less uncertainty about the illness, fewer prostate cancer-specific hormonal symptoms in patients and fewer general symptoms in both patients and their partners during the 12-month follow-up.

Other demographics (i.e., *patient's age* and *partner's education level*) and cancerrelated factors (i.e., *time, phase of illness,* and *prostate cancer-specific symptoms: bowel, urine, and sexual*) were not related to QOL over time. The *role* effect (patient vs partner), after controlling for all of the bio-psycho-social variables, remained insignificant, suggesting that patients and partners had similar QOL at baseline.

None of the interactions was significantly related to QOL in patients and their partners. (1) The insignificant effect of the interaction between <u>role</u> and <u>time</u> on QOL indicates that the patterns of change in QOL over time did not vary by role. (2) The insignificant effect of the interaction between <u>role</u> and <u>phase of illness</u> suggests that patients and partners with different phases of illness shared similar patterns of change in their QOL. (3) The insignificant interaction between <u>time</u> and <u>phase of illness</u> indicates couples in different phase of illness shared similar patterns of change in their QOL.

Finally, the variance in the outcome variable (i.e., QOL) at the intra-individual,

intra-couples, and inter-couple levels remained statistically significant in the full model. The random effect of time-linear also remained significant, suggesting that each individual's QOL followed a different linear pattern of change over time. These results suggest that there are additional factors at individual and/or couple levels, which were not included in this study, affect QOL of patients and their partners.

#### Results of Step 2: Primary Results of Mediation Effects Testing (Aim Two)

Three models (Table 4.6) were fitted to examine the possible mediation effects of levels of dyadic communication on the relationships between selected predictors and QOL. Path 1 was the reduced model derived from Step 1 by eliminating predictors that were not significantly related to the dependent variable using backward selection. In Path 1, baseline predictors (i.e., patient's education, partner's age, family income, and phase of illness) and certain time-varying variables (i.e., social support, uncertainty about the illness, prostate cancer-specific hormonal symptoms, and general symptoms) were significantly related to the QOL of patients and their partners.

#### Insert Table 4.6 Here

#### Results of Model Fitting Step 2: Mediation Testing

Path 2 tested the relationships between the predictors and the potential mediator (i.e., levels of dyadic communication). The results showed that couples' levels of dyadic communication were significantly related to social support, uncertainty about the illness, prostate cancer-specific hormonal symptoms, time since diagnosis, and phase of illness. There was no evidence of significant relationships between couples' levels of dyadic communication and their role, demographics, and general symptoms. Neither was the random effect of time linear significant. All these insignificant fixed and random effects were ineligible for mediation testing, and thus, were eliminated from the process.

To test the mediation effects of levels of dyadic communication on the relationships between the predictors and QOL, Path 3 was fitted by adding the potential

mediators (i.e., levels of dyadic communication) to Path 1. The results (Table 4.6) indicated couples' communication partially mediated the relationships between social support, uncertainty about the illness, and prostate cancer-related hormonal symptoms reported by men and their partners and their QOL. Although more social support, less uncertainty, and fewer prostate cancer hormonal symptoms remained significantly associated with better QOL over time after controlling for the potential mediator, the levels of dyadic communication reported by patients and partners reduced the magnitudes of the estimated fixed effects of these predictors by 10-20%. Specifically, more perceived dyadic communication between patients and partners reduced the negative effect of uncertainty on their QOL, it also decreased the protective effect of social support on QOL. The positive associations between fewer prostate cancer-related hormonal symptoms and better QOL were slightly reduced by dyadic communication between partners.

#### DISCUSSION

One of the important contributions of this study is that it provided a theory-based, longitudinal analysis of how the trajectory of QOL of both prostate cancer patients and their spouses was affected by a set of bio-psychosocial factors over time. While most previous and current studies on QOL in cancer patients and partners use measures at one time point, this research, using multilevel modeling, examined whether the relationships between time-varying predictors and the dependent variable changed over time. The utilization of MLM also makes it possible to compare the differences in QOL over time between patients and their partners, and between couples in different phases of illness, while taking into consideration of time-varying variables. The results from this study provided evidence that might otherwise have gone undetected by the traditional analytical method, e.g., repeated measure ANOVA.<sup>52, 53</sup>

Multilevel models flexibly modeled the correlated residuals of observations on the

dependent variable, i.e., QOL, across time by recognizing a nested structure of repeated observations within individuals, who were in turn nested within couples (Figure 3.2). The participants, being followed at four points in time, acted as their own controls in this longitudinal study. The partition of significant variances at different levels in this study demonstrates that QOL differs at individual and at couple levels, suggesting there is a need to include variables at these different levels in future research when investigating QOL during cancer survivorship.

The first interesting findings of this study is that certain baseline demographic variables and time-varying bio-psychosocial variables were significantly related to the trajectories of QOL in prostate cancer patients and their partners over time. Among the time-varying predictors, social support was a key variable for both patients and their partners. More perceived social support from other friends and relatives was associated with better QOL in patients and their partners over time. This result is consistent with previous studies, which indicated that more social support was directly or indirectly associated with better mental QOL, less depression, and anxiety in patients and their partners.

In this study, however, the effect of social support from other friends or relatives on QOL is comparatively small. This may be related to the fact that prostate cancer is a private disease that is associated with symptoms (e.g., incontinence and impotence) that patients and partners may not want to share with others. Fear of stigmatization may inhibit couples from discussing their symptoms or seeking help from others.<sup>58</sup> <sup>59</sup> In fact, cancer patients and families often report high levels of unmet supportive care needs.<sup>60, 61, <sup>62</sup> As time since diagnosis passes, the amount of social support that patients and their families receive also may decrease.<sup>63</sup></sup>

Uncertainty about the illness was another important factor associated with QOL in patients and partners over time: more uncertainty about the illness was associated
with lower QOL in both patients and their partners. This finding is consistent with Mishel's uncertainty theory <sup>64, 65</sup> and with findings of previous cross-sectional studies in cancer patients and partners.<sup>36</sup> This finding also provides an empirical basis for interventions that target both cancer patients and their partners and try to improve their QOL through uncertainty management.

Another clinically relevant finding is the relationship between symptom distress and QOL in patients and their partners. Among all prostate cancer-specific symptoms (i.e., bowel, hormonal, sexual, and urinary), only patients' hormonal symptoms (e.g., hot flashes, fatigue, breast tenderness, and weight gain) were significantly related to QOL of both patients and partners. The non-significant relationships between most prostate cancer-specific symptoms and QOL may provide quantitative evidence to support the findings of previous qualitative research, in which cancer patients reported that their current QOL had little to do with their cancer or its treatment.<sup>66</sup> Research showed that prostate cancer patients usually place other social concerns ahead of their health status to preserve their feelings of "normalcy" and dignity, as well as to sustain important social relations in the face of the illness.<sup>67</sup> The values and expectations of couples facing prostate cancer often are quite different from the urologists who emphasize patients' survival, complications, urinary symptoms, sexual ability, and activities of daily living.<sup>68</sup> Further, these findings not only confirmed previous research findings about the effects of prostate cancer-specific symptoms on QOL,<sup>4</sup> they also extended prior work to a new area that has been rarely reported—assessing the effects of hormonal symptoms on QOL in patients and partners over time.<sup>50</sup>

This study also showed that general symptoms (e.g., fatigue, sleep difficulty, concentration, etc) experienced by patients and their partners were negatively associated with their QOL. This result is consistent with previous studies, which reported that cancer patients, especially the elderly, often had the most complaints about various

symptoms associated with poor physical, mental, and social QOL.<sup>69</sup> Our findings further demonstrate that, while coping with prostate cancer as a "team member," partners' QOL is affected by both their own symptoms.

These findings alert health care providers of the need to closely attend to spousal caregivers' health instead of solely focusing on the QOL of cancer patients because both persons are affected by the increased demands associated with the illness and treatment as well as their age-related health issues. The associationd between partners' symptoms and their QOL has often been ignored in the past because the QOL and survival of cancer patients have been the foci of clinical practice and research. This research found the negative association between general symptoms and couples' QOL by looking at couples' symptoms simultaneously. This result may partially explain earlier research findings that have shown caregivers of family members with cancer often had significantly poorer global QOL when compared to caregivers of non-cancer patients. Married caregivers, in particular, have a significantly poorer QOL than non-married caregivers.<sup>70</sup>

Among the factors that were measured at baseline, patient's education level, partner's age, and family income were significantly related to the trajectories of QOL of patients and their partners over time. The association between partners' older age and better QOL in couples in this study may be related to the fact that, among the study participants, most (84.8%) of the younger partners (<60 years of age) worked outside the home while less than 20% of partners 60 years and older worked. Younger partners may have to care for the patient while dealing with competing demands such as employment and child care; added caregiving responsibilities may consequently compromise their QOL over time. Consistent with Kim et al's research findings,<sup>71</sup> this result suggests that the more social roles a caregiver carries out, the more likely the caregiver is to experience stress and negative adjustment.

The positive association between partners' older age and couples' better QOL over time may be related to the fact that the majority of the study participants were married, with an average of about 32 years of the relationship. In this relatively elderly population with long-standing relationships, partners may have developed a deeper knowledge and understanding of each other over the years, leaving them better able to adapt to cancer—another chronic illness. It also may be noteworthy that sexuality is no longer considered a fundamental part of existence among some elderly aged 65 and above, particularly in aged women.<sup>72</sup> The pressure that a prostate cancer patient may put upon himself to perform sexually (e.g., obtain an erection), thus, may not be as great as when the partner is at a younger age.

Family income in this study was positively related to couples' QOL; higher family income at baseline predicted better QOL in patients and partners over time. The finding of this longitudinal study confirmed the results of previous cross-sectional studies.<sup>73</sup> As previous research has shown that financial concerns are prevalent among cancer patients and family members,<sup>68, 74, 75</sup> more income may have given men and their partners a sense of security and personal control that reduce their stress and improve their QOL. Meanwhile, more income also may make it possible for couples to purchase tangible materials and resources that help them better cope with the illness and caregiving.

Another important finding of this study is the effect of open communication on couples' QOL. This novel result not only confirmed the findings of research in breast cancer patients <sup>17, 18, 19, 20, 76</sup> but also provided direct, quantitative evidence for the benefits of open communication on QOL in the context of prostate cancer. Previous research often demonstrated the direct positive effect of open communication on emotional distress or its indirect effect on QOL through relationship satisfaction.<sup>76, 77, 78</sup>

Regarding the mediation effects of communication, more open communication

reduced the negative effects of uncertainty on QOL. Communication is an important coping strategy for prostate cancer patients and their partners that helps develop, maintain, or alter their perception of the situation. Wortman noted that couples can help clarify the meaning of their feelings by discussing them frankly and openly with a sympathetic listener.<sup>79, 80</sup> For couples facing cancer-related uncertainty, communicating openly with each other enables them to define the problem and to solve the problem. Open dyadic communication also may reduce the negative emotions and strengthen positive emotions by promoting understanding and acceptance of the disease.

However, communication also was found to partially reduce the protective effects of social support from friends and other relatives. It is possible that, because of the private nature of prostate cancer, the more couples share with each other about the illness and related issues, the less they rely upon external resources for support. In fact, prostate cancer patients usually rely on their wives for validation and support. Open communication and high emotional expressiveness in the relationship is an important means of providing mutual support to each partner, a factor that has been strongly related to marital satisfaction in couples coping with cancer <sup>76, 81</sup> and their adjustment to survivorship.<sup>82, 83</sup> The finding from this study indicated that more social support from other friends and relatives was associated with better QOL in patients and their partners, albeit to a lesser extent when compared to their support from each other through open communication. These findings alert health care providers of the need for developing strategies to help couples not only mobilize but balance their supportive resources from each other and from other people while coping with cancer.

More interestingly, communication between cancer patients and their partners reduced the positive association between fewer prostate cancer-specific hormonal symptoms and better QOL, yet it did not mediate the effects of general symptoms and other prostate cancer-specific symptoms on couples' QOL. In other words, while the

findings may warrant further investigation, they provide initial support to the findings of previous qualitative research:<sup>59</sup> men typically minimize the impacts of the ongoing bowel, urinary, and sexual problems. Most couples engage in "don't talk, don't ask" strategies when it comes to prostate cancer-related symptoms because of a variety of reasons, e.g., men's perceived need for minimizing the threats of the illness to aid coping, men's desire to avoid burdening others, and their partners being cautious about what they talk about in response to men's reticence.<sup>59, 84</sup> Although our study only found mild mediation effects of communication on the relationships between hormonal symptoms and QOL, concealing symptoms makes couples less likely to obtain help and support from each other or from other people, and consequently, have more negative impacts on couples' QOL. These results also may suggest that health care providers need to help couples develop better strategies so that they communicate symptoms and their effects more effectively.

The above mentioned research findings demonstrate that dyadic communication between partners does not always automatically make things better. There is a need to further study what types and quality of communication between patients and their partners may benefit couples the most as well as the mechanism of how open dyadic communication and different aspects of bio-psychosocial factors affect couples' QOL during their survivorship. Some of these questions may be better addressed by qualitative research (e.g., observation) or other quantitative methods (e.g., moderation). Therefore, future research needs to combine qualitative and quantitative approaches to disentangle the complex interactions between cancer patients and their partners.

Finally, this study has limitations that warrant discussion. First, the treatment information was not included. Many individuals in this study had undergone more than one treatment and therefore could not be classified into a single category. Yet there were far too many treatment combinations to analyze with the existing sample and too few

subjects to utilize multivariate analyses to separate the treatment effects statistically. Second, the attrition was primarily due to the death in patients with advanced cancer. Third, the research participants were primarily well-educated, middle class and Caucasian (about 84%). Although 13% were African American, the low number of participants from Native American, Asian, or Hispanic groups, and people with low sociodemographical status limits the diversity of the sample and the generalizability of the findings. Finally, this prospective research focuses only on patients with prostate cancer (all men) and their partners (all women), and thus, could not address the influence of gender versus role (patient or partner) on their QOL.

## **Research implications**

Couple and family data often present particular challenges to family researchers. Multilevel models are powerful and flexible tools to analyze couple and family data.<sup>85</sup> By acknowledging a nested structure of repeated observations within individuals, who were in turn nested within couples, MLM techniques take into consideration the interactions between couples, rather than solely consider the patient and his partner as two individuals with similarities and differences. The results from this study provide evidence that QOL of prostate cancer patients and their partners is affected by factors at intraindividual, intra-couple, and inter-couple levels. Using MLM to accurately capture the changes of QOL in individuals and couples while taking into consideration certain baseline and time-varying bio-psychosocial factors, this research adds to the traditional approaches in family research.<sup>85</sup> Thus, the method described above has broad application and should be of interest to family researchers beyond specific illness or treatment.

## **Clinical implications**

The research provides evidence that is relevant to the care for individuals and families coping with prostate cancer at different points in the illness trajectory. Clinicians

are well-positioned to provide information to patients and their partners on how to reduce uncertainty and manage symptom distress. They also can help couples obtain support from internal (e.g., promote open communication between partners) and external sources (e.g., effectively use resources available from other family members and friends). These efforts will support and strengthen couples' adaptive abilities, help them take greater control of their lives, and ultimately, improve their QOL.



Figure 4.1 Couple's Cancer-related Communication Model



Path 1







Figure 4.2 Mediation Effect Testing Process and Steps

Variable	Instrument	Cronbach's Alpha			
		Patient	Partner		
Outcome variable					
Quality of Life	Functional Assessment of Chronic Illness Therapy-General (FACT-G)	.90	.90		
Predictors					
Age*	Risk for Distress Scale (RFD) <sup>#</sup>	na*	na*		
Education*	RFD	na*	na*		
Role (Patient vs Partner)*	RFD	na*	na*		
Length of Relationship*	RFD	na*	na*		
Phase of Illness*	Medical History questionnaire	na*	na*		
Months since diagnosis	Medical History Questionnaire	na*	na*		
Social Support	Personal Resource Questionnaire	.89	.90		
Uncertainty about the Illness	Mishel Uncertainty In Illness Scale	.91	.91		
Level of dyadic communication	Lewis Mutuality and Interpersonal Sensitivity Scale (MIS)	.90	.91		
Prostate Cancer-Specific	EPIC (Expanded Prostate Cancer				
Symptoms:	Index Composite)				
Bowel	• •	.84	na†		
Hormonal		.74	na†		
Sexual		.90	na†		
Urinary		.80	na†		
General Symptoms	RFD_Symptom Subscale	.80	.76		

# Table 4.1 Variables and Measurements Used in the Analysis

Formerly named Omega Screening Questionnaire (OSQ)

\*Assessed at <u>baseline</u> only Reproducibility <.90 (test-retest reliability)

<sup>†</sup> Partner version of EPIC consists of a single item for each symptom

Table 4.2 Comparison between Multilevel Modeling and Classic Analytical Methods

Reasons	Multilevel Modeling	Repeated Measure ANOVA	Multiple Regression
Handles repeated measure designs	Yes	Yes	No (Violation of Assumption: independence of observation)
Addresses research question (e.g., trajectory of change)	Yes (Time: categorical & continuous)	No (Time: Categorical)	NA
Includes time-varying predictors	Yes	No	NA
Handles missing data advantage (Data collection schedule is person-specific. Subjects with partial missing measurement(s) at some wave(s) can be included in the analysis)	Yes	No	NA
Simultaneously Captures variances at different levels (e.g., intra-person, intra-couple, and inter-couple)	Yes	No	NA

Chara	40	Patient Sp stic			0
		(N=134)	(N=134)	τ	Ρ
Mean Age (Year)		62.57	58.92	00.54	001
(SD, Range)		(9.22, 42-90)	9.22, 42-90) (9.65, 34-84)		<.001
Mean Education (	Year)	16.13	14.68	40.00	. 001
(SD, Range)		(3.63, 8-29)	(2.68, 8-22)	12.39	<.001
Mean Years of Ma	rriage	01 7E (14	26 22 65)		
(SD, Range)		31.75 (14.	20, .33-05)	-	-
Characteristic	Characteristic		Spouse*		
Characteristic		(%)	(%)	Chi-sq (di)	ρ
Phases of Illness	Localized	64.9	-		
	Advanced	23.1	-	62.70 (df=2)	<.001
	Recurrent	11.9	-		
Self-reported Fam < \$30,000	ily Income	6.5	8.1		
\$30,001 - \$	50,000	22.0	18.7	C2 (4t 2)	80
\$50,001 - \$	575,000	18.7	20.3	.63 (di=3)	.89
> \$75, 001		52.8	52.8		
Presently Working No	ļ	54.5	42.5	2 92 (df_1)	05
Yes		45.5	57.5	t       t $34$ ) $30.54$ $92$ $30.54$ $34-84$ ) $68$ $8-22$ ) $12.39$ $8-22$ ) $ b$ ) $ Jse^*$ Chi-sq (df) $b$ ) $62.70 (df=2)$ $.1$ $.63 (df=3)$ $.3$ $.63 (df=3)$ $.8$ $.5$ $.5$ $3.82 (df=1)$ $.7$ $5.94 (df=1)$ $.8$ $.4$ $.4$ $-$	.05
Having Other Hea No	Ith Problems	35.1	50.7		. 001
Yes		64.9	49.3	ວ.94 (ül=1)	<.001
Race					
White		85.1	82.8		
African Ame	erican	13.4	13.4	-	-
Other (e.g.,	Multiracial)	1.5	3.8		

# Table 4.3 Descriptive Statistics for Research Participants at Baseline

\* Based on non-missing cases

	Baseline						4-month follow-up						
- Variables	Patient				Partner			Patient			Partner		
-	Ν	Mean	SD	Ν	Mean	SD	Ν	Mean	SD	Ν	Mean	SD	
Quality of Life <sup>[1]</sup>	134	85.20	13.09	134	85.63	11.87	124	84.95	12.39	124	83.82	13.07	
Social Support <sup>[1]</sup>	134	88.18	12.12	134	85.24	14.25	124	86.69	13.13	124	84.52	15.12	
Uncertainty <sup>[2]</sup>	134	60.54	15.53	134	61.84	16.05	124	60.31	17.16	124	62.90	16.91	
Levels of dyadic communication <sup>[1]</sup>	130	3.72	.66	132	3.70	.63	120	3.63	.73	122	3.51	.78	
Pca Specific Symptoms_Urine <sup>[1]</sup>	133	77.29	16.01	134	4.08	1.18	124	81.19	15.85	124	4.18	1.13	
Pca Specific Symptoms_Bowel[ <sup>1]</sup>	131	88.71	12.01	134	4.58	.87	122	90.05	12.73	124	4.65	.82	
Pca Specific Symptoms_Sexual <sup>[1]</sup>	130	26.76	21.92	132	3.30	1.49	123	29.13	23.04	123	3.16	1.60	
PCa Specific Symptoms_Hormo <sup>[1]</sup>	134	82.16	15.01	134	4.08	1.19	124	83.09	15.13	124	4.07	1.27	
General Symptom Score <sup>[2]</sup>	134	7.07	4.35	134	5.50	3.82	124	6.43	4.24	124	6.23	4.48	

# Table 4.4 Descriptive analysis results

<sup>[1]</sup> Higher scores \_ more positive results: better QOL, more communication, more support from others, and less Pca specific symptoms <sup>[2]</sup> Higher scores indicate more negative results: more uncertainty about the illness and more symptom distress such as fatigue, nausea, and difficulty sleeping.

	8-month follow-up							12-month follow-up					
Variables	Patient			Partner			Patient			Partner			
-	Ν	Mean	SD	Ν	Mean	SD	Ν	Mean	SD	Ν	Mean	SD	
Quality of Life <sup>[1]</sup>	122	86.54	12.83	122	83.85	14.27	114	86.52	12.60	119	84.01	14.93	
Social Support <sup>[1]</sup>	122	86.99	12.02	122	83.98	14.41	114	87.34	13.50	119	84.10	16.05	
Uncertainty <sup>[2]</sup>	122	58.78	14.91	121	61.66	16.98	114	57.08	15.62	114	59.95	16.69	
Levels of dyadic communication <sup>[1]</sup>	119	3.73	.64	120	3.50	.73	111	3.64	.68	116	3.45	.76	
Pca Specific Symptoms_Urine <sup>[1]</sup>	120	82.79	14.15	121	4.22	1.10	113	83.57	13.93	114	4.30	1.05	
Pca Specific Symptoms_Bowel[1]	120	89.96	12.39	121	4.62	.82	112	90.63	11.13	114	4.61	.82	
Pca Specific Symptoms_Sexual <sup>[1]</sup>	119	29.53	23.65	120	3.23	1.57	112	32.43	24.49	112	3.21	1.58	
PCa Specific Symptoms_Hormo <sup>[1]</sup>	122	85.02	14.53	120	4.12	1.20	111	85.71	13.75	114	4.07	1.17	
General Symptom Score <sup>[2]</sup>	122	6.30	4.55	122	6.19	4.31	114	5.82	4.08	119	6.04	4.55	

Table 4.4 Descriptive analysis results (Cont'd)

<sup>[1]</sup> Higher scores \_ more positive results: better QOL, more communication, more support from others, and less Pca specific symptoms <sup>[2]</sup> Higher scores indicate more negative results: more uncertainty about the illness and more symptom distress such as fatigue, nausea, and difficulty sleeping.

		Crude Mode			Adjusted M	odel	Full Model in Step 1			
	Parameter F		Parameter SE <i>p</i> Estimate		Parameter Estimate	SE	Р	Parameter Estimate	SE p	
	Intercept	84.72	.89	<.001	87.16	1.30	<.001	75.10	4.45	<.001
	Fixed Effects									
	Age _Patient							07	.10	.45
ors	Age _Partner							.25	.08	<.01
dicto	Education _Patient							34	.13	<.05
Prec	Education _Partner							21	.20	.28
he	Family Income							1.19	.50	<.05
seli	Role: Patient				1.37	1.12	.23	2.87	2.01	.17
Ba	Phase of Illness: Localized							2.29	2.24	.31
	Phase of Illness: Recurrent							4.86	3.79	.20
	Time (Months since Diagnosis)				10	.05	.06	01	.06	.86
les	Time_Squared				1.00x 10 <sup>-5</sup>	4.04 x 10 <sup>-4</sup>	.24	2.00 x 10-5	4.6x10-4	.97
riab	Social Support [1]							.22	.02	<.001
Vai	Uncertainty [2]							22	.02	<.001
/ing	PCa Specific Symptoms_Urine[1]							.07	.30	.83
vaŋ	PCa Specific Symptoms_Bowel[1]							41	.29	.15
ne-j	PCa Specific Symptoms_Sexual[1]							.24	.18	.19
Ē	PCa Specific Symptoms_Hormonal [1]							1.24	.31	<.001
	General symptom Score [2]							-1.32	.08	<.001
S	Time* Role: Time*Patient				.02	.04	.67	02	.03	.51
tion	Role*Phase of Illness: Patient*localized							-1.58	1.94	.42
raci	Patient*Biomedical Recurrent							45	3.18	.89
Inte	Time*Phase of Illness: Time*Localized							04	.07	.53
	Time*Biomedical Recurrent							3.15x10 <sup>-4</sup>	.04	.99
	Fixed Effects									
	Residual [Intra-individual]	41.90	2.21	<.001	40.83	2.21	<.001	27.92	1.60	<.001
	Intercept [Intra-couple]	80.86	11.52	<.001	56.98	11.36	<.001	11.70	4.09	<.001

 Table 4.5 Models in Step 1: Model Fitting to Obtain the Final Parsimonious Model

Intercept [Inter-couple]	58.67 14.25 <.001	47.58	12.13 <.001	6.35	3.53 <.05
Time [Slope: Intra-couple]		.01	.01 .06	.01	- <.01

[1] Higher score=more positive results: more social support; fewer symptoms; [2] Higher score=more negative results: more uncertainty and general symptoms (e.g., fatigue or pain)

**Table 4.6** Results of Model Fitting Step 2: Mediation Testing [1]

Model		Path 1 Total Effect: Predictors & QOL			P Effect on Predictors &	ath 2 the Med Commu	iator: nication	Path 3 Direct Effect Model: Mediation Model			
Dependent variable			QOL		Comm	nunicatio	on	QOL			
Parameter	Magnitude of Decrease	Parameter Estimate	Std. Error	р	Parameter Estimate	Std. Error	Р	Parameter Estimate	Std. Error	р	
Intercept		73.37	3.91	<.001	3.80	.41	<.001	58.06	4.15	<.001	
Communication								4.04	.46	<.001	
Role: Patient		1.58	.94	.09	.10	.05	.06	.70	.66	.29	
Age _Spouse		.20	.05	<.001	.01	.01	.16	.18	.05	<.001	
Education _Patient		38	.13	<.01	001	.01	.96	38	.12	<.01	
Family Income		.97	.50	<.05	02	.05	.66	1.11	.46	<.05	
Phase of Illness: Localized		.57	1.34	.68	49	.13	<.001	1.97	1.31	.14	
Phase of Illness: Reoccurrence		4.20	1.65	<.01	06	.17	.74	4.50	1.54	<.01	
Months since Diagnosis		02	.02	.36	01	.002	<.001	03	.04	.46	
Social Support	Partial: 15.98%	.23	.02	<.001	.01	.001	<.001	.19	.02	<.001	
Uncertainty	Partial: 20.13%	23	.02	<.001	01	.001	<.001	18	.02	<.001	
PCa Specific Symptoms_Hormonal	Partial: 9.20%	1.26	.30	<.001	.05	.02	<.01	1.14	.29	<.001	
General Symptom Score		-1.27	.08	<.001	01	.01	.33	-1.26	.07	<.001	
Variance Estimates											
Residual		27.97	1.57	<.001	.11	.01	<.001	25.97	1.48	<.001	
Inter-Individual within Couple		23.29	4.10	<.001	.13	.02	<.001	19.03	3.58	<.001	
Inter-couple		6.66	3.58	.065	.17	.03	<.001	5.91	3.15	<.001	

Note: [1] Statistics are based on all cases with valid data for all variables in these three models (Nobservation=886).

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# CHAPTER V CONCLUSIONS

This dissertation attempted to describe the changes over time in the levels of dyadic communication between patients and their partners coping with different phases of prostate cancer, as well as to examine whether communication mediates the effects of bio-psychosocial factors on couples' QOL during their survivorship. Using the multilevel modeling technique, this research analyzed the longitudinal dyadic data from a randomized clinical trial (Northouse *et al.*, 2007). In the following section, findings from this research, their implications for practice and research, and future directions will be summarized.

# THE PATTERNS OF CHANGE IN

#### **COUPLES' CANCER-RELATED COMMUNICATION OVER TIME**

This research has found no significant difference in levels of dyadic communication between patients and their partners at the time of diagnosis. Although the levels of dyadic communication decreased over time in a curvilinear pattern for both patients and their partners, the patterns of change varied by role with partners' perceptions of levels of dyadic communication decreasing more rapidly over time than those of patients. With regard to the phase effects on levels of dyadic communication over time, couples' levels of dyadic communication at the time of diagnosis varied by phase of illness. On average, couples with localized illness had significantly lower levels of dyadic communication than couples in the advanced and biochemical recurrent illness. Couples' levels of dyadic communication decreased over time and the patterns of change did not vary by phase of illness over time.

This study also found that couples' levels of dyadic communication were affected by some time-varying family and cancer-related factors, i.e., *social support, uncertainty about the illness,* and *prostate cancer-specific hormonal symptoms*. Patients and/or their partners who reported higher perceived social support, lower uncertainty about the illness, and fewer hormonal symptoms in patients had higher levels of dyadic communication. Baseline *age, education,* and *length of relationship,* and time-varying *prostate cancer-specific bowel, sexual, and urinary symptoms,* and *general symptoms* were not significantly related to couples' levels of dyadic communication over time.

#### QUALITY OF LIFE OF PATIENTS AND THEIR PARTNERS OVER TIME

The results of a series of multilevel models showed QOL of patients and their partners is affected by factors at three levels: intra-individual (i.e., *social support*, *uncertainty, prostate cancer-specific hormonal symptoms*, and *general symptoms*), intracouple (i.e., *patient's education level* and *partner's age*), and inter-couple (i.e., *family income*). Specifically, less education in patients, older age in partners, higher family incomes at baseline were associated with better QOL for patients and their partners. Better QOL also was associated with time-varying variables including higher levels of social support, less uncertainty about the illness, fewer prostate cancer-specific hormonal symptoms in patients and fewer general symptoms in both patients and their partners during the 12-month follow-ups. After controlling for all selected bio-psychosocial variables, this study did not find significant differences in QOL between patients and their partners, or between couples from different phases of illness at baseline or over time.

Guided by Baron and Kenny's mediation testing steps (Baron & Kenny, 1986), this research found couples' dyadic communication partially mediated the relationships between social support, uncertainty about the illness, and prostate cancer-related hormonal symptoms reported by men and their partners and their QOL. Specifically,

more open dyadic communication between patients and partners reduced the negative effects of uncertainty on their QOL, but it also decreased the protective effects of social support on QOL. The positive associations between fewer prostate cancer-related hormonal symptoms and better QOL also were slightly reduced by more open dyadic communication between partners.

### **RESEARCH IMPLICATIONS**

The important contribution of this study is the use of statistical analytical techniques (i.e., multilevel modeling) that are consistent with a theoretical framework that conceives coping with cancer as a task for both individual patients and their families (i.e., partners). Couple and family data often present particular challenges to family researchers. Multilevel models are powerful and flexible tools to analyze couple and family data. By acknowledging a nested structure of repeated observations within individuals, who were in turn nested within couples, the complex modeling technique takes into consideration the interactions between partners, rather than solely consider the patient and his partner as two individuals with similarities and differences. The results from this study provide evidence about the dynamic interaction process between patients and their partners as well as information on how these interactions affect couples' QOL.

The utilization of complex modeling allows the examination of patterns of change in couples' dyadic communication and QOL when taking into consideration the effects of time-varying bio-psychosocial factors. Thus, the survivorship experiences of individuals and couples are accurately captured. The results of this research demonstrate that patients' cancer survivorship experiences (e.g., dyadic communication and QOL) are affected by factors at intra-personal, intra-couple, and inter-couple levels, suggesting the need to include variables at these different levels in future research when investigating QOL during cancer survivorship.

This dissertation work not only has expanded the findings of previous research in communication and QOL, it adds to the traditional approaches in family research. The analytical method has broad application and should be of interest to family researchers investigating a variety of family health issues.

### **CLINICAL IMPLICATIONS**

The research provides information that is relevant to the care of individuals and families coping with prostate cancer at different phases of the illness. During the course of cancer diagnosis, treatment, and recurrence, clinicians need to take into consideration the social context of patients' cancer experiences: their family members, especially their spouses, are also affected by the illness. Family members' physical health and psychological responses to the illness and their interactions with the patient affect patients' survivorship. Thus, attending to the care needs of family members may benefit cancer patients' overall QOL.

The findings of this study indicate that certain factors such as uncertainty, symptom distress, social support and dyadic communication affect patients' and partners' quality of life. Clinicians who care for prostate cancer patients and their spouses are in a unique position to assist them by reducing their uncertainty, managing symptom distress, promoting more open communication between partners, and encouraging them to use supportive resources available from other family members and friends. These strategies and endeavors will help couples' adaptation and improve their QOL.

# DIRECTIONS FOR FUTURE RESEARCH

<u>First</u>, it is essential that future research is conducted in a more diverse population consisting couples from different ethno-cultural backgrounds. Such information will provide an in-depth understanding on how social and cultural contexts affect couples' dyadic communication and how dyadic communication affects QOL in couples with

different backgrounds during cancer survivorship. Second, replication in a sample of cancer patients of both genders and their partners would help investigate how gender affects couples' dyadic communication, and consequently, affects their QOL. Third, future longitudinal research needs to explore other aspects of communication (e.g., protective buffering, content of communication, and communication needs) and their effects on QOL in patients and their families. Such research will further our understanding of the multidimensional nature of their communication. Fourth, inclusion of other relevant physical-psycho-social factors (e.g., marital relationship satisfaction, personality, and distress) in studying dyadic communication and its effects on QOL in patients and their family members will add to the available knowledge of cancer populations. Fifth, triangulation of gualitative and guantitative research methods will help researchers understand the mechanism through which open communication affects different aspects of QOL in couples' survivorship, i.e., to identify what types and quality of dyadic communication between patients and their partners may be most beneficial to both of them (e.g., communication that strengthens their relationships and promotes a sense of bonding and trust) or what communication may be destructive and cause distress. Finally, the inclusion of other family members, in addition to patients' spouses, will help researchers and clinicians to explore the nature of their interactions which may differ from the interactions of patients and their spouses. This information is critical for developing interventions to strengthen patient-family relationships and to facilitate adaptive coping.

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