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## UNIVERSITY OF MIAMI

## WHO MATTERS? THE EFFECTS OF SOURCES OF SOCIAL SUPPORT ON QUALITY OF LIFE IN PROSTATE CANCER SURVIVORS AND THEIR SPOUSAL CAREGIVERS

By

Eric S. Zhou

A DISSERTATION

Submitted to the Faculty of the University of Miami in partial fulfillment of the requirements for the degree of Doctor of Philosophy

Coral Gables, Florida

August 2012



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## UNIVERSITY OF MIAMI

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## WHO MATTERS? THE EFFECTS OF SOURCES OF SOCIAL SUPPORT ON QUALITY OF LIFE IN PROSTATE CANCER SURVIVORS AND THEIR SPOUSAL CAREGIVERS

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ZHOU, ERIC SHUAI <u>Who Matters?</u> <u>The Effects of Sources of Social Support</u> <u>On Quality of Life in Prostate Cancer Survivors</u> <u>And Their Spousal Caregivers</u>

Abstract of a dissertation at the University of Miami

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Improvements in public awareness and in regular screening for prostate cancer (PC) have resulted in dramatic increases in survival for men diagnosed with localized stage disease. However, this has resulted in a significant, and growing, population of men, who are now placed in the difficult position of having to find ways to cope with the physical and mental challenges that can develop following their diagnosis. Existing literature suggests that positive social support can act to help PC survivors adjust physically and mentally to the disease. Historically, the social support construct has been separated into two primary forms: 1) structural support, which describes the quantity and framework of an individual's support network and 2) functional support, which describes the quality of the support that the individual perceives. Several salient sources of support have been identified, with the individual's spouse most often noted as being the primary caregiver for PC survivors. Although the long-term task of caregiving for a PC survivor can be especially challenging, little research has investigated the adjustment process of spousal caregivers of PC survivors. The limited research which has evaluated quality of life outcomes in these populations has primarily done so independently of one another, rather than considering the two groups as a dyadic unit. The current study proposed to address several key limitations of our current knowledge by: 1) document the levels and relationships among physical and mental quality of life and sources of social support in



the understudied populations of PC survivors and their spousal caregivers and 2) evaluate the effects of different sources of social support on physical and psychological quality of life in a dyadic model that considers both survivor and caregiver functioning. Results from the current study suggest that both the PC survivor and his spousal caregiver report lower than normative levels of significant other support, while the spousal caregiver reported lower than normative levels of family and friend support, as well. The specified actor-partner interdependence model indicated that for the PC survivor his perceptions of significant other support were significantly related to his level of physical quality of life  $(\beta = .33, p < .05)$  and his perceptions of friend support were significantly related to his level of mental quality of life ( $\beta$ =.43, p<.05). For the spousal caregiver, her perceptions of friend support were significantly associated with her level of mental quality of life  $(\beta = .38, p < .05)$ . The introduction of age into the model, as a co-variate of physical and mental quality of life, did not affect the relationships between sources of support and quality of life. However, the introduction of age and number of medical co-morbidities into the model, as co-variates of physical and mental quality of life, caused the relationship between PC survivor significant other support with his physical quality of life to become non-significant. These results indicate that unique sources of social support have implications in the adjustment process for PC survivors and their spousal caregivers and are valuable targets for future psychosocial intervention work designed to influence their quality of life.



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#### **Chapter 1: Introduction**

Cancer still remains the "big C word" to many of the approximately 1.53 million Americans who were diagnosed with the disease in 2010 (American Cancer Society, 2010). Despite our many advances in prevention, screening, treatment, and recovery knowledge, cancer persists as a disease that can create significant fear and distress in those affected. As a result of these improvements in medical treatment, more cancer survivors are forced to cope with long-term adjustment difficulties in daily functioning if they are not able to successfully adjust to challenges that arise following a cancer diagnosis (Cordova et al, 2001; Maunsell, Brisson & Deschenes, 1995). This course of cancer reflects a shift from one which focuses on maximizing the quality of acute disease care toward a chronic illness management model, where issues that may impact survivor quality of life must be examined.

#### Prostate Cancer

The cancer population that may best illustrate the need for adopting a chronic illness model in understanding cancer survivorship consists of the men who have been diagnosed with prostate cancer (PC). Over the course of their lifetime, approximately 1 in 6 men born in the US today were diagnosed with PC. These staggering statistics make PC the most common cancer among American men (American Cancer Society, 2010). An estimated 217,700 men were diagnosed with PC in the United States in 2010, adding to more than two million American men already living with the disease. Of those currently suffering from PC, approximately 32,000 died due to the disease in 2010. The median age for a diagnosis of PC is 68 years of age, with the majority of men diagnosed



1

between 55-85 years of age (Horner, 2009). Those men diagnosed within the past two decades have experienced significant improvements in the screening of PC. Early detection of the disease, using the prostate specific antigen (PSA) test and the inclusion of a regular digital rectal examination in physical examinations for older men have resulted in a greater proportion of men diagnosed with the disease in the localized stage. For a man diagnosed with localized PC the prognosis is positive, with 5-year relative survival rates approaching 100% (American Cancer Society, 2010).

Men who survive the disease are faced with a lengthy list of newfound challenges they must address. Issues ranging from adjusting to the impact of a cancer diagnosis, to identifying the best treatment, to coping with treatment-related side effects, to long-term existential fears can all detrimentally affect the quality of life for the survivor (Schag et al., 1994; Stanford et al., 2000; Eton, Lepore & Helgeson, 2005). For most survivors, their families are the ones that take on the burden of helping them cope with the longterm adjustment challenges they are facing (Brody, 1985). The social support network of the PC survivor can be called upon to provide a range of support, from driving the men to appointments with their urologist, to acting as an activity partner to keep the survivor physically fit, to consoling them when they receive a PSA score that is higher than expected. In particular, the physical and mental recovery process for cancer survivors often depends on one primary caregiver – their spouse (Nijboer et al., 1998), who appears to provide the most comprehensive and least stressful support for patients (Johnson, 1983).

Although the salutary role that caregivers play in a survivor's adjustment process has been well documented, mounting evidence suggests that the physical and mental



burden they experience can often be greater than the survivor's experience, when coping with their own cancer. Thus, caregivers may also benefit from receiving some form of social support. Having access to support appears to mitigate some of the negative effects of PC caregiving on their physical and mental quality of life. For example, support appears to buffer the emotional stress experienced by caregivers and is associated with lower levels of depressive and anxiety symptoms (Li, Seltzer & Greenberg, 1997; Ergh et al., 2002). Furthermore, caregivers who are able to access support networks that allow them to engage in recreational social activities report decreased levels of distress (Thompson Jr. et al., 1993). Unfortunately, PC caregivers have been an understudied population in the existing literature.

As PC involves numerous challenges that the couple faces together, including treatment choice, side effects of treatment, which can affect aspects of the relationship (e.g., sexual dysfunction), fears of losing a partner and so forth, the disease has often been referred to as a "couple's disease" (Lewis, 1990; Harden et al., 2002). Despite the interconnected nature of the disease, the dyadic adjustment process of PC is not well understood. Instead, much of the existing literature has focused on individual aspects of the adjustment process from either a survivor's or a caregiver's perspective, but rarely incorporating both viewpoints simultaneously. This underdeveloped understanding of dyadic functioning is apparent in the limited literature that has evaluated the dyadic impact of social support in the PC survivor and caregiver population. Although the survivor and his spousal caregiver often share social networks, the mutual influence of this support has been previously understood only at an individual level, rather than a dyadic level.



#### Treatments for Prostate Cancer

For the significant number of men diagnosed with PC at the localized stage (80.9%; SEER, http://seer.cancer.gov), current treatment options, such as radical prostatectomy (RP) and radiation therapy (RT), have proven to be highly effective, with 5-year relative survival rates close to 100% (American Cancer Society, 2010). RP is a surgical option and involves the removal of the prostate gland and surrounding tissue, whereas RT involves the use of radiation to lyse cancer cells. The radiation source can be internal, via the implantation of a radioactive seed within the prostate gland, or external. The benefits of survival associated with these treatment options for localized disease are often offset by the physical and mental challenges created by diagnosis, treatment, and subsequent side effects of treatment. In particular, survivors often experience significant and chronic treatment-related physical side effects, such as urinary, sexual, and/or bowel dysfunction (Litwin et al., 1995; Litwin et al., 1998; Potosky et al., 2004; Korfage et al., 2005; Miller et al., 2005). When compared with age-matched controls, men who have been treated for PC report significantly greater functional declines in urinary, sexual, and bowel functioning (Hoffman et al., 2003). In PC survivors one year post-treatment, individuals who chose either RP or RT reported significant side effects of treatment. For example, 21% of survivors who chose RP reported urinary incontinence and 73% reported sexual dysfunction, while 22% of survivors who chose RT experienced urinary obstruction and 60% experienced sexual dysfunction (Clark, Wray & Ashton, 2001). Post-treatment, another area of notable concern for PC survivors is sexual functioning (Robinson, Moritz & Fung, 2002). Men



choosing either RP or RT both experienced concerns ranging from impotence to a loss of sexual potency (Stanford et al., 2000; Crook, Esche & Futter, 1996).

However, the PC experience for localized survivors can be different from what men diagnosed with advanced stage PC experience. This is primarily due to the different treatment options available for either group. The spread of the cancer outside of the prostate gland, indicative of advanced PC (metastatic PC or distant stage PC), is most commonly treated with hormone therapy (HT). HT, also referred to as androgen deprivation, and rogen suppression, or chemical castration therapy, is less invasive than other treatment options, such as the removal of the testes (SEER, http://seer.cancer.gov). The aim of HT is to reduce levels of androgens within the PC survivor's body, which may reduce the size of the cancer and/or reduce its rate of growth. However, HT is associated with a wide variety of endocrine system related side effects (Kornblith et al., 2001; Horner, 2009). For example, HT has been associated with fatigue, weight gain, nausea, hot flashes, pain, constipation, and urinary dysfunction (Clark, Wray & Ashton, 2001; Nygard, Norum & Due, 2001), and men who received 1 year of HT reported increased sexual dysfunction (e.g., impotence, loss of libido) compared with no-treatment controls (Potosky et al., 2002). Despite all of the challenges advanced PC survivors face throughout treatment, survival is not guaranteed. Although the overall survival rates for PC are high, those diagnosed with advanced PC face a much lower 5-year relative survival rate of 31% (Horner, 2009).



#### Quality of Life of Prostate Cancer Survivors

The cancer experience, from diagnosis through treatment through recovery, for both localized and advanced stage PC survivors, can dramatically affect the overall quality of life for these men (Herr, 1997). However, prior to the 1990's, the concept of quality of life was not well studied. The quality of life of cancer survivors was evaluated based primarily upon the oncologist's report of the survivor's functioning (Osoba, 1994). Within the past several decades, the field of oncology has significantly shifted toward incorporating the survivor's perceptions of his/her own functioning as a major source of information regarding quality of life (Herr, 1997). Quality of life has been conceptualized as the assessment of an individual's level of functioning resulting from disease and its treatment (Testa & Simonson, 1996). Four primary realms of quality of life are generally evaluated: physical, mental, functional, and social. The *physical* aspects of quality of life include factors such as the extent of bodily discomfort felt by the individual and an overall evaluation of self-health. *Mental* aspects considered to be a part of quality of life include subjective factors such as how happy they have been to how frequently they have been feeling anxious. *Functional* quality of life refers to the ability of the individual to perform daily tasks, such as being able to bathe, dress oneself, and climbing stairs at the office. Finally, *social* quality of life describes factors such as the individual's perception of how much time they are able to spend attending social events.

Due to the heightened potential for physical side effects of treatment, significant research attention has been focused on evaluating the physical quality of life in PC survivors. For PC survivors, treatment can create a host of urinary, bowel, and/or sexual side effects that can greatly compromise the physical quality of life of these men (Litwin



et al., 1995; Potosky et al., 2004; Korfage et al., 2005; Miller et al., 2005; Clark, Wray & Ashton, 2001; Nygard, Norum & Due, 2001). Altogether, the physical dysfunction experienced by PC survivors following treatment has been demonstrated to compromise quality of life up to 4 years post-treatment (Blank & Bellizzi, 2006; Korfage et al., 2005; Lilleby et al., 2005).

Additionally, PC survivors may experience challenging short- and long-term stressors that can cause decrements in mental quality of life. For these men, the mental challenges can begin as early as waiting in their physician's office for biopsy results and extends through the stress of a PC diagnosis, finding ways to cope with the physical challenges of treatment, and finally in dealing with concerns about recurrence and mortality. As a result of these challenges, the mental quality of life for PC survivors has also received significant research attention, and the effects, ranging from depression, to anxiety, to general mental dysfunction, appear to be significant. For example, in a group of PC survivors receiving HT, the rate of major depressive disorder was 32 times the national rate in men over the age of 65 (Pirl et al., 2002). Further evidence in HT populations notes that men who receive HT report impaired mental health functioning up to 1 year post-treatment, compared with survivors who did not receive HT (Herr & O'Sullivan, 2000). Men treated with RT showed similar patterns, with higher than general population rates of depression and anxiety (Fowler Jr et al., 1995), even up to five years post-treatment (Korfage et al., 2006). It is in this post-treatment time period that some survivors experience heightened anxiety as a result of fluctuations in their PC state, as evidenced by changes in their PSA levels (Roth et al., 2006). For these survivors, the ongoing monitoring of their disease status creates what has been referred to as the



"walking worried," as a result of the anxiety caused by disease monitoring (Herr, 1997). Research has demonstrated that advanced PC survivors experience high levels of anxiety as a consequence of the ongoing monitoring of their PC disease status with regular PSA testing (Lofters et al., 2002; Latini et al., 2007). Current literature suggests that up to 38% of individuals post-cancer diagnosis report suffering from major depression, with up to 58% experiencing some depression spectrum symptomatology (Massie, 2004), and up to 23% reporting clinical levels of anxiety (Stark & House, 2000). Furthermore, 12.4% of cancer survivors are estimated to meet criteria for a joint depression and anxiety diagnosis (Brintzenhofe-Szoc et al., 2009).

## Quality of Life of Spousal Caregivers of Prostate Cancer Survivors

#### Caregiving

Caregiving for an individual encompasses a wide spectrum of activities and experiences that are associated with providing help or assistance to another individual and can be considered as the behavioral expression of caring for someone else (Pearlin et al., 1990). Many responsibilities are associated with the caregiving experience that present adjustment challenges for the caregiver, as the consequences often include spending more time attending to work-like activities and less time pursuing leisure activities. The burden associated with caregiving consists of both the physical effort that is expended in order to provide care for the recipient (Schulz, Visintainer & Williamson, 1990; Given et al., 1990; Wallhagen, 1992) and the mental stress that is involved in the process (Moritz, Kasl & Berkman, 1989; Given et al., 1990).



Our understanding of the process of actively caring for an individual suffering from a chronic physical illness is best understood in several patient populations. The best studied populations have been of caregivers of patients suffering from chronic rheumatoid arthritis (Brouwer et al., 2004), dementia (Schulz et al., 1995), specifically Alzheimer's disease (Grant et al., 2002), Parkinson's (Martinez-Martin et al., 2005), diabetes (Langa et al., 2002), and for the frail elderly (Stone, Cafferata & Sangl, 1987). The evidence across all of these chronic illness populations suggests that caring for an individual who has experienced a diminishment in their ability to perform basic activities of daily living is a mentally and physically draining task (Schulz, Visintainer & Williamson, 1990). The caregiving process involves a substantial dedication of time (Riemsma, 1998), which creates a subjective sense of an immense amount of personal burden (Montgomery, Gonyea & Hooyman, 1985). This devotion of time and sense of guilt when not in a caregiving role can limit caregivers from being able to receive adequate rest, pursue personal interests, or complete necessary activities, such as taking medications or going for doctor's visits (Langa et al., 2002; Burton et al., 1997). Thus, it is not surprising that increases in caregiving responsibilities are associated with increases in the rates of physical and mental co-morbidities (Schulz et al., 1995; Haley et al., 1987).

Although cancer can now be considered a chronic illness, caregivers of cancer survivors experience a somewhat unique set of challenges compared with those caring for other chronic illness populations. In particular, many cancer survivors do not suffer from the same level of physical and/or mental deficits in functioning that are experienced by patients suffering from other chronic illnesses, such as dementia (Clipp, 1993). Thus, the relationship between the cancer caregiver and their caregiving recipient can be



significantly different from the nature of other caregiving relationships. This unique caregiving experience makes it is particularly important to identify the specific challenges that affect cancer caregivers and the factors that are associated with the overall adjustment process within these dyads.

#### Spousal Caregivers

The spouse is typically the primary caregiver for the cancer survivors and, consequently, experiences many of the trials and tribulations that the survivor does (Nijboer et al., 1998). Research suggests that the correlation is high between the physical and mental quality of life of caregivers and caregiving recipients (e.g., George & Gwyther, 1986). This close relationship is further evidenced by research that shows that PC caregivers experience even higher levels of cancer-related distress than their care recipients (Cliff & MacDonagh, 2000).

A paucity of research suggests that the challenges associated with cancer caregiving can affect physical quality of life in caregivers. It appears that cancer caregivers are subject to an exacerbation of pre-existing medical conditions, and they report greater levels of exhaustion, when compared to non-caregivers (Oberst et al., 1989). These decrements in physical health have been associated with dysregulation of inflammatory signalling pathways that can have negative consequences for long-term health in cancer caregivers (Rohleder et al., 2009). Self-reported physical quality of life is also impacted, as cancer caregivers have reported lower subjective physical quality of life, when compared to age-matched controls (Haley et al., 2001). These lower levels of subjective physical quality of life agree with objective measures of physical health (e.g.,



medication use) in cancer caregiver populations (Pinquart & Sorensen, 2003). PC caregivers have reported lower physical quality of life than the PC survivors they are responsible for (Kim et al., 2008), a finding which was also illustrated in an African-American PC survivor and caregiver population (Campbell et al., 2004).

The impact of cancer caregiving on their mental quality of life is much better understood (e.g., Harden et al., 2002; Nijboer et al., 1998). Research suggests that at the time of a cancer diagnosis, the rates of clinically diagnosable depression and anxiety disorders in spousal caregivers are already two times the community rate and significantly higher than the survivor's rates (Couper et al., 2006; Pinquart & Sorensen, 2003). These self-reported rates of depression and anxiety match with clinician ratings of mental functioning (Pinquart & Sorensen, 2003). Following diagnosis, the cancer caregiving experience is often so difficult that caregivers report equal or greater mental distress compared with the survivor up to 2 years post-diagnosis (Northouse & Stetz, 1989; Kornblith et al., 1994; Couper et al., 2006; Langer, Abrams & Syrjala, 2003; Cliff & MacDonagh, 2000; Fletcher et al., 2008). As a consequence of these mental challenges, an estimated 25% of caregivers report seeking some form of mental health treatment following a care recipient's cancer diagnosis (Vanderwerker et al., 2005). Female caregivers may be at a particular risk for decrements in quality of life, as they have been shown to report greater mental distress and a lower overall quality of life than male partners, even after controlling for the physical health of the survivor (Hagedoorn et al., 2000). In PC populations, the spouse has been shown to report higher levels of anger, depression, anxiety, and poorer overall mental quality of life, when compared to the PC survivor they are caring for (Banthia et al., 2003; Campbell et al., 2004). The high rates



of psychological morbidity in spousal caregivers of cancer survivors, particularly spousal caregivers of PC survivors, may be due, in part, to the average age at which men are diagnosed with PC. Men are generally diagnosed later in life (Horner, 2009), when social networks may be reduced (Charles & Carstensen, 2010). Thus, the spousal caregivers often lack a sufficient social support network that they can rely upon in times of duress (Hagedoorn et al., 2008). This may be of particular concern, as women tend to report less support from their spouse than men do, and women tend to benefit from support from larger networks of support (Schwarzer & Gutiérrez-Doña, 2005; Hann et al., 2002).

#### A Neglected Population: Prostate Cancer Spousal Caregivers

Although a significant body of research has identified caregivers, including cancer, as being at a significant risk for some form of physical or psychological dysfunction as a result of the caregiving experience, they are often forgotten by researchers. Researchers have come to consider the caregiver as a "hidden patient" as a result of the challenging role they play and emphasize the need to better understand their adjustment in light of their struggles (Fengler & Goodrich, 1979; Schulz, Visintainer & Williamson, 1990; Given et al., 1990). In particular, despite evidence suggesting that PC caregivers may, in fact, be at a greater risk for decrements in psychosocial functioning than PC survivors, the work has been limited to specifically document their quality of life or evaluate factors associated with their adjustment process. This relatively weak understanding of the impact of PC on the caregiver underlies the small number of clinical interventions that have been developed to assist PC caregivers in their adjustment



process. In this narrow amount of work, evidence suggests that when PC caregivers and survivors are provided with a family-based clinical intervention PC caregivers experience greater levels of psychosocial improvement than PC survivors do. An intervention designed to improve the cancer appraisal process and coping strategies, including communication skills, for the PC dyad was effective in improving a host of psychosocial factors for the PC spousal caregiver, including overall quality of life at 4-months postintervention, and caregiving appraisals, communication ability, and perceived physical symptom distress at 8-months post-intervention (Northouse et al., 2007). However, the effects of the intervention for the PC survivor were far more limited. They only reported improved self-efficacy and communication at 4-months post-intervention (Northouse et al., 2007). Other research has demonstrated that psychosocial interventions can improve the PC spouse's adaptive coping skills (Manne et al., 2004), preparedness for the caregiving experience (Giarelli, McCorkle & Monturo, 2003), and that even a single session intervention can reduce levels of perceived stress up to one year, post-PC survivor of RP (Thornton, Perez & Meyerowitz, 2004).

These findings highlight the importance of including PC spouses in the program for PC care, both from research and clinical perspectives. Thus far, the shared nature of PC has been primarily evaluated from the perspective of just the survivor. A deeper understanding of the spouse's perspective, including factors that may facilitate her caregiving role and adjustment process is needed (Northhouse et al., 2007). This level of knowledge regarding the spouse's PC process has direct implications on the clinical support that can be offered for this underserved population. Rather than being looked upon as an outside observer to the PC process, or simply as a care provider, it is



important to recognize the PC spouse as an individual who also requires clinical attention (Northouse et al., 2007). Improvements in PC spouse functioning may result in an increased ability to care for the PC survivor, translating into better quality of life for the dyad.

#### Dyadic Mutuality of Prostate Cancer Adjustment

The shared cancer experience between the PC survivor and their spousal caregiver is one which is uniquely intertwined. Perhaps more so than with many other chronic illnesses or cancer populations, the ups and downs of the journey through PC are experienced equally by both members of the dyad. Evidence suggests that the stressors which affect one partner can often spill over and influence the other's physical and mental quality of life, highlighting the extent of dyadic mutuality in cancer populations (Manne, 1998; Hodges, Humpris & MacFarlane, 2005). Limited research has identified the inter-relationship between a PC survivor's and spousal caregiver's physical quality of life (Kim et al., 2008; Zhou et al., under review). Furthermore, researchers have reported that spouses or partners of PC survivors report similar levels of psychological distress (Kornblith et al., 1994) and that caregivers of advanced cancer survivors were significantly more likely to meet criteria for a psychiatric diagnosis if the survivor met such criteria (Bambauer et al., 2006). In part, this mutuality between PC survivor and caregiver is different from other caregiver/caregiving recipient relationships because of the unique ability of the caregiving recipient (the PC survivor) to simultaneously provide care back to the caregiver. This dyadic support system presents a unique perspective into the shared process of adjustment to PC.



This dyadic process is unique to certain patient populations, including PC populations. With many other patient populations, the caregiving process is often more uni-dimensional. When one individual in an adult relationship develops an illness that chronically impairs their ability to function independently, an imbalance in care provision and receipt develops. For example, when a spouse develops Alzheimer's disease, the caregiver must cope with mental side effects that increase in intensity over time. This mental dysfunction can dramatically impair the ability of the patient to care for him/herself, thus placing the caregiver in the challenging role of providing the majority of support in the relationship (Grant et al., 2002). This imbalance is one which can serve to dramatically alter the foundational nature of that relationship. As a result of the shift in the direction and extent of care provision, from relationship involving shared support to one which favors one individual, the relationship can experience duress. Both the provider, who must dedicate personal time and efforts toward caregiving, and the recipient, who is aware of the imbalance within the relationship, understand the shifting roles and the challenges the caregiver now faces (Pearlin, 1983; Wallhagen, 1992). As a result of the increasing energy and time that the caregiver dedicates to the caregiving process, they may have less time available to spend on pleasurable activities, including seeing friends or leisure pursuits (Gilleard et al., 1984; Zarit, Reever & Bach-Petersen, 1980).

Unlike Alzheimer's and many other chronic illness cases, the caregiving/care receipt process for PC has been reported to be one in which the spouse acts as a partner, rather than 'just' a caregiver (Giarelli, McCorkle & Monturo, 2003). With this particular disease, a strong sense of mutuality exists in the support process as both the PC survivor



and the spousal caregiver are often able to provide and receive support from one another (Butler et al., 2000; Maliski, Heilemann & McCorckle, 2001). These intimate dyadic ties between the survivor and caregiver can be viewed as an extension of the "fundamental human motivation" (Baumeister & Leary, 1995) to connect with others.

Basic attachment theory identifies the need for humans to form and maintain social relationships from birth (e.g., Bowlby, 1969). Several characteristics of this motivation exist to develop social ties that underlie its prevalence in affecting our thoughts and actions. Most notably, the ease with which bonds are formed and the reluctance for humans to sever existing bonds serve to underscore the importance of social bonds in our identity. Taking this notion of the intimacy of developed bonds one step further, Sbarra and Hazan (2008) propose a model of co-regulation within intimate partnerships that defines the effects of the strong social ties that are established between two individuals, such as the one that is formed within the PC dyad. It is hypothesized that when one, or both, members of a dyad perceives stressors (i.e., as a result of a PC diagnosis), the family system is dysregulated and this has repercussions for the physical functioning of both dyadic partners. This model of co-regulation is founded upon the notion that the dyadic relationship represents a social bond that is strengthened through repeated social contact with one another. In most dyads that remain together over time, such as is the case with marital relationships, the individuals in the dyad become conditioned to a state of mental and physical calm and comfort when interacting with their partner (Depue & Morrone-Strupinsky, 2005). A disruption to any aspect of the dyadic system is hypothesized to impact both members of the dyad. Thus, when the



quality of life of one member of a dyad is impacted, it stands to reason that the quality of life of the other member of the dyad may be influenced as well.

Despite this acknowledged importance of the dyad, the existing literature evaluating the adjustment process in PC survivors and their spousal caregivers is alarmingly one-sided. Researchers have hypothesized that our past focus on individuals, rather than the dyad, in the literature may be attributable to factors such as the individualistic cultural focus of the United States (Smith & Bond, 1994) and the limited development of statistical models capable of evaluating dyadic research questions (Kenny, Kashy & Cook, 2006). Regardless of the reasoning, a better understanding is needed of how couples adjust together to repair physical and mental quality of life, following a stressful life event such as PC.

The notion of examining how stress affects quality of life from a dyadic perspective is a recent direction, when researchers began to evaluate the stress paradigm in couples beginning in the 1990s (e.g., Giunta & Compas, 1993). Dyadic stressors, such as PC treatment-related side effects, represent a form of stress that is unique from that experience in an individual context. Added layers of complexity to dyadic stressors differentiate them from individual stressors. Bodenmann (2005) suggests that they involve shared concerns between two individuals, who have an active social relationship. Furthermore, in caregiver situations, maintaining the continuity of a social system is important to allow both partners of the dyad to be thoroughly engaged (Bodenmann, 2005).

Dyadic stress can be conceptualized along three dimensions: 1) whether the individual is affected directly or indirectly by the stressor, 2) if the stressor originated



from within the couple or outside of the relationship, and 3) the timing of when each partner becomes actively involved in the coping process (Bodenmann, 2005). For PC survivors and their caregivers, the dyadic stressors associated with the disease and treatment can be classified along these dimensions. First, the survivor is directly affected mentally and physically by the dyadic stressor (the diagnosis of cancer and the treatmentrelated side effects). Although the caregiver is not afflicted with disease, she also experiences the diagnosis and treatment of her partner as a direct dyadic stressor. This is because she faces challenges such as caregiving stress and the possibility of the death of her partner (Bodenmann, 2005). Second, the origin of the stressors associated with PC is primarily within the couple. The dyad shares in the stress of the health dilemma and the associated care of the PC survivor. However, it is important to note that some of the stress may originate externally to the dyad in the form of challenges that the survivor encounters by himself. For example, the survivor may face roadblocks to proper treatment when dealing with an unsympathetic employer who refuses to permit sufficient time off work or an oncologist who is hurried and does not provide proper health services. Finally, the time sequence of PC stress can often be similar in nature. The dyad can be presented with challenges that must be addressed simultaneously, thereby affecting both members to some extent (Harden et al., 2002; Banthia et al., 2003). This has received recent research attention, with interventions designed to help the PC dyad cope with the psychosocial and physical stressors together, rather than separately (Weber et al., 2004). However, it should be noted that exceptions to this can occur, with some possible stressors developing sequentially. For example, if the coping response to PC of



one partner is maladaptive (e.g., substance abuse), this may develop into a PC-related stressor that affects the dyad.

#### Dyadic Coping for Prostate Cancer Survivors and Their Spousal Caregivers

The shared coping process for PC survivors and their spousal caregivers can have a significant, and positive, influence on the overall quality of life for both dyadic members. According to Bodenmann's model of dyadic coping (Bodenmann, 1995; Bodenmann, 1997; Bodenmann, 2005), positive dyadic coping can occur when one partner assists the other with their coping efforts. This can take on the form of both problem-focused (e.g., assisting with day-to-day tasks, offering information relevant to treatment, etc.) and emotion-focused (e.g., expressing to the partner your faith in his recovery, hearing out your partner when he is describing his worries) coping strategies. Positive dyadic coping serves the purposes of both supporting the partner and also reducing the individual's stress, when one's partner has unresolved issues (Bodenmann, 1995). This can result in an interaction between the quality of life of the dyad, wherein the members of the dyad can help one another improve their own and each other's psychosocial functioning.

The process by which a PC survivor and his spousal caregiver support one another, while also receiving support from sources exterior to their dyad, can be complicated. The conceptualization of how the dyadic coping process occurs has taken a number of forms in the literature. First, it has been theorized as simply being the coping efforts of the individual in the context of a dyad (e.g., a marriage; Pearlin & Schooler, 1978). In this model, the stressors that are faced by individuals in the dyad are addressed



by that individual alone, without the involvement of their partner. The dyadic relationship merely serves as the backdrop against which the individual coping efforts occur. In this case, no support would be provided by either the PC survivor or caregiver to one another.

A second approach to describing how the dyadic coping process occurs does not completely sever the connection between the individual coping efforts within the dyad, as does the first model. Rather, this approach emphasizes the interaction between each individual's coping efforts (Barbarin, Hughes & Chesler, 1985). Within this model, it is important to consider the congruence or match between the coping efforts of each individual (Revenson, 1994). When the two partners are more congruent in their coping efforts, they are more likely to arrive closer to their joint goal compared to a couple who is dissimilar in their coping efforts. Any incongruency in coping may serve to impede the overall coping efforts of the dyad. In the case of the PC dyad, a case example could be imagined whereby a survivor is impeded in his recovery efforts because he prefers to use emotion-focused coping strategies, while his spouse prefers to provide rationalized, informational coping support.

A third approach to conceptualizing dyadic coping has been termed both empathic coping and relationship-focused coping (DeLongis & O'Brien, 1990; Coyne & Smith, 1991). This model centers upon both the well-being of the individuals and the well-being of the dyadic relationship. Thus, individual coping efforts are considered in the context of how they affect the well-being of the partner and the functioning of the dyadic relationship. Within the scope of this model are two aspects of coping: 1) active engagement, which entails involving both partners in discussions to explore the problem



and attempting to constructively resolve the problem and 2) protective buffering, which may involve minimizing the worries of a partner through conversation, giving in to the partner's wishes, or suppressing anger at the partner (Coyne & Smith, 1991; Coyne et al., 2001). In the context of a PC couple, a survivor who is angry at his spouse for her lack of involvement in his rehabilitation process may dramatically affect both the functioning of the relationship and the dyadic coping process for the couple.

Finally, the fourth model for conceptualizing dyadic coping is based upon the transactional stress theory (Lazarus & Folkman, 1984). The theory seeks to consider the system in which the stressor occurs and the process of the coping (Bodenmann, 1995; Bodenmann, 1997). In this model, the appraisal of any stress by one partner is communicated to the other partner. It is then that the dyad proceeds to respond with some form of dyadic coping. It should be noted that the stress response by the partner can be active or passive by simply ignoring the stress that she perceives in her partner. It is important to consider the stress and coping process from a systems perspective in this model. The effects of one individual's coping efforts must be considered in the context of how it affects the partner and the dyadic relationship. Reciprocity exists in the relationship, where one partner's well-being and level of satisfaction with the relationship is affected by the other partner. Because of this, both individuals in the dyad are motivated to engage in some form of coping whenever one or both members of the dyad are faced with a stressor (Bodenmann, 2005). Second, the process of dyadic coping exists as one aspect of the larger coping process. This process also includes individual efforts at coping and the use of a larger social support network. Finally, the process of dyadic coping may involve both positive and negative aspects of coping. As this



approach best describes the extensive back and forth process that takes place within a dyad, before a dyadic coping effort is achieved, we will base our model of the interaction in a PC dyad on this approach. It can be seen that in any form of PC coping that the interplay between the individuals in the dyad will dramatically shape the way in which the coping efforts assist or hinder quality of life adjustments in the couple.

Understanding the conceptual nature of a stressor from an individual or a dyadic perspective has implications for the adjustment process that occurs subsequent to the individual's exposure to the stress. As PC-related stressors are conceptualized as ones that directly affect both the survivor and caregiver, originate internally within the dyad, and affect the dyad simultaneously, it follows that they can often be addressed via dyadic, rather than individual, forms of coping. For the purposes of the current study, if we take a transactional stress approach to dyadic coping, we can conceptualize these changes in overall stress through the constant exchange of experiences and coping processes between partners, which serves to influence their own and their partner's state of functioning. This adjustment process for the PC dyad is one that has an interconnected nature between one individual's coping efforts and the quality of life with the other partner. The coping factors that promote adjustment for one individual are ones that have the potential to influence the other individual's coping efforts and quality of life. In Figure 1, an outline of Bodenmann's dyadic coping model as it applies to the current study sample of PC survivors and their spousal caregivers is presented.



#### Social Support

The burden of adjusting to life after cancer can be overwhelming and one that individuals are simply not prepared to handle. This can have significant and negative effects on the physical and mental quality of life for both PC survivors and their spousal caregivers. However, one aspect of an individual's environment that has repeatedly been associated with positive adjustment, following exposure to a life stressor, has been being able to access social support. Social support has been broadly defined as the perception an individual is part of a social network founded upon mutual assistance, guidance, and feedback about life experiences (Caplan, 1974; Wills, 1991). Social support is able to improve survivor quality of life through several possible mechanisms. For example, social support may help individuals validate their negative emotions in times of crisis and serves to educate them about the health-related options they have available (Demange et al., 2004). Another possible reason why social support can play such a vital role in minimizing quality of life decrements is that it may help to improve an individual's use of their own coping strategies and to help increase positive, or decrease negative, health behaviors (Baum, Revenson & Singer, 2001). In general, social support appears to positively affect quality of life in difficult times. However, different aspects of social support appear to play different roles in impacting quality of life. Two particularly salient constructs in social support have been studied to refine our knowledge of what specifically makes it so effective in helping individuals cope with stress; a structural and a functional aspect of the social support (Wills & Fegan, 2001).



#### Structural Social Support and Quality of Life

The structure of social support has also been referred to as social integration. This describes aspects of social support that relate to the number of social relationships an individual has, the frequency of contact with that network, and the framework of that network (Friedman & Silver, 2007; Cohen & Janicki-Deverts, 2009). First investigated by Berkman and Syme in 1979, their seminal study tracked a group of California residents over the course of a nine year follow-up period. Their findings indicated that individuals with a greater number of social ties were less likely to die during the study, even after adjusting for a broad range of risk factors for mortality, such as self-reported physical health status at baseline, socioeconomic status, smoking, alcohol consumption, obesity, and level of physical activity (Berkman & Syme, 1979). During the past couple of decades, a wealth of research has supported the association of increased levels of social integration with positive physical health outcomes.

In studies with general healthy populations, higher levels of structural support have been linked to a myriad of positive physical health benefits. For example, more social ties have been associated with reduced susceptibility to the common cold (Cohen et al., 1997) and most importantly with lowered mortality (Berkman, 1995; Seeman, 1996) within general populations. In chronic illness populations, the benefits of increased social integration are also apparent. The most convincing research associating social support with health repercussions has been conducted with survivors suffering from cardiovascular disease. Strong evidence suggests that structural social support confers lower risk for cardiovascular disease development (Uchino, 2004; Uchino, 2006). This may be through a stress buffering mechanism (Cohen & Wills, 1985) affecting the



individual's cardiovascular reactivity to stressful situations (Lepore, 1998). Laboratory evidence for such a phenomenon is found in the literature as the presence of a friend was associated with lower blood pressure reactivity to a laboratory stressor task (Kamarck et al., 1990). Further evidence for the role of structural social support in the development of cardiovascular disease has been found with increasing atherosclerosis in cardiovascular patients. Longitudinal studies investigating survivors at risk for developing cardiovascular disease show that more socially integrated individuals developed less arterial calcification (Kop et al., 2005; Wang, Mittleman & Orth-Gomer, 2005), experienced fewer strokes (Rutledge et al., 2008), and had reduced mortality (Rutledge et al., 2004) compared with control populations. The effects of structural social support are also seen prominently in cancer survivors. Breast cancer (BC) survivors who reported greater diversity in social network had a lower rate of cancer recurrence (Helgeson, Cohen & Fritz, 1998). Furthermore, more social ties have been related to better immune system functioning in ovarian cancer survivors, particularly for older adults (Uchino et al., 1996). In the limited research evaluating the effects of structural support on physical health, no studies have evaluated how physical quality of life is affected by higher or lower levels of structural support.

Mentally, the positive effects of structural social support have also been identified. Overall, it appears that increased structural support is associated with protective effects, while lower levels of structural support (such as with socially isolated individuals or those experiencing a loss of social ties, etc.) are associated with lower levels of mental quality of life (Seeman, 1996). For example, evidence suggests that those adult populations with a higher number of social ties are less likely to experience



reduced cognitive decline during the aging process (Fratiglioni, Pallard-Borg & Winblad, 2004), mental distress in day to day living (Johnson, 1991), and those adults who report a greater variety of sources of support and more contact with support sources are less likely to report depressive symptomatology (Dean, Kolody & Wood, 1990; Oxman et al., 1992). The loss of close social ties, such as those experienced when an individual loses his/her spouse due to cognitive impairment, has been associated with increased levels of depression (Moritz, Kasl & Berkman, 1989). Similarly, the loss of close social ties due to the death of a loved one has also been associated with poorer overall mental health (Bowling, 1987).

#### Sources of Support

These aforementioned findings suggest a direct association between structural social support and physical and mental quality of life outcomes. The findings also lead to an important question: which social relationships are most significantly associated with good quality of life? As adults spend the majority of their non-working hours with their *spouse* (Bureau of Labor Statistics, 2010), one's spouse would apparently have the greatest influence on health and quality of life. Large scale epidemiological studies have identified an association between being married with higher overall quality of life and a lower risk for mortality (Vebrugge, 1989; Burman & Margolin, 1992). A landmark study with a large cancer population selected from the Norwegian Cancer Registry data between 1960 and 1991 evaluated the deaths of over 150,000 cancer survivors. Results suggest that the mortality rate for never-married and divorced survivors is 15% higher than for married survivors (Kravdal, 2001). These findings have been replicated in PC



populations. An investigation of publicly available PC mortality data collected for over 145,000 men between 1973 and 1990 revealed that married PC survivors had longer median survival times, when compared to single, widowed, separated, or divorced survivors, after controlling for age, stage of cancer, ethnic group identification, and treatment choice (Krongrad et al., 1996). Mentally, it appears that support from one's spouse was the best predictor of mood and subjective health (Walen & Lachman, 2000). In post-hospitalized patients over the age of 65, spousal support was associated with the least patient stress (Johnson, 1983). Research in cancer populations indicates similar findings. Cancer survivors who reported lower marital satisfaction also reported higher levels of depression and anxiety symptoms and higher overall mental distress (Rodrigue & Park, 1996).

Research evaluating the effects of other sources of social support on quality of life has presented mixed findings. Prior research has mostly investigated two additional sources of support: the family and friends. For many adults, an important source of support remains other *family members* (Seitz, Rosenbaum & Apfel, 1985). Ranging from siblings to adult children, the family bond is often considered an integral part of an individual's support network (Nee & Wong, 1985). In PC populations, it appears that members of the family, such as the children of the survivor, are very much affected by the PC experience (Bruun et al., 2010). The literature has demonstrated that family members can make a contribution to quality of life. In an elderly adult population, higher levels of perceived support from immediate family are significantly associated with lower depressive symptomatology (Dean, Kolody & Wood, 1990). However, it appears that the influence of the spouse is far greater (Dean, Kolody & Wood, 1990). Interestingly,



another study found that distant relatives made no statistically significant contribution toward a reduction in depression in the participant (Dean, Kolody & Wood, 1990). In chronic illness populations, adolescents with HIV reported that family members were the most important source of social support, which may result from the limited social network size of these socially stigmatized youth. Higher levels of reported satisfaction with family support were associated with lower levels of depression in this population (Abramowitz et al., 2009). These results are mirrored in cancer populations. The association between perceived support from family with lower depression is stronger than the relationship between spousal support and depression (Hann et al., 1995). This construct has also been evaluated in work stress situations. Findings generally suggest that support from family members was more closely related to likelihood of increased work stress than support from co-workers or supervisors (Baruch-Feldman et al., 2002; Deeter-Schmelz & Ramsey, 1997).

The final important source of support that has been identified has been the influence of *friends* on the quality of life of an individual (Verbrugge, 1977). Within an elderly population, the support of adult friends helped buffer against depressive symptomatology, although these effects were not as strong as those of the spouse (Dean, Kolody & Wood, 1990). However, in another study of the elderly, the researchers concluded that the spouse was not perceived as being the primary source of support. Rather, close friends were identified as the best source of support and their presence was associated with the highest perceptions of emotional support availability and adult children were perceived to provide the most instrumental support (Seeman & Berkman, 1988). Concurring with that research, elderly patients who had recently experienced



cardiac surgery reported lower levels of depression only when they perceived support from friends and not from their spouse (Oxman et al., 1994). Cancer survivors report much of the same. Those who perceive support from friends are less likely to report depression than those who perceive support from a spouse (Hann et al., 1995).

As this area of research has not been thoroughly explored, the understanding of why different sources of support impact an individual in different ways is insufficient. The clearest distinction has been made between relationships that an individual has with family members and friends. It has been suggested that these relationships may differ because the support provided by friends is provided with a greater sense of reciprocity that may not be as prominent in relationships with family members (Antonucci & Jackson, 1987; Wenger, 1990). This can serve to allow the support recipient to provide voluntary assistance back to friends, without the feelings of obligation that may be tied to support from family, thereby offering the individual a sense of personal competence (Wenger, 1990). Other researchers have hypothesized that these differences in relationships can be attributed to possible issues that arise with family roles that change in situations where one individual requires support (Cicirelli, 1983).

Other research, however, has suggested that no specific source of support is the most influential. Research has indicated that higher perceived quality of support from all sources (spouse, friends, and family) were all associated with post-traumatic growth in a mixed-stage sample of breast cancer survivors (Bozo, Gündoğdu & Büyükasik-Çolak, 2009). General cancer survivors have reported that both family and friends are equally important sources of emotional and informational support during their cancer adjustment process (Rose, 1990). Another interesting alternative explanation is that more support



from more sources is most beneficial due to an additive effect. Researchers have reported that if elderly individuals perceive support from both family and friends they are more likely to report better physical health and lower depression than low support from one or both of those sources (DuPertuis, Aldwin & Bossé, 2001).

#### Functional Social Support and Quality of Life

Another salient aspect of social support is functional support, which refers to the quality of the social support that is perceived to be available. Multiple domains of functional support can be considered when evaluating the quality of the support provided: instrumental, emotional, and informational support (Friedman & Silver, 2007). Instrumental support describes the various forms of tangible assistance that an individual receives in daily life. This could refer to tasks such as being provided a ride to a meeting with an oncologist or cooking dinner for a survivor. Emotional support refers to the non-tangible support that helps to make an individual feel cared for and which serves to improve the sense of self-worth. Finally, information support is the process of receiving information, help, and advice from others regarding stressors. This may serve to decrease distress because it provides the individual with a sense of control over the situation (House, Landis & Umberson, 1988).

It has been noted that it is the perception of, rather than the actual, quality of the functional support provided that is the most important factor in predicting its effects on physical and mental functioning and quality of life. The majority of the existing research evaluating quality of life outcomes has provided information regarding the effects of perceiving higher compared with lower quality general functional support, rather than



narrowing their focus to one specific domain of support. The most dramatic effects of functional support on physical health have been studies which demonstrated that perceptions of more support are associated with lower mortality among healthy adults (Falk et al., 1992; Rosengren et al., 1993). In chronic illness populations, the effects of functional support on physical quality of life have been established in the existing literature. Perceptions of greater levels of support have been associated with less functional disability and pain and reduced mortality following heart attacks or a diagnosis of HIV (Demange et al., 2003; Evers et al., 2003; Lett et al., 2005; Patterson et al., 1996). Likewise, BC survivors who perceive greater availability of functional support experience a longer disease-free interval and lower mortality (Funch & Marshall, 1983; Maunsell, Brisson & Deschenes, 1995; Waxler-Morrison et al., 1991; Gidron & Ronson, 2008). On the opposite end, BC survivors who report being unable to access functional support are more likely to report declines in functional status (Michael et al., 2000). In men with PC, perceptions of poorer functional support have been associated with lower physical quality of life (Helgeson et al., 2001; Poole et al., 2001). Preliminary research has also examined the relationship between functional support and physiological functioning. In particular, attention has been focused on natural killer cell activity, which plays a significant role in monitoring cancerous cells (Abbas & Lichtman, 2003). In ovarian cancer survivors, it appears that perceiving more supportive social relationships was associated with higher levels of natural killer cell cytotoxicity (Lutgendorf et al., 2005). Similar relationships between functional support and physical quality of life have also been reported for caregivers. In dementia caregivers, perceived functional support was associated with self-reported physical quality of life, even after controlling for the



magnitude of caregiving stress (Haley et al., 1987). Caregivers of the physicallydisabled report lower physical quality of life, when they were unable to properly access functional support (Schulz et al., 2006).

The effects of functional support on mental quality of life are similar to those with physical quality of life. In a healthy adult population, perceptions of more functional support were associated with higher levels of emotional well-being (Antonucci & Akiyama, 1987; Falk et al., 1992). In individuals who have recently experienced a heart attack or an HIV diagnosis, those who reported greater levels of support were less likely to report depressive symptomatology (Krishnan et al., 1998; Demange et al., 2003). Caregivers of disabled adults reported higher levels of depression and lower mental quality of life when they believed that they had poor quality support (Schulz et al., 2006). Similar relationships have been established in cancer populations. In a general adult caregiver population, lower levels of perceived functional support (particularly instrumental support) were associated with poorer mental quality of life (Miller et al., 2001). Furthermore, in another general cancer population, the role of functional support was further evidenced. Over a 6-month period, if the caregiver experienced a decline in the quality of their social interactions they were more likely to report depressive symptomatology (Nijboer et al., 2006). With BC survivors, higher levels of functional support availability have been associated with lower anxiety and depression and higher overall emotional well-being (Neuling & Winefield, 1988; Manne et al., 2005; Bloom et al., 2001). Limited research conducted within PC populations has suggested that men who perceived lower levels of social support reported greater poorer mental quality of life (Balderson & Towell, 2003; Helgeson et al., 2001; Poole et al., 2001). One study



was conducted with the aim of improving functional support in PC survivors. It demonstrated that survivors who participated in an intervention that facilitated the discussion of emotions in a positive group setting reported lower levels of depression following the intervention (Weber et al., 2004). Caregiver populations have comparable findings. After controlling for the influence of caregiver stress, levels of functional support were associated with depression and overall life satisfaction (Haley et al., 1987; Haley et al., 1996).

# Negative Support

While benefits may be accrued from positive social support, such support may also have costs associated with it. Therefore in recent years, the opposing side of the picture, perceptions of negative social support, has been investigated. Support interactions can be maladaptive, as they may involve criticism and hostility, causing the support recipient to want to avoid such interactions in the future (Frick et al., 2005). Accumulating evidence has documented that these negative social interactions may have implications for physical and mental health. For example, when an individual perceives negative support, they are more likely to have a greater number of medical morbidities and increased mortality (Stroebe, Schut & Stroebe, 2007). Cancer survivors also reported similar results. In a general cancer population, perceiving negative social support was associated with lower levels of overall quality of life (van Weert et al., 2007). Caregivers of chronic illness patients also demonstrated similar patterns. In caregivers of amyotrophic lateral sclerosis patients, levels of caregiver distress up to 20 months postbaseline were predicted by initial perceptions of negative support from individuals that



the caregiver identified as important to their lives (Goldstein et al., 2006). Similar associations between negative social support and increased levels of depression were also found within a population of Alzheimer's caregivers (Schulz & Williamson, 1991).

# Gender Effects

Existing research has suggested that gender differences may affect the impact of structural and functional support. Structurally, it appears that women tend to perceive more support from a broader support base and to be more comfortable disclosing personal information with this range of resources. In research conducted within a population of elderly, women tended to report having larger social networks than men (Antonucci & Akiyama, 1987). Women's networks tend to be more multi-faceted, and they report more support from friends and other family and being more comfortable confiding in people other than just their spouse (Antonucci & Akiyama, 1987; Harrison, Maguire & Pitceathly, 1995; van Daalen, Sanders & Willemsen, 2005). These gender effects are not limited to just the structure of social support, as males and females perceive differences in the quality of their support. Women appear to perceive more support from their social support networks (Antonucci & Akiyama, 1987), and men reported perceiving significantly less emotional and informational support from friends and being less satisfied with their friendships than women (Olson & Shultz, 1994; Antonucci & Akiyama, 1987). Interestingly, women tend to report receiving less support from their spouses than men do, and this gap slightly increases as the dyad ages (Schwarzer & Gutiérrez-Doña, 2005). In direct contrast, men tend to report greater satisfaction with the relationship they have with their spouses than women do (Antonucci



& Akiyama, 1987). Researchers hypothesize that this increased satisfaction may be due in part to the greater dependency on their spouses that men demonstrate for instrumental, emotional, and informational support (Antonucci & Akiyama, 1987; Harrison, Maguire & Pitceathly, 1995). These gender differences have consequences in mental functioning, as having a greater number of friends or family members providing support was demonstrated to be associated with lower depression in female, but not male, cancer survivors (Hann et al., 2002).

#### Integration of Structural and Functional Support

The existing literature has demonstrated the relationships between both the quantitative and qualitative aspects of support with physical and mental quality of life. It has been suggested that the structure of an individual's social support system and the level of perceived satisfaction with that social support system may act through independent mechanisms to affect quality of life (Zimet et al., 1988). A review of the literature identifies differences in how the structure and function of support affect quality of life outcomes. Although both factors play a significant role in influencing how an individual adjusts to life challenges, it appears that perceptions of the quality of support may be more strongly associated with quality of life outcomes than the structure of that support (Sarason et al., 1983; Brandt & Weinert, 1981; Wilcox, 1981). However, despite the separate effects of structural and functional support on quality of life, much of the existing social support literature has only sought to examine one aspect at a time, instead of both.



The earliest studies that evaluated structural support sought to evaluate differences that relationships the elderly have with their adult children compared with those with their friends. Researchers considered whether an individual's adult children bear their filial responsibility and are good resources for their parents. The literature identified that the effects of relationships one has with family differ from those one has with their friends (e.g., Arling, 1976). Frequent interactions between elderly individuals and their friends appeared to provide morale and subjective well-being benefits, while no such relationship was found with frequent interactions with their adult children and other relatives (Arling, 1976; Blau, 1981; Lee & Ellithorpe, 1982). However, this initial literature is limited by their measurement of the support received from various social resources. The literature measured the frequency of interactions with different groups, as a proxy for the quality of that support. As social contact may be a source of stress, as well as support, it is important to assess individual perceptions of support quality, rather than just amount of contact (Wellman, 1981).

Thus, it appears that it may be important to integrate the two constructs together. This would permit researchers to simultaneously evaluate both the quantity and the quality of support. One identified method of considering both aspects of social support has been to evaluate perceptions of the quality of support from different sources. Beginning as early as the mid-1970s, researchers began measuring support from different members of one's social support network (e.g., Arling, 1976; Kahn & Antonucci, 1980). Initially, researchers sought to quantify the perceived social support from every individual within one's social network. A drawback of this approach was how time consuming this process became. Consequently, researchers began to consider



categorizing members of the participant's network (e.g., all people in general, closest friend, etc.) and evaluating how those groups differentially affected functioning (e.g., Abbey, Abramis & Caplan, 1985). Although it would appear that identifying how unique sources of support within an individual's social network may differentially affect that individual's quality of life is a salient research area, the construct remains vastly understudied.

#### Limitations of Existing Literature and Current Study

As a result of a diagnosis of cancer, treatment-related side effects, fears associated with disease monitoring, and possible recurrence and/or mortality, PC survivors are faced with the difficult task of navigating a lengthy list of challenges that threatens to compromise their physical and mental quality of life. Having access to a positive social support network may serve to positively affect a PC survivor's quality of life. For these men, the most important source of support is often their spouse. Generally the primary caregiver for the PC survivor, the spouse is engaged in an active role in the adjustment process and is often affected by PC as much as the survivor is if not more so. Thus, the caregiver also can experience decrements in physical and mental quality of life following a PC diagnosis. Despite the significant, and growing, population of PC survivors and spousal caregivers in the U.S., they remain vastly understudied groups. Much of the existing literature has examined the effects of social support in either general cancer or BC populations. However, evidence suggests that the impact of social relationships on quality of life is affected by the specific cancer site, due to the distinct physical and mental challenges associated with every diagnosis (Ell et al., 1992). In particular,



spousal caregivers of PC survivors remain a particularly underserved population. Several compelling research and clinical reasons support further investigation into factors associated with their quality of life. Furthermore, the coping process for PC exhibits a high level of mutuality, as the PC survivor and his spousal caregiver share overlap within their mutual adjustment processes. Unfortunately, insufficient research attention has been given to the inter-related roles of each individual member in the PC experience.

First, the current study sought to document levels of physical and mental quality of life in the understudied populations of PC survivors and their spousal caregivers. Second, it has been demonstrated that positive social support is associated with higher levels of physical and mental quality of life in all cancer populations. However, prior research has generally focused on examining the effects of either the structure or the function of support independently of one another. This study proposed to integrate those two aspects of social support by evaluating how support of varying quality from different sources can uniquely impact quality of life. This is particularly interesting as the existing literature has presented conflicting findings on how perceiving support from a spouse, compared with other family members or with friends, affects well-being in general, chronic illness, and cancer-specific populations. Finally, much of the existing literature has evaluated cancer survivor and caregiver functioning independently of one another. This approach neglects the dyadic influences that may be in play in determining how well the PC survivor and his spousal caregiver adjust to the cancer experience. This one-sided evaluation of a dyadic interaction has been termed 'pseudo-unilaterality' (Duncan et al., 1984), as it fails to consider the impact that the caregiver's characteristics has on survivor functioning and vice versa. This study sought to address this limitation by evaluating



survivor and caregiver functioning simultaneously utilizing advanced statistical modeling of data that have been collected concurrently.

#### Establishing Actor-Partner Interdependence Model

The influence that one partner can have on the other's thoughts, emotions, and behaviors can be significant (Kenny, Kashy & Cook, 2006). To statistically evaluate this dyadic interaction, the actor-partner interdependence model (APIM) was utilized. The APIM permitted us to model and evaluate both actor effects and partner effects. The most straightforward example of the APIM has two actor and two partner effects (Figure 1). The actor effects can be thought of as an intrapersonal effect, while the partner effect can be considered an interpersonal effect. The actor effect refers to the impact of a person's score on an independent variable on that same person's outcome variable score, while controlling for the effects of the partner's independent variable. The partner effect refers to the impact of a person's score on an independent variable on the partner's outcome variable score, while controlling for the effects of that partner's independent variable. This model enables researchers to effectively conceptualize how partners influence one another, as it effectively models the statistical interdependence that exists between PC couples. The APIM has been increasingly applied in evaluating questions among a breadth of research areas, including attachment style (Campbell et al., 2001), leisure pursuits and relationship satisfaction (Berg et al., 2001), and health promotion behavior in older married couples (Franks et al., 2004).

Several aspects of the APIM apply to the current study sample, and must be clearly delineated prior to any analyses. The most fundamental aspect of APIM is the



assumption of non-independence between members of the dyad. In the case of the marital dyad between PC survivor and caregiver, the linkage between the couple can be defined as both a voluntary and a kinship linkage. Additionally, the PC dyad is a distinguishable dyad based upon the unique gender of the survivor and caregiver. Finally, the analyses for the proposed study investigated within-dyad variation in the independent variables.

Research questions evaluating dyadic issues may be addressed in several ways: the use of repeated-measures analysis of variance (ANOVA), mixed-model ANOVA, multi-level modeling (MLM), and structural equation modeling (SEM). The use of ANOVA techniques is preferred when evaluating more straightforward models which do not contain any missing data. However, the calculation and interpretation of results from involving three or more independent variables using ANOVA, particularly if any data are missing, is not advised (Cook & Kenny, 2005; Kenny, Kashy & Cook, 2006). In such cases, the use of advanced statistical modeling, such as MLM or SEM, is preferred. As the current study incorporates six independent variables, advanced statistical modeling techniques were implemented.

To estimate models with distinguishable dyads, as is the case with the current study sample, it is possible to approach this statistically using either MLM or SEM. Regardless of which statistical approach is taken, the basic framework of the APIM structure is the same. Within that structure, the error variances of the outcome variables are inter-correlated, which represents the unexplained non-independence between those variables. As the composition of the proposed study sample suggests that they are a voluntary, kinship linked dyad, the independent variables will also be inter-correlated.



Given the three unique statistical methods for estimating an APIM, it has been suggested that SEM may be the simplest and most straightforward data-analytic method (Kenny, Kashy & Cook, 2006) and were utilized in the current study analyses.

SEM enables researchers to estimate the APIM parameters as they visually appear in a conceptual model, and this can often simplify the interpretation of results from APIM analyses. Another benefit of utilizing SEM to estimate an APIM is the ability to use one of several procedures to address the issue of measurement error. Among the available statistical methods, it has been suggested that SEM provides the best estimate of measurement error (Kenny, Kashy & Cook, 2006). Researchers can use one of a number of strategies to consider measurement error, including the disattenuation strategy, the instrumental variable solution, or the latent variable strategy. Although the most common approach to the issue is via the latent variable strategy, it cannot be utilized in the proposed study because of the need for at least three unique measures for every construct evaluated. The proposed study cannot utilize latent variables, since only two measures were used for quality of life and using a latent variable to represent all sources of social support would prevent further analyses of the differential effects of the sources. The dis-attenuation strategy was implemented, which fixes the error variance for a variable based upon a prior knowledge of the reliability of that particular measure in the current study and previously established internal consistency of the measure.

The process of using SEM to evaluate any statistical model is comprised of four steps: 1) the specification of the model, 2) asking if that particular model can be identified given the number of measured variables and specified paths, 3) choosing a statistical software package to estimate the model parameters, and 4) testing to see if the



model provides adequate model fit (Kline, 2004). The specification of the model involves identifying the exogenous (variables that are not caused by any others in the model) and endogenous variables (variables that are caused by exogenous ones). In the case of the current study model (Figure 3), the exogenous variables are the unique sources of social support (MSPSS), while the endogenous variables were the individual's physical and mental quality of life (SF-36). As the APIMs include non-independence between the dyadic member's individual scores, a correlation between all independent variables and dependent variables, respectively, were specified within the model. When utilizing SEM to estimate the APIM, the coefficients cannot be standardized separately for the PC survivor and caregiver, as is often done in other SEM models. This is because standardizing the coefficients will cause the coefficients to be incomparable across the dyad (Kenny, Kashy & Cook, 2006). Thus, un-standardized coefficients were used and reported for the proposed study. For interpretation purposes, it is best to center all scores around the grand mean of both individual's scores (Kenny, Kashy & Cook, 2006). Amos software 18.0 (Arbuckle, 2006) were utilized to estimate the study model. The statistical evaluation of the proposed APIMs were estimated using full information, maximum likelihood estimation. This approach utilizes an iterative solution to derive parameter estimates using all information from all sets of equations simultaneously to find the best statistical model possible (Schumacker & Marcoulides, 1998). Finally, to test to see if a model provides adequate fit, a number of fit indices can be considered. Among the available fit indices, several are most commonly used in the evaluation of model fit, including the comparative fit index (CFI), which compares the estimated model to the



null model, and the root mean square error of approximation (RMSEA), which is an absolute measure of model fit.

## Covariates Associated with Study Outcomes

Several potential covariates have been previously demonstrated in the literature to have an effect on quality of life outcomes in PC populations. These covariates may influence any significant relationships that are identified between sources of social support with our study outcomes. In particular, age has been associated with both physical and mental quality of life outcomes (Stanford et al., 2000; Bjorck, Hopp & Jones, 1999), and socioeconomic factors such as household income (Liu et al., 2001; Byers et al., 2008) and level of education (Liu et al., 2001; Byers et al., 2008) have been associated with incidence and mortality in PC populations. Furthermore, the influence of medical co-morbidities was considered as this too has been identified as being a significant contributor to quality of life outcomes in PC populations (e.g., Zhou, Penedo & Bustillo, 2010; Zhou, Penedo & Lewis, 2010).

#### Study Aims and Hypotheses

#### Specific Aim 1

To examine the relationships between the PC survivor's and spousal caregiver's reported levels on study variables (three sources of social support scores and two quality of life scores).



# Hypothesis 1a:

- The survivor's and spousal caregiver's perceived significant other support scores are significantly related with one another.
- The survivor's and spousal caregiver's perceived family members and friends support scores are not significantly related with one another.
- The survivor's and spousal caregiver's physical health scores are significantly related with one another.
- The survivor's and spousal caregiver's mental health scores are significantly related with one another.

# Hypothesis 1b:

- The survivors will report higher levels of significant other support than family or friend support.
- The spousal caregivers will report comparable levels of support from all sources (significant other, family, and friends).
- The survivors will report higher levels of mental quality of life than physical quality of life.
- The spousal caregivers will report comparable levels of physical and mental quality of life.

# Specific Aim 2

To establish an actor-partner interdependence model which describes adequately the relationship between perceived support from the spouse, family members, and friends



with physical and mental quality of life for PC survivors and their spousal caregivers at the individual and dyadic level (Figure 3).

# Specific Aim 3

To examine the unique effects of perceived support from different sources (*significant other, family, friends*) on their own (*actor effects*) and their partner's (*partner effects*) quality of life (*physical and mental*) in PC survivors and their spousal caregivers.

### Hypothesis 3a:

- Survivors who perceived higher levels of support from his <u>significant</u> other will report better physical and mental quality of life (*actor effect*).
- Survivors who perceived higher levels of support from his <u>family</u> will report better physical and mental quality of life (*actor effect*).
- Survivors who perceived higher levels of support from his <u>friends</u> will report better physical and mental quality of life (*actor effect*).
- The effects of perceived support from the <u>significant other</u> on physical and mental quality of life will be <u>greater than those from family or</u> <u>friends</u>.

#### Hypothesis 3b:

 Spousal caregivers who perceived higher levels of support from her significant other will report better physical and mental quality of life (actor effect).



- Spousal caregivers who perceived higher levels of support from her <u>family</u> will also report better physical and mental quality of life (*actor effect*).
- Spousal caregivers who perceived higher levels of support from her <u>friends</u> will also report better physical and mental quality of life (*actor effect*).
- The effects of perceived support on physical and mental quality of life from all <u>three major sources will be comparable</u>.

# Hypothesis 3c:

- Survivors whose spousal caregivers perceived higher levels of support from her <u>spouse</u> will report better physical and mental quality of life (*partner effect*).
- Survivors whose spousal caregivers perceived higher levels of support from her <u>family</u> will report better physical and mental quality of life (*partner effect*).
- Survivors whose spousal caregivers perceived higher levels of support from her <u>friends</u> will report better physical and mental quality of life (*partner effect*).
- The effect of perceived support on the partner's physical and mental quality of life from all <u>three major sources will be comparable</u>.



# Hypothesis 3d:

- Spousal caregivers whose PC survivors perceived higher levels of support from his <u>spouse</u> will report better physical and mental quality of life (*partner effect*).
- Spousal caregivers whose PC survivors perceived higher levels of support from his <u>family</u> will report better physical and mental quality of life (*partner effect*).
- Spousal caregivers whose PC survivors perceived higher levels of support from his <u>friends</u> will report better physical and mental quality of life (*partner effect*).
- The effect of perceived support from the <u>significant other</u> on the survivor's physical and mental quality of life will be <u>greater than those</u> <u>from family or friends</u>.

# Specific Aim 4

To explore whether the unique effects of perceived support from different sources on their own and their partner's quality of life (*physical and mental*) would remain after consideration of variances accounted for by covariates.

# Hypothesis 4:

- The significant relationships between sources of social support with physical and mental quality of life outcomes will remain significant following the introduction of significant covariates to the study model.



#### **Chapter 2: Methods**

The primary objective of this study is to evaluate the unique effects of three separate sources of social support on quality of life in PC survivors and their spousal caregivers, from a dyadic coping perspective. Specifically, we documented levels of physical and mental quality of life within the sample of PC survivor and spousal caregiver dyads and evaluated how support from a spouse, family members, and friends can differentially affect that quality of life. These analyses were guided by the APIM.

# **Participants**

The current research utilized existing data that has been collected for the American Cancer Society's Study of Cancer Survivors-I (SCS-I) and the first cohort of the National Quality of Life Survey for Caregivers. The SCS-I was designed to evaluate the quality of life in cancer survivors, who had been diagnosed with one of the 10 most common cancers in the U.S. The study accessed 11 Surveillance, Epidemiology and End Results (SEER; http://seer.cancer.gov)/National Program of Cancer Registries (NCPR; http://cdc.gov) state cancer registries and identified a total of 19,294 cancer survivors as potential participants for the study. In particular, the study made an attempt to include representation across previously understudied cancer populations, such as younger survivors, racial and ethnic minorities, and survivors of cancers with high mortality rates (e.g., lung, kidney; Smith, et al., 2007).

To be eligible to participate in the SCS-I study, the cancer survivor had to have met the following inclusion criteria:



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- Be 18 years of age or older, at diagnosis
- Have been diagnosed with cancer within the previous 12 months (except for New Jersey, which had a 15-month window of diagnosis)
- Have been diagnosed with cancer in one of the 10 highest sites of U.S.
   incidence (bladder, breast, colorectal, kidney, lung, non-Hodgkin
   lymphoma, ovarian, prostate, skin melanoma, or uterine)
- Have been diagnosed with a SEER summary stage of localized, regional, or distance cancer (with the exception of bladder cancer, which included *in situ* cancer)
- Be sufficiently mentally competent and able to communicate in English or
   Spanish to be able to complete the survey
- Be an American resident in the target state at the time of diagnosis

A total of 5,775 individuals completed the SCS-I survivor survey by telephone or mail. Of the full registry sample, 29.8% of those initially identified completed the survivor survey (Smith, et al., 2007). From the full identified registry sample, 3,104 individuals, representing 33.6% of the full registry, were diagnosed with PC. Of that sample, 1,129 individuals, comprising 36.4% of all PC survivors, completed the survey. Only participants who were diagnosed with localized stage disease were evaluated for the current study.

The National Quality of Life Survey for Caregivers identified potential participants immediately following the completion of the SCS-I survey by the survivor. When a survivor completed a SCS-I survey, they were asked to nominate a family-like individual, who provided consistent help to them. If the survivor identified a caregiver,



they were then mailed a National Quality of Life Survey for Caregivers survey packet. The packet contained a letter introducing the study, information on frequently asked questions regarding the study, and a phone card loaded with 60 minutes of talk time as a token of appreciation for their possible participation. The act of returning a completed survey was considered a verification of informed consent for the study. If the caregiver did not return their packet after three weeks had elapsed, they were given a follow-up reminder phone call. If the caregiver did not return their packet after five weeks had elapsed, another packet was mailed to their residence, without a phone card. If the caregiver did not return their packet after eight weeks had elapsed, another follow-up phone call was placed. The caregiver study procedure and materials were approved by the Emory University Institutional Review Board (Kim et al., 2009). A total of 2,358 survivors, representing 42.4% of those who completed the survey and 12.6% of the identified sample, nominated a caregiver to complete the survey (Kim et al., 2009). Of the nominated caregivers, 1,110 completed and returned their caregiver surveys. Of these completed surveys, a total of 124 were completed by caregivers of localized PC survivors.

#### Measures

#### Sources of Social Support

The Multidimensional Scale of Perceived Social Support (MSPSS) was designed to provide a comprehensive inventory allowing researchers to effectively evaluate the impact of different sources of subjective social support. The MSPSS is a 12-item measure on which individuals are asked to rate from 1 (Very Strongly Disagree) to 7



(Very Strongly Agree) the extent to which they agree with statements regarding their perceptions of their social support network. The MSPSS is designed to provide specific information on three sources of social support, which represents different groups from whom the individual perceives support from their spouse, family, and friends. Internal consistency of the subscales reported in a scale development publication was acceptable (Cronbach's  $\alpha$  for Significant Other=.72, Family=.85, Friends=.75; Zimet, 1988). Furthermore, the overall measure and the subscales have all demonstrated good test-retest reliability (between .72-.85; Zimet, 1988). The MSPSS has been used previously to evaluate social support research questions within cancer populations (Hann et al., 1995; Hann et al., 2002; Bozo, Gündoğdu & Büyükasik-Çolak, 2009). The items of the MSPSS are listed in Appendix 1.

# *Quality of Life*

To evaluate physical and mental quality of life, the Medical Outcomes Study-Short Form Health Survey (SF-36) will be utilized. The SF-36 is a broad measure of subjective health and well-being. It is a 36-item measure that generates 8 unique subscales that combine to form two summary measures: physical health and mental health. The physical health summary measure is comprised of the physical functioning, role-physical, bodily pain, and general health subscales. The mental health summary measure is comprised of the vitality, social functioning, role-emotional, and mental health summary measures. The SF-36 has been used extensively in research within both general and chronic illness populations, including PC survivors, and has been demonstrated to be



a valid and reliable measure across all of these populations (Ware & Sherbourne, 1992; Albertsen et al., 1997; Litwin et al., 1998; Lubeck et al., 1997).

# Study Sample Covariates

In the current study, the background information section of the survivor and caregiver surveys inquired as to relevant sociodemographic, medical, and caregiving characteristics that were used in study analyses. Specifically, the following characteristics were reported for both the PC survivor and their spousal caregiver:

Sociodemographic:

- Age
- Level of education
- Total household income
- Employment status

# Medical:

- Co-morbidities

Caregiving:

- Number of months spent caregiving

# Statistical Analysis Plans

## Preliminary Analyses

The preliminary statistical analyses for the proposed study were conducted using SPSS version 18.0 (Allen & Bennett, 2010). The means and standard deviations of the key sociodemographic, medical, and caregiving characteristics were calculated and reported. The most common medical co-morbidities were reported, and comparisons



using chi-square tests were conducted between the common PC survivor and spousal caregiver co-morbidities.

As the proposed SEM model used maximum likelihood estimation, it is important to evaluate all study variables for internal consistency and normality. If the univariate frequency distributions for any of the variables exhibit an abnormal distribution pattern, the Bollen-Stine bootstrap were implemented (Bollen & Stine, 1993). As non-independence is an essential characteristic of dyadic data, non-independence were evaluated within the current sample. To evaluate non-independence, the Pearson product-moment correlation coefficient and paired t-test were calculated between the dyadic member's scores on each measurement scale. As the field of dyadic data analysis is still in its developing stages, a review of 75 dyadic analyses yielded only two which reported non-independence testing results. Thus, no current consensus exists on what appropriate cut-off score for non-independence is sufficient (Kenny, Kashy & Cook, 2006). Consequently, a paired relationship between two variables at the generally accepted p<.05 level was utilized as a cut-off score for non-independence.

#### Testing Study Aims and Hypotheses

#### Specific Aim 1

To evaluate the relationships among the survivor's and spousal caregiver's scores on the three sources of social support and their physical and mental quality of life, we first calculated Pearson correlation coefficients to evaluate whether the survivor's scores on all of the individual measures (three unique sources of social support and physical and mental quality of life) are significantly related with his spousal caregiver's reported



scores on the same measures. Subsequently, we utilized paired samples t-tests to determine the existence of within-group (PC survivor and spousal caregiver) differences on their levels of reported support from the three sources (significant other, family, and friends) and their physical and mental quality of life. Finally, descriptive information regarding U.S. population, and cancer specific norms was provided for both the MSPSS and the SF-36 for the PC survivor.

# Specific Aim 2

To specify an APIM that describes the dyadic relationship between sources of support with physical and mental quality of life for PC survivors and their spousal caregivers, the three unique sources of social support (spouse, family, or friend) for both the PC survivor and spousal caregiver are specified as exogenous variables that predict actor and partner effects for physical and mental quality of life of both individuals. The model is a recursive model, as no variables are reciprocally related such that each affects and depends on one another. The model was evaluated based on available fit indices. Model fit was determined using several statistical indices:  $\chi^2$  value, CFI, normed fit index (NFI), and the RMSEA. Good model fit was indicated if relative  $\chi^2 < 2$  (Ullman, 2001), CFI>.95 (Hu & Bentler, 1999), NFI>.90 (Byrne, 1994), and RMSEA<.08 (Kline, 2004). Theory and statistical indices guided the appropriate modifications to the initial model to achieve adequate model fit. We evaluated the modification indices recommended by Amos 18.0 in order to identify potential changes that should be made to statistically strengthen the study model. Modifications were made only if they were



theoretically supported. A chi-square test was conducted to evaluate whether this revised model provides significantly better or worse model fit than the basic model.

# Specific Aim 3

To determine the unique effects of perceived support from different sources on actor and partner quality of life, an SEM path analysis was conducted. Once we identified a theoretically sound model that achieved adequate fit, we were able to address the specific questions of whether these unique sources of support can differentially influence quality of life in both the survivor and his spousal caregiver. To accomplish this, we constrained the paths for specific actor or partner effects to be equal. This allowed us to identify whether the effects are significantly different from one another. For example, we can evaluate whether the actor effects for support from family or friends affecting PC survivor physical quality of life by constraining the paths between the two parameters to PC survivor physical quality of life to be equal. Then, we calculated the model fit of the constrained model. A chi-square test was conducted subsequently to evaluate the goodness of fit of the unconstrained model, compared with the constrained model. If a chi-square test between the two models reveals that the constrained model provides significantly worse fit, this would indicate that the two actor effects are significantly different (Schumacker & Marcoulides, 1998).

# Specific Aim 4

Consideration was given to a number of sociodemographic and medical characteristics that may significantly influence the relationship between sources of social



support with quality of life outcomes: age, education, income, number of medical comorbidities, and caregiving duration. To evaluate whether these potential covariates should be included in any subsequent analyses, Pearson product-moment correlation coefficients or ANOVA were calculated between the outcome variables with the potential covariates. Utilizing the statistically sound model that was previously identified, the influence of the potentially significant covariates that may affect the relationships between sources of support with physical and mental quality of life was evaluated. Theoretical and statistical implications were considered in order to guide the incorporation of specific covariates in subsequent study models. In particular, as the age of the individual has been previously associated with physical and mental quality of life outcomes (e.g., Stanford et al., 2000; Bjorck, Hopp & Jones, 1999; Jenkinson, Coulter & Wright, 1993), the relative influence of age were considered in our analyses. Furthermore, the influence of medical co-morbidities were considered, as this too has been identified as being a significant contributor to quality of life outcomes in PC populations (e.g., Zhou, Penedo & Bustillo, 2010; Zhou, Penedo & Lewis, 2010). Statistical models incorporating covariates that provide both sound statistical and theoretical fit were evaluated for the impact that the addition of those covariates has on the relationships between unique sources of social support with mental and physical health for both PC survivors and their spousal caregivers.



#### **Chapter 3: Results**

#### Descriptives of Sample Characteristics

Of the 124 PC survivors and spousal caregiver dyads that met the inclusion criteria, 93 dyads provided valid data of the study variables, which were included in the analyses. Independent samples t-tests revealed that the subset of 93 dyads who reported complete data did not differ significantly (p<.05) from the overall group of localized PC survivors/spousal caregivers (124 dyads) with respect to demographic (age, ethnicity, education, income), medical (number of medical co-morbidities) or psychosocial (caregiving months, sources of social support, physical health, mental health) variables. However, the PC survivors with complete data had been diagnosed more recently (27.0 months compared with 27.8 months; t=3.7, p<.05) and caregivers of the dyads with complete data reported lower levels of family support (MSPSS family support score of 21.6 compared with 22.3; t=3.3, p<.05) than the dyads with incomplete data.

As shown Table 1, the participants included in the analyses were in their early 60s, primarily non-Hispanic white, relatively well educated and affluent, and employed. In addition, the spousal caregivers reported having provided approximately 13.4 months of care for their PC survivor (SD=12.1 months), with a range between 1-72 months of prior care. The PC population in the current study is younger than the average PC survivor (median age for PC diagnosis is 68 years; Horner, 2009). Moreover, the PC survivor in the current study was significantly older than his spousal caregiver (p<.05).

Medical characteristics of the participants are shown in Table 2. PC survivors were approximately 27.8 months post-diagnosis (SD=3.9 months). Furthermore, approximately 51.6% of the PC survivors and 58.1% of their spousal caregivers reported



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having at least one medical co-morbidity, and 23.7% of PC survivors and 11.8% of spousal caregivers reporting having two or more medical co-morbidities. Compared to a sample of U.S.-based survivors across all cancer sites, a lower proportion of the current sample reported a medical co-morbidity, as 68.7% of that sample reported having at least one medical co-morbidity (Ogle et al., 2000). The most common co-morbid conditions reported by PC survivors were high blood pressure, a heart condition, diabetes, or circulatory problems, which were similar to co-morbidities reported by cancer survivors in prior research (high blood pressure and diabetes; Ogle et al., 2000). The spousal caregiver most commonly reported high blood pressure, arthritis, a heart condition, or osteoporosis. Again, these findings were similar to medical co-morbidities previously reported in populations of female caregivers of PC survivors (arthritis and high blood pressure; Fletcher et al., 2008).

Psychosocial characteristics of the current sample can be seen in Table 3. With regard to sources of social support, both the PC survivor and his spousal caregiver reported lower levels of significant other support compared with the younger adult group (p<.05; mean age=26.5 years; Dahlem, Zimet & Walker, 1991). However, the PC survivor reported more support from their family and their friends, when compared to the same sample (p<.05; Dahlem, Zimet & Walker, 1991). When compared to a similarly aged adult sample (mean age=67.5 years), both the PC survivor and spousal caregiver reported lower significant other, family, and friend support, with the exception of the PC survivor's level of family support (p<.05; Stanley, Beck & Zebb, 1988).

With respect to quality of life, PC survivors in the current sample reported physical (49.6) and mental (53.7) quality of life scores that were above those reported in



a U.S. normative sample of men from a similar age range (physical: 47.2, mental: 53.2; Turner-Bowker, Bartley & Ware Jr., 2002) and an older localized PC survivor population (mean age: 74.7 years, physical: 45.9, mental: 52.4; Arredondo et al., 2004). Similarly, their spousal caregivers mostly reported physical (48.1) and mental (51.9) quality of life scores that were above scores reported by similarly aged women (age range: 55-64 years of age) from a U.S. normative sample (physical: 46.3, mental; 50.2; Turner-Bowker, Bartley & Ware Jr., 2002) and a general sample of cancer caregivers (physical: 49.0, mental: 48.2; Weitzner, McMillan & Jacobsen, 1999).

# Testing Specific Aim 1: Relationships of Social Support and Quality of Life Between Prostate Cancer Survivors and Spousal Caregivers

Results (Table 3) indicate that none of the three sources of social support scores (significant other, family, or friends) were significantly correlated with each other between the PC survivors and their spousal caregivers (*ps*>.05). These findings provided support of **Hypothesis 1a**: PC survivor's and spousal caregiver's perceived family members and friends support scores would be not significantly related with one another, but did not support Hypothesis 1a: PC survivor's and spousal caregiver's perceived significant other support scores would be significantly related with each other.

On the other hand, results indicated that both the physical and mental quality of life for PC survivor's and their spousal caregivers were significantly correlated with one another (ps<.01). These findings supported Hypothesis 1a: PC survivor's and spousal caregiver's physical health and mental health scores would be significantly related with one another.



To evaluate **Hypothesis 1b**, paired samples t-tests were conducted. Results evaluating differences among three social support scores within survivors (Table 3) indicated that the PC survivor's level of significant other support was significantly less than their level of family (t=-11.2, p<.01) and friend support (t=-7.9, p<.01). Additionally, their level of friend support was significantly lower than their level of family support (t=6.8, p<.01). These results do not support the portion of Hypothesis 1b that hypothesized that PC survivors would report higher levels of significant other support compared with family or friend support.

For the spousal caregivers, their reported level of friend support was significantly lower than significant other support (t=2.7, p<.01). However, their level of significant other support was similar to their level of family support (t=1.5, p>.05), and their level of friend support was similar to their level of family support (t=-1.7, p>.05). These do not support the portion of Hypothesis 1b that hypothesized that the spousal caregivers would report comparable levels of support from all sources.

Furthermore, both the PC survivor (t=-3.0, p<.01) and their spousal caregiver reported significantly higher mental quality of life, when compared to their own physical quality of life (t=-2.4, p<.05). These findings supported the portion of Hypothesis 1b that hypothesized that PC survivors would report higher levels of mental quality when compared to their physical quality of life. However, these findings did not support the portion of Hypothesis 1b that hypothesized that the spousal caregivers would report comparable levels of physical and mental quality of life.



# Testing Specific Aim 2: Specifying a Study Model

In order to accomplish Specific Aim 2, it was necessary to identify an APIM that would describe the relationships between perceived support from the significant other, family, and friends with mental and physical quality of life for PC survivors and their spousal caregivers at the individual- and dyadic-level. The basic model, without allowing error variances to be correlated with each other among any of the predictor (sources of social support) variables did not provide adequate model fit  $(\chi^{2}[19]=356.4, CFI=.01, NFI=.07, RMSEA=.44)$ . In order to identify a reliable measurement model for the study, the modification indices were examined for their possible inclusion in the model design. The first covariances allowed to correlated within the model were between spousal caregiver significant other support with spousal caregiver family support; the largest modification index=65.7. Adding the covariance did not result in adequate model fit: relative  $\chi^2$ =17.5, CFI=.13, NFI=.18, RMSEA=.42. The next model added the covariance between spousal caregiver significant other support with spousal caregiver friend support, with a modification index of 49.2. This model did not provide adequate model fit: relative  $\chi^2$ =18.1, CFI=.14, NFI=.20, RMSEA=.43. The next model added the covariance between PC survivor significant other support with PC survivor family support, with a modification index of 45.7. This model did not provide adequate model fit: relative  $\chi^2$ =16.3, CFI=.28, NFI=.32, RMSEA=.41. The next model added the covariance between spousal caregiver friend support with spousal caregiver family support, with a modification index of 37.3. This model did not provide adequate model fit: relative  $\chi^2$ =13.2, CFI=.46, NFI=.49, RMSEA=.36. The next model added the



covariance between PC survivor friend support with PC survivor family support, with a modification index of 13.2. This model did not provide adequate model fit: relative  $\chi^2$ =9.3 CFI=.66, NFI=.66, RMSEA=.30. The next model added the covariance between PC survivor significant other support with PC survivor friend support, with a modification index of 30.0. Thus, this model incorporated covariances between each of the PC survivor's and spousal caregiver's sources of support. The model (Model 7 in Table 4; Figure 4) provided acceptable model fit ( $\chi^2$ [13]=17.5, CFI=.99, NFI=.96, RMSEA=.06). The introduction of covariances between each individual's source of support is to be expected, as overlap occurs between an individual's perceptions of social support, regardless of the source (Zimet, 1988). A  $\chi^2$ -difference test was conducted between the basic model without any covariances and with the re-specified model, which incorporated covariances between each source of support for the PC survivor and their spousal caregiver (Figure 4), and indicated that the model with covariances is a significantly better fit for the data ( $\chi^2_{diff}[6]=338.9$ , p<.01). Thus, a reliable structural model, called Study Model, is presented in Figure 4.

#### Testing Specific Aim 3: Effects of Social Support on Quality of Life

This particular aim sought to evaluate the unique effects of perceived support from different sources (spouse, family, friends) on their own and their partner's physical and mental quality of life for the PC survivors and their spousal caregivers. The study model was evaluated to investigate how the three unique sources of support are related to quality of life outcomes for both the PC survivor and his spousal caregiver. Subsequent



analyses will evaluate the contribution of potential covariates to the study outcomes (see Covariate Analysis section below).

**Hypothesis 3a** predicted that actor effects would be found between all three sources of support (significant other, family, and friend) on both physical and mental quality of life for the PC survivor and also suggested that the effect of perceived support from the significant other on physical and mental quality of life would be greater than those from family or friends. Results from the model (seen in Table 6) reveal two significant actor effects between unique sources of social support with quality of life outcomes only for the PC survivor. First, higher levels of significant other support were related to higher physical quality of life for the PC survivor ( $\beta$ =.33, *p*<.05). The second actor effect identified partial support for Hypothesis 3a, which was the relationship between higher levels of friend support and higher mental quality of life ( $\beta$ =.43, *p*<.05).

To further evaluate whether the significant effect of significant other support on *physical* quality of life for the PC survivor was greater than that of family or friend support, two additional models were evaluated. First, a model constraining the paths between significant other support and family support with PC survivor physical quality of life to be equal was considered. Next, a model constraining the paths between significant other support with PC survivor physical quality of life to be equal was considered. Next, a model constraining the paths between significant other support with PC survivor physical quality of life to be equal was evaluated. The  $\chi^2$ -difference tests between both constrained models compared with the Study Model seen in Figure 4 demonstrated that the constrained models provided significantly worse fit (significant other support and family support constrained to be equal  $\chi^2_{diff}[1]=11.9$ , p<.01; significant other support and friend support constrained to be equal  $\chi^2_{diff}[1]=6.4$ , p<.05). These results show statistically significant differences



between the actor effects of significant other support on PC survivor physical quality of life, when compared to the actor effects of family or friend support. This result provides partial support for Hypothesis 3a.

Next, to evaluate whether the effect of friend support on PC survivor *mental* quality of life was greater than those from other sources of social support, two additional models were evaluated. First, a model constraining the paths between friend support and significant other support with PC survivor mental quality of life to be equal was considered. Next, a model constraining the paths between friend support and family support with PC survivor mental quality of life to be equal was evaluated. The  $\chi^2$ -difference tests between both constrained models compared with the Study Model seen in Figure 4 (*p*<.05) demonstrated that the constrained models provided significantly worse fit (significant other support and friend support constrained to be equal  $\chi^2_{diff}$ [1]=4.5, p<.05; family support and friend support constrained to be equal  $\chi^2_{diff}$ [1]=6.6, p<.05). The results indicate statistically significant differences between the actor effects of friend support on PC survivor mental quality of life, when compared to the actor effects of significant other or family support. This result does not support Hypothesis 3a.

**Hypothesis 3b** predicted actor effects between all three sources of support (significant other, family, and friend) on both physical and mental quality of life for the spousal caregiver and that the effects of perceived support from all three sources on physical and mental quality of life would be comparable. Results shown in Table 5 indicate one significant actor effect between higher levels of friend support with higher levels of mental quality of life ( $\beta$ =.38, p<.05). The result provides partial support for Hypothesis 3b. To evaluate whether the effect of friend support on spousal caregiver



mental quality of life was greater than other sources, two additional models were evaluated. First, a model constraining the paths between friend support and significant other support with spousal caregiver mental quality of life to be equal was considered. Next, a model constraining the paths between friend support and family support with spousal caregiver mental quality of life to be equal was evaluated. The  $\chi^2$ -difference tests between both constrained models compared with the Study Model seen in Figure 4 (*p*<.05) demonstrated that the constrained models provided significantly worse fit (significant other support and friend support constrained to be equal  $\chi^2_{diff}$ [1]=8.0, p<.01; friend support and family support constrained to be equal  $\chi^2_{diff}$ [1]=5.1, *p*<.05). This indicates statistically significant differences between the actor effects of friend support on spousal caregiver mental quality of life, when compared to the actor effects of significant other or family support. The result does not support Hypothesis 3b.

**Hypothesis 3c** predicted partner effects between all three sources of support perceived by the spousal caregiver (significant other, family, and friend) on both physical and mental quality of life for the PC survivor and that the effects of perceived support from all three sources on physical and mental quality of life would be comparable. No significant partner effects for the spousal caregiver's perceived levels of social support on PC survivors' quality of life were identified, failing support for Hypothesis 3c.

**Hypothesis 3d** predicted partner effects between all three sources of support perceived by the PC survivor (significant other, family, and friend) on both physical and mental quality of life for the spousal caregiver and that the effects of perceived support from all three sources on physical and mental quality of life would be comparable. No



significant partner effects for the PC survivor's perceived levels of social support on spousal caregivers' quality of life were identified, failing support for Hypothesis 3d.

# Testing Specific Aim 4: Effects of Covariates on Social Support and Quality of Life <u>Outcomes</u>

Following the statistical analyses of the Study Model, which clearly outlines the effects of unique sources of social support on quality of life outcomes (Figure 4), it is important to delineate the possibility that other factors may have a significant influence on the relationship between sources of social support with physical and mental quality of life. Initially, a number of demographic and disease-specific variables that have previously been demonstrated to have an effect on quality of life outcomes in PC and spousal caregiver populations were *a priori* considered as potential covariates, including age, education, income, number of medical co-morbidities, and caregiving duration. Bivariate correlations and ANOVAs between possible covariates and quality of life outcome measures (SF-36 physical and mental quality of life) were evaluated to determine whether they should be incorporated in the main analyses of the study. Significance was determined at p<.10, and covariates significantly related with study outcome measures were subsequently considered as control factors in the final study models.

As shown in Table 5, the covariates significantly associated with the PC survivor's mental quality of life were the PC survivor's age, education, and number of medical co-morbidities. The covariates significantly associated with the PC survivor's physical quality of life were the PC survivor's age and number of medical co-morbidities.



For the spousal caregiver, the covariates significantly associated with her mental quality of life were her age and number of medical co-morbidities. Finally, the covariates significantly associated with the spousal caregiver's physical quality of life were the spousal caregiver's household income and number of medical co-morbidities. In summary, age, education, and co-morbidity of each individual were related to the indicators of quality of life. Thus, these three variables were considered as covariates when re-evaluating the Study Model.

The first covariate Study Model evaluated the influence of age on both PC survivor and spousal caregiver quality of life outcomes. Results indicated that this model provided good model fit ( $\chi^2$ [29]=29.3, CFI=.99, NFI=.95, RMSEA=.01). When compared with Study Model without any covariates, the two models were not statistically different from one another ( $\chi^2_{diff}$ [16]=11.8, p>.05). In this age-covariate model, the three actor effects for both the PC survivor and his spousal caregiver remained significant (see Table 5 under Study Model including Age as a Covariate). For the PC survivors, higher levels of significant other support were related to higher physical quality of life ( $\beta$ =.30, p<.05) and higher levels of friend support were related to higher mental quality of life ( $\beta$ =.44, p<.05). For the spousal caregivers, higher levels of friend support were related to higher mental quality of life ( $\beta$ =.41, p<.05). The individual's age was significantly related to individuals' mental and physical quality of life (p<.05).

Next, a model evaluating the influence of adding a relationship between the PC survivor's education with his mental quality of life to the Study Model was evaluated. This statistical model did not provide adequate model fit ( $\chi^2$ [31]=74.2, CFI=.73, NFI=.69,



RMSEA=.30), and the Study Model provided significantly better fit than this model  $(\chi^2_{diff}[18]=62.4, p>.01).$ 

The influence of the number of medical co-morbidities on both PC survivor and spousal caregiver quality of life outcomes was also evaluated. Despite closely approaching statistical fit, this model did not provide adequate fit with the data  $(\chi^2[29]=53.9, CFI=.93, NFI=.88, RMSEA=.10)$ , and the Study Model provided significantly better fit than this model  $(\chi^2_{diff}[16]=36.4, p>.05)$ .

Since age alone was the significant covariate, the next covariate model evaluated the influence of both age and number of medical co-morbidities on both PC survivor and spousal caregiver quality of life outcomes. Results indicated that this age and comorbidity covariate model provided adequate model fit ( $\chi^2$ [49]=69.2, CFI=.96, NFI=.92, RMSEA=.06). When the age and co-morbidity covariate model was compared to the Study Model without any covariates (Figure 4), the two models were statistically different from one another ( $\chi^2_{diff}$ [36]=51.8, p<.05). In the age and co-morbidity covariate model (see Table 5 under Study Model including Age and Co-morbidity as Covariates), the same actor effects of friend support on the PC survivor's mental health ( $\beta$ =.42, p<.05) and of friend support on the spousal caregiver's mental health ( $\beta$ =.38, p<.01) were found. However, different from the Study Model, the actor effect of significant other support on the PC survivor's physical health became non-significant ( $\beta$ =.26, p>.05). The individual's age was revealed to be a significant covariate of both mental and physical quality of life for the PC survivor and his spousal caregiver, while the individual's number of medical co-morbidities was a significant covariate of mental and physical



quality of life for the PC survivor and of physical quality of life for the spousal caregiver (ps < .05).

The final covariate model tested included all the three covariates (age, comorbidity, and education) in the Study Model. Results indicated that this full covariate model did not provide adequate model fit ( $\chi^2$ [49]=69.2, CFI=.87, NFI=.77, RMSEA=.11), and the Study Model provided significantly better fit than this model ( $\chi^2_{diff}$ [36]=32.8, *p*>.05).

Results from the series of analyses including various covariates provided partial support for Hypothesis 4. In summary, as shown in Table 7, three actor effects were significant in the Study Model: 1) significant other support on the PC survivor's physical health; 2) friend support on the PC survivor's mental health; and 3) friend support on the spousal caregiver's mental health. Considering other factors that might influence these effects, age and co-morbidity turned out to be significant covariates. While individual's age played a significant role in explaining further variance in both physical and mental health, but did not influence the relationship between sources of social support and quality of life, individual's co-morbidity was a significant factor for both quality of life and the relationship between sources of social support and quality of life. Specifically, the relationship between significant other support on the PC survivor's physical health became non-significant, when considering the PC survivor's co-morbidity.



#### **Chapter 4: Discussion**

The current study sought to examine the relationships between three unique sources of social support (significant other, family, and friends) with physical and mental quality of life in localized PC survivors and their spousal caregivers using an actorpartner interdependence model. Results indicated that the PC survivor's physical quality of life was related to his level of significant other support; and the mental quality of life of both PC survivors and his spousal caregivers were related to their own levels of friend support after controlling for the individual's age. These findings identify specific sources of support as having significant effects on the quality of life for both PC survivors and their spousal caregivers and highlight the different support needs that they may have during their adjustment process. These social support differences have implications for researchers and clinicians, who are responsible for the care of PC survivors and their spousal caregivers.

### Social Support and Quality of Life

Despite our understanding that positive social support is associated with better physical and mental quality of life outcomes in cancer populations, we have an imprecise understanding of how different structural components (significant other, family, and friend support) of social support influence quality of life outcomes. To address this gap in the current literature, the current study evaluated the potential influence that significant other, family, and friend support have on physical and mental quality of life in PC survivors and their spousal caregivers.



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The basic Study Model without any covariates (Figure 4) achieved acceptable model fit and provided a clear idea of the relationships between significant other, family, and friend support with their level of physical and mental functioning. Despite the lower than normative levels of support reported by the PC survivor and his spousal caregiver, results indicated three significant actor effects in this model. The first relationship between PC survivor significant other support with PC survivor physical quality of life is supported by extensive literature that demonstrates the important influence that a significant other has on a PC survivor's health. Most notably, evidence indicates a relationship between being married with lower mortality in PC survivors (Krongrad et al., 1996). However, this relationship has not been well-explored in other cancer survivorship populations or with caregiver populations. It is hypothesized that the high levels of support the PC survivors report receiving from their support networks may positively influence PC survivor health through improved health behaviors (e.g., smoking cessation, increased physical activity, and improved eating habits; Helgeson, 2004) and through the immunological improvements that result from reductions in levels of perceived stress (Carlson et al., 2007).

The second significant relationship demonstrated is between PC survivor friend support and PC survivor mental quality of life. This relationship has also received support within the existing literature. It has been previously demonstrated that close friends have been identified as an excellent source of emotional support (Seeman & Berkman, 1988), and cancer survivors reported lower levels of depression, when perceiving quality support from their friends (Hann et al., 1995). Furthermore, within an elderly population, the support of adult friends helped buffer against depressive



symptomatology (Dean, Kolody & Wood, 1990). These relationships also have been demonstrated in chronic illness populations (Oxman et al., 1994), underscoring the significant impact that friend support can have on quality of life. Despite literature which has shown that women are more comfortable than men with accessing emotional and informational support from their friends (Olson & Shultz, 1994; Antonucci & Akiyama, 1987), it appears that the critical relationships PC survivors have with their friends are ones that can positively affect their mental health, above and beyond the support that other sources provide. It may be that having friends who act as members of their support network not only provide the survivor with an additional support resource, but also may provide him with opportunities to explore his social interests and therefore provide him with an effective outlet for his stress and positively affect his mental quality of life. For PC survivors, the significant relationship between friend support and their mental quality of life may be that their friends are of a similar age, so they also are experiencing similar health challenges. Their ability to empathize with one another's medical difficulties as a result of similar experiences may permit the friends of the PC survivor to better assuage his concerns regarding his cancer than the PC survivor's significant other or family (Crohan & Antonucci, 1989).

Similarly to PC survivors, the third significant relationship was between spousal caregiver friend support with spousal caregiver mental quality of life. This relationship is supported within the current body of literature, as existing research has suggested that women report a significant amount of support from their friends and feel comfortable in confiding their life challenges to their friends (Antonucci & Akiyama, 1987; Harrison, Maguire & Pitceathly, 1995; van Daalen, Sanders & Willemsen, 2005). Women have



been shown to have an ability to emotionally and informationally connect with their support networks (Olson & Shultz, 1994; Antonucci & Akiyama, 1987). Thus, the role that friend support plays in the mental health of the spousal caregiver may be unique, when compared to the role of friend support in the mental health recovery of the PC survivor due to these differences. Rather than offering the PC survivors an option to explore social opportunities, the friends of spousal caregivers may play a stronger role in enabling them to have a resource to explore their mental stressors, and thus, better psychologically process their struggles.

It is interesting to note that we found no statistically significant relationships between family support and an individual's level of physical or mental quality of life. This is unexpected, as evidence has suggested that family members of PC survivors are often significantly affected by the PC experience (Bruun et al., 2010) and can make a contribution to an individual's quality of life (Dean, Kolody & Wood, 1990). It is possible that despite perceiving adequate family support several factors may have resulted in the non-significant effect it had on adjustment for PC survivors and their spousal caregivers. Individuals who perceive family support may also view it as being provided with 'strings attached.' A body of literature suggests that the recipient of family support can feel as though the support needs to be re-paid in some fashion, and thus, feels obligated to reciprocate the favor at a later time (Antonucci & Jackson, 1987; Wenger, 1990). This lingering obligation may serve to negate the positive impact that the support had in the first place. Additionally, it is possible that the family support provided was in an undesired form or came at an inopportune time (Field et al., 2008), and the PC survivors and their spousal caregivers perceived the support experience negatively.



Perceptions of negative support have been associated with lower levels of overall quality of life among cancer survivors (van Weert et al., 2007) and chronic illness caregivers (Goldstein et al., 2006; Schulz & Williamson, 1991). Furthermore, it is possible that cultural background, and the extent to which the individual reports a collectivistic compared with an individualistic view on family, may play a significant role in influencing the extent of the relationship between levels of family support with quality of life outcomes. Prior literature has demonstrated that family members of chronic illness patients can view the caregiving process differently depending on their ethnic background. Finally, it is also reasonable to attribute the lack of significant effects of family support to the broad definition of family support. The MSPSS survey used for this study only asks for the participant's perceptions of overall family support and does not specify one particular family source. Thus, it may be that this broad definition resulted in the positive and negative impact of multiple sources of family support negating one another, thereby resulting in the non-significant effects on quality of life outcomes.

A second unexpected null finding was the lack of significant relationships between the spousal caregiver's friend support with her level of physical quality of life and family support with her levels of physical and mental quality of life. Prior literature points to gender differences in the ability of men and women to access their support networks. Women are better able to perceive support from a broader support base, are more comfortable disclosing personal information with this range of resources (Antonucci & Akiyama, 1987), their social networks tend to be more multi-faceted, they report more support from friends and other family, and are more comfortable confiding in people other than just their spouse (Antonucci & Akiyama, 1987; Harrison, Maguire &



Pitceathly, 1995; van Daalen, Sanders & Willemsen, 2005). Thus, it was hypothesized that the spousal caregiver would be in a position where she could potentially derive benefits from these resources within her social support network. It is possible that the spousal caregivers in the current study did not evidence these benefits because they have, on average spent over a year caring for their PC survivors. This may have caused them to neglect many of their social relationships with other facets of their support network due to the chronicity of their caregiving burden. In addition to the cancer care that the spousal caregivers in the current sample provided, over 63% of these women were also simultaneously employed. As the PC survivors in the current sample often did not work (42% were unemployed) or may have had to work reduced hours following their cancer diagnosis, their spousal caregivers may have needed to maintain, or increase, their work commitments in order to maintain the household finances, in addition to their caregiving duties. Their increase in the amount of time dedicated to both employment and caregiving responsibilities may limit them from being able to pursue personal relationships and from spending time in leisure pursuits with other members of their social network (Langa et al., 2002; Burton et al., 1997). Additionally, as individual's age, the social network size gets pared down (Charles & Carstensen, 2010). Therefore, it may be possible that the social networks of the spousal caregivers were already more limited than desired, as some evidence suggests that spousal caregivers of chronic illness patients can often lack a sufficient social support network that they can rely upon (Hagedoorn et al., 2008).

The model that incorporated the individual's age as a covariate of their own level of physical and mental quality of life provides valuable information regarding the



influence of social support resources on quality of life outcomes. In this model, the introduction of age as a covariate did not affect the significance of any of the previously identified paths between the unique sources of support with an individual's physical or mental quality of life in the Study Model seen in Figure 4 (without any covariates). This suggests that the significant effects of PC survivor significant other support on PC survivor physical quality of life, PC survivor friend support on PC survivor mental quality of life, and spousal caregiver friend support on spousal caregiver mental quality of life exist above and beyond the influence that the aging process has on quality of life outcomes. It is interesting that the addition of age to the Study Model without any covariates did not affect any of the relationships between sources of social support with physical and mental quality of life. In particular, the average age of the current sample (63.5 years) captures a critical phase in the lifespan of many individuals: retirement. For those in the U.S., the age at which individuals receive full retirement benefits is between 65-67 years of age (United States Government, 2011), with the average age of retirement among Americans at approximately 63 years, and rising (Gendell & Siegel, 1996). The lack of impact on the relationships between sources of social support with quality of life may be due to the fact that the impact that social relationships have on quality of life may not be linear relationships over the course of the aging process. Rather, it may be that the effect of social support tends to stabilize once a certain age is reached. The majority of the current sample is between the approximate ages of 54.2-72.8 years (mean=63.5 years  $\pm$  SD=9.3 years), suggesting that perhaps once an individual reaches his or her 50s, the effect of support may reach a plateau and not be significantly influenced as they age. Therefore, it is conceivable that the introduction of age to the Study Model did not



influence the relationships between sources of support with quality of life outcomes due to the average age of the participants in the current study. It is possible that the stressors associated with PC did not as dramatically influence the quality of their interpersonal relationships as much as it could have if they were younger.

On the other hand, the inclusion of medical co-morbidities into the model with age as a co-variate resulted in the path between PC survivor significant other support with PC survivor physical quality of life becoming non-significance. The results indicate that although that the PC survivor's perceptions of spousal support is an important factor for his own physical quality of life, such contribution may not exceed what medical comorbidities do to PC survivors' physical health. In the current study, over 51% of the PC survivors reported having at least one medical co-morbidity, which is a lower proportion than a sample of U.S.-based survivors across all cancer sites (Ogle et al., 2000). In the current study, the PC survivors were most likely to report having high blood pressure, a heart condition, diabetes or circulatory problems. Prior research has noted that the most common chronic diseases co-morbid with cancer include hypertension and cardiovascular disease (Ogle et al., 2000) and, in particular, the percentage of participants in the current sample reporting high blood pressure was comparable to prior research conducted within populations of localized PC survivors (37.6% in the current sample compared with 37.5% in Litwin et al., 1995). It may be that the presence of medical co-morbidities, on top of PC, simply creates too many decrements in health functioning. Thus, despite the quality care provided by their significant other, the impact of further physical challenges for the PC survivor negates the positive impact of spousal support. Evidence suggests that the number of medical co-morbidities is a relevant prognostic factor for physical health in



cancer survivors (Piccirillo et al., 2004; Ogle et al., 2000). As a significant number of PC survivors reported having at least one medical co-morbidity (51.7% in the current sample), it appears that for many PC survivors an important consideration is the impact that additional chronic illness(es) may have on their quality of life. Furthermore, the addition of other chronic diseases can have a profound impact beyond quality of life, potentially influencing the recovery process from PC (Ogle et al., 2000). Similarly, their spousal caregivers reported having at least one medical co-morbidity, with the most commonly reported co-morbidities being high blood pressure, arthritis, a heart condition, and osteoporosis. Prior research conducted within a population of female caregivers of PC survivors reported common medical co-morbidities being arthritis (43.1%) and high blood pressure (36.2%; Fletcher et al., 2008).

Despite the absence of a greater number of significant relationships evidencing the relationship between sources of social support with physical and mental quality of life outcomes, the participants in the current study appeared to have successfully navigated the challenges associated with PC survivorship, as they reported relatively high levels of quality of life. First, the PC survivors in the current sample reported physical and mental quality of life scores that were above those from U.S. normative, and localized PC survivor samples (Turner-Bowker, Bartley & Ware Jr., 2002; Arredondo et al., 2004). It appears that despite the challenges associated with PC the survivors in the current sample report functioning at a high level physically and mentally. This is to be expected, especially with respect to mental quality of life, given the upward trend of an individual's perceptions over the lifespan (Turner-Bowker, Bartley & Ware Jr., 2002). Older individuals tend to be more psychologically mature, with their mental quality of life



linked more to their intrinsic values, rather than material goods, and demonstrate a more reasonable outlook on their life expectations (Sheldon & Kasser, 2001). Furthermore, many cancer survivors report an improved perspective on life following a cancer diagnosis through a re-evaluation of their life meaning and accomplishments (e.g., Arman et al., 2001; Kinsinger et al., 2006). This benefit finding process may help to explain why both PC survivors and their spousal caregivers reported relatively high physical quality of life in the current sample. Benefit finding can contribute to post-cancer personal growth and increases in positive thinking regarding the cancer experience. Existing literature has identified a connection between positive thinking about cancer and the progression of the disease (Greer et al., 1990). It is believed that this "positive fighting spirit," which may develop post-diagnosis (Greer et al., 1992), may act upon physical outcomes through improvements in the use of positive coping strategies and improved health behaviors (Dunkel-Schetter et al., 1992; Wilkinson & Kitzinger, 2000; Lewis et al., 2006; Helgeson et al., 2004). Despite the unexpected finding that the physical quality of life in localized PC survivors in the current sample is higher than prior samples, evidence of this high level of physical functioning has been found in other localized PC survivor populations (Zhou, Penedo & Lewis et al., 2010). It was hypothesized in this research that subsets of localized PC survivors are at a notable risk for physical dysfunction, particularly those who are highly stressed (Zhou, Penedo & Lewis et al., 2010).

Similar to the PC survivors, their spousal caregivers mostly reported physical and mental quality of life scores that were above those reported from a U.S. normative sample and a sample of cancer caregivers (Turner-Bowker, Bartley & Ware Jr., 2002; Weitzner,



McMillan & Jacobsen, 1999). When considering the lower than expected levels of support from their significant other, family and friends, their relatively high levels of functioning in the current study was unexpected. The higher than expected quality of life may be further evidence of the incredible resilience that caregivers have previously demonstrated (Northouse, Templin & Mood, 2001). Despite being faced with such significant challenges, chronic illness caregivers have exhibited tremendous displays of personal strength, and an ability to overcome the many difficulties associated with the caregiving process (Garity, 1997). Similar to the PC survivors in the current study, the spousal caregivers may have managed to derive benefits from the cancer experience of their significant other, and discovered positive growth opportunities amidst the disease experience.

## Dyadic Influences in the Relationship between Sources of Social Support and Quality of Life

The closely linked relationship between the PC survivor and his spousal caregiver plays a critical role in how both individuals adjust to PC. However, the dyadic nature of that relationship has not been clearly evaluated in past research, with only a handful of studies evaluating dyadic adjustment in PC populations. To address this gap, an actorpartner interdependence model was specified to enable us to consider any potential partner effects that may be present within the current study sample. The shared experience of PC, between the survivor with his spousal caregiver, has been documented in the existing literature, with evidence suggesting that one individual's stressors may influence the other's level of physical and mental functioning (Kim et al., 2008; Zhou et



al., in press). However, the findings provided by the three models evaluated in the current study all did not demonstrate any statistically significant partner effects. This suggests that in the current sample of PC survivors with their spousal caregivers, that there was not a significant influence of one's own perceptions of levels of social support on their partner's physical or mental quality of life. This was unexpected given the existing literature evidencing a strong PC dyadic experience.

Despite the lack of crossover effects seen in the current study, it is important to note that this does not indicate that crossover effects are not possible for the PC dyad. Rather, there are a number of study specific reasons which may have contributed to the lack of a 'spill over' effect from one partner's source of support with the other partner's quality of life outcomes. First, this may be due to the lower than normative levels of support that were reported by both the PC survivor and the spousal caregiver. These lower levels of perceived support by both partners may suggest that there is perhaps a threshold level of support that an individual must receive in order to be effectively influence his partner's quality of life that was not reached in the current study. The lowered perceptions of support in the current sample may be reflective of difficulties that were created, or potentially exacerbated, by the stressors associated with PC and PC caregiving. Second, the low levels of significant other support reported by the PC survivor and his spousal caregiver may be indicative of poorer than expected interactions within the marital relationship. Thus, the dyad may not be in a position to communicate and share their mutual experience as much as we had anticipated. Therefore, the potentially positive influence of one's perceptions of quality support on their partner's quality of life may have gone unnoticed. There is literature which supports the notion



that some cancer dyads may be struggling with relationship functioning due to the challenges associated with the disease. Evidence suggests that they report lower than normative relationship satisfaction, marital cohesion, and sense of consensus within the marriage (Toseland, Blanchard & McCallion, 1995), thus, possibly influencing the extent to which partner effects are seen. Furthermore, it is possible that this mid-survivorship phase of the PC experience is contributing to the lack of crossover effects. The PC survivor in the current study is most likely not undergoing active treatment and, thus, there is a greater sense of calm in the PC storm. There may be reduced efforts to provide support, or to communicate within the dyad regarding PC as it is not actively an issue that requires medical attention. This dyad may be adjusting to life after PC, and attempting to normalize their lives once again. Finally, the limited sample size of the current study may have impacted our ability to detect any significant crossover effects.

In particular, the lower levels of support identified between the significant others in the current study sample were unexpected. Both the PC survivor and spousal caregiver reported lower levels of significant other support than an adult sample of a younger age group (PC survivor's significant other support: 21.6, spousal caregiver's significant other support: 22.9, younger adult's significant other support: 23.8; Dahlem, Zimet & Walker, 1991), while an even greater discrepancy exists between their significant other support levels, when comparing our sample to a similarly aged adult sample (26.4; Stanley, Beck & Zebb, 1988). The PC survivor appears to be augmenting his weaker relationship with his significant other by turning to his family and friends for support. The levels of family (25.7) and friend (24.1) support were similar to, or higher than, other samples (younger adults family: 21.2, younger adults friend: 22.0, older adults family: 25.2, older adults



friend: 25.6), suggesting that the relationships the PC survivor has with other components of his social network are functioning at levels similar to those prior to his cancer diagnosis.

However, the spousal caregiver does not appear to be reporting similarly close relationships with her family and friends. Unlike the PC survivor, who reported higher family and friend support, the spousal caregiver reported comparable levels of support between all three sources. It is notable that the spousal caregiver reported lower levels of family (22.3) and friend (21.7) support than a similarly aged adult group (25.2 and 25.6, respectively). It appears that the spousal caregiver is at a deficit for social support across all parts of her social network. These troubling numbers suggest that both the PC survivor and his spousal caregiver require clinical attention in order to ensure that they are able to cultivate, recognize, and access the support resources they have within their social network.

In particular, the lower than normative levels of significant other support that the PC survivor are reporting is of concern, as they are generally one another's primary (and sometimes sole) source of support. The PC survivor is notably reporting levels of significant other support that are much less than their reported levels of family or friend support. It is possible that the burdens associated with being a cancer survivor and those associated with cancer caregiving are placing a higher level of strain upon the relationship, which may be creating difficulties (e.g., an inability to communicate with one another) that are reflected in their perceived levels of support from their significant other. Existing literature supports this notion, as evidence suggests a significant relationship between the quality of communications between patient and caregiver, with



caregiver burden and stress levels (Savundranayagam, Hummert & Montgomery, 2005; Ripich, 1994). Thus, it may be that the considerable challenges faced by the PC dyad are presenting obstacles that negatively affect the supportive relationship that the PC survivor and spousal caregiver shared prior to their cancer experience. Therefore, an individual's perceptions of support may be unable to positively impact the partner's level of quality of life. It is also possible that the participants in the current study, many of whom were employed at the time of study completion, spent a significant portion of their time at work, and had access to social support resources at their place of employment. This may have lessened their dependence on support from their spousal partner.

Although the spousal dyad is most commonly considered when evaluating cancer survivors, it is important to note that there are other dyads in the cancer realm that deserve attention. In particular, there is an emerging body of literature which has evaluated the experiences of adult children who care for a cancer survivor. These relationships are unique as the adult children can often be committed to caring for their own family, as well as actively pursuing career interests that conflict with their role as a caregiver. This dynamic is one which is not well understood, and deserves to be considered.

### Limitations and Suggestions for Future Work

Although the current study made significant strides in improving our understanding of the role that social support plays in the unique populations of localized PC survivors and their spousal caregivers, several areas can be improved in further work that would serve to clarify the findings presented. First, in spite of the incredible efforts



made by those responsible for study design and recruiters to include as broad a demographic sample as possible, several aspects of our study population are limited. The sample was primarily non-Hispanic white and was relatively affluent. Also, the current study was comprised solely of localized PC survivors. The fact that all of the survivors in the current study are men and that all of their spousal caregivers were women may limit the generalizability of these findings to other cancer sites. In particular, cancer primarily affecting women (e.g., breast), or gender neutral cancers (e.g., lung) may demonstrate differential effects of support on quality of life outcomes, depending on the relationships the dyad has. Future research should continue the effort to recruit minority populations, particularly those from lower socioeconomic strata, to present as unbiased a representation as possible of the cancer experience. Furthermore, it would be incredibly valuable to replicate this study in other cancer populations in order to determine whether the effects demonstrated are limited to this male-dominated cancer, or whether there may be a significant gender role in influencing the effects of sources of support on quality of life outcomes.

Second, despite the unique contribution made to the existing social support literature of evaluating the influence of different sources of support, the categories need better specification. In particular, when an individual is asked about his/her perceptions of support from their family, future work conducted in this field may wish to specify particular members of the family they are interested in evaluating. Existing literature evaluating the role of family support on adjustment has demonstrated that adult children can play a role in the PC experience (Bruun et al., 2010), while more distant relatives do not appear to significantly influence adjustment (Dean, Kolody & Wood, 1990). This



raises the question of how the dilution of family relatedness may impact their potential to influence PC survivor and spousal caregiver quality of life. It would be advisable for future work to evaluate how the different sources of family support may differentially influence adjustment. The clarification of which sources of family support are relevant is critical to understanding how to tailor interventions designed to improve family-based support.

Third, the measurement of physical and mental quality of life in the current study utilized a self-report measure. Although the measure has been used frequently in the literature and has demonstrated a high degree of concordance with non-self-report measurements of quality of life (e.g., medication use, doctor's visits, clinical diagnoses of mental illness etc.; Turner-Bowker, Bartley & Ware, 2002), it would be valuable for future researchers to consider evaluating quality of life using other non-self-report measures to ensure that the impact of social support on quality of life can be demonstrated with real world outcomes. Additionally, the participants in the current study indicated a higher than normative level of physical and mental quality of life. Thus, the results presented may not be representative of all PC survivors and their spousal caregivers.

Fourth, there are significant components within the PC survivorship and caregiving experience that were not captured with the current study measures. In particular, the current study did not evaluate potentially important characteristics that have implications on the social support needs, as well as quality of life outcomes for the PC survivors and their spousal caregivers. For both the PC survivor and the spousal caregiver, the current study did not evaluate any personality variables (e.g., masculinity,



neuroticism and coping style) which may significantly impact the individual's ability and desire to seek and accept support from their social network. With respect to the PC survivor, the type of treatment that he underwent can have significant implications to dyadic functioning, as different forms of treatment can differentially impact sexual, urinary and bowel functioning. With respect to the spousal caregiver, the current study did not evaluate information with respect to the types of caregiving tasks the caregiver provided while actively caring for the PC survivor, and the extent of her caregiving role with respect to both her perceived and actual extent of involvement in the caregiving process. Dyadically, the current study did not evaluate the current state of relationship functioning, which may play a role in the quality of support that one partner perceives from the other.

Fifth, the psychosocial measures (MSPSS and SF-36) which evaluated the levels of social support and quality of life in the current study requested that the participants report their current levels of support and quality of life, at the time of study completion. As this was post-diagnosis, when the couple was in the mid-survivorship phase of the cancer experience, this information may not fully represent the challenges that they experienced during the moments immediately post-diagnosis, and during the treatment phase of PC.

Finally, as these analyses were conducted at a single time point using a crosssectional design, we cannot draw causal inferences from the results provided. In particular, the relationship between physical health with the relationship a PC survivor has with his spousal caregiver may be bi-directional, based on findings in prior literature. Future work should make a concerted effort to use a longitudinal design to provide a



better understanding of the inter-relationships between sources of social support with physical and mental quality of life in PC survivors and their spousal caregivers.

## Conclusion: Research and Clinical Implications of Current Study

The findings from the current study provide compelling findings for PC survivors and their spousal caregivers that should be considered by both researchers and clinicians. The study sample provided information regarding how PC survivors and their spousal survivors are functioning at a point in the illness trajectory that is not well established: 1) at approximately 27.8 months post-diagnosis, 2) they are not newly diagnosed, and 3) they are not long-term survivors. This mid-survivorship period presents unique challenges in that the pressing matters of treatment and immediacy of PC needs may have passed, but the dyad potentially has not yet fully processed the impact of PC and moved on to the long-term survivorship phase. The results from the current study suggest that these individuals have significant deficits within the social support network. In particular, both the PC survivor and their spousal caregiver reported lower than normative levels of significant other support.

This issue may be attributed to several reasons. First, this may be a reflection of the challenges associated with this mid-survivorship phase. It is possible that the PC survivor and his spousal caregiver have addressed the initial turmoil associated with a cancer diagnosis and subsequent treatment and are no longer experiencing the pressing urgency to demonstrate cancer care, therefore reducing perceptions of available support. The relaxing of the level of support one provides the other may present psychosocial challenges that require clinical attention, as the need for support does not stop at the end



of cancer treatment. Second, the deficits in significant other support could be indicative of possible fissures in the foundation of the relationship, suggesting problems which require clinical attention. Further evidence demonstrating the potential issue within the dyad is seen with the lack of significant partner, or crossover, effects from one individual to another. The study models demonstrated that while an individual's perceptions of positive social support were associated with higher levels of individual physical and mental quality of life no such relationships existed between an individual's perceptions of support and his/her partner's quality of life. This disconnect between partners further illustrates the issues that the dyad are encountering within their day to day efforts to manage the PC and maintain a healthy relationship. The quality of the relationship and the sense that the marriage is comprised of a team of two, rather than individual units, appears to suffer following a cancer diagnosis (Toseland, Blanchard & McCallion, 1995). It is important to consider the possibility that the effects of social support on quality of life outcomes may be present in specific sub-groups of PC survivors and their spousal caregivers. In future work, it would be advisable to identify those PC survivors and their spousal caregivers who may stand to benefit the most from receiving training on improving their ability to access social support. In particular, it may be important to consider the stage of the cancer experience that the dyad is experiencing. Those undergoing active treatment may benefit more from specific forms of support, when compared to those who have already adjusted to the side effects of treatment, and are addressing the long-term challenges associated with cancer survivorship. This may offer clinicians a bigger 'bang for their buck,' when conducting an intervention targeted toward improving one individual's functioning and, perhaps, ultimately being able to



influence both partners. Though limited, the psychosocial intervention work conducted within cancer dyads is promising. One intervention targeted toward improving coping skills and communication strategies conducted within cancer populations found evidence suggesting that the 5-session, manualized intervention had the ability to not only improve the level of supportive communication within the dyad, but also reduce psychological distress and improved sexual adjustment (Scott, Halford & Ward, 2004).

Despite evidence that indicates that men tend to report receiving support from less varied sources than women (Schwarzer & Gutiérrez-Doña, 2005; Hann et al., 2002), the spousal caregivers in the current study reported deficits in social support from all sources. It may well be that in the current sample the extensive time commitment of the caregiving demands the spousal caregivers must shoulder and the high rate of concurrent employment for the women (at a level higher than PC survivors) are so significant that they simply do not have the time or energy to pursue social relationships with others (Scharlach & Boyd, 1989). A substantial body of literature has documented the extensive burden that caregivers experience and the incredible challenges that they face, when attempting to maintain a personal life, in the face of their caregiving responsibilities (e.g., Brouwer et al., 2004; Blood et al., 1994; Montgomery, Gonyea & Hooyman, 1985). It is evident that they are a population that is struggling under the weight of their responsibilities and is a group that requires further clinical and research attention. Spousal caregivers often are unable to access a sufficient support network during these times of duress to effectively cope with their stressors (Hagedoorn et al., 2008), and evaluating how professionals can better enhance their social support is needed. A familybased clinical intervention designed to enhance cancer appraisal, coping strategies, and



communication skills among PC survivors and their caregivers resulted in improvements in caregiving appraisals, communication with their partner, physical symptom distress, and overall quality of life for the caregiver (Northouse et al., 2007). Other interventions have shown that it is possible for a psychosocial intervention to improve the spousal caregiver's adaptive coping skills (Manne et al., 2004), their feelings of how prepared they are for their caregiving experience (Giarelli, McCorkle & Monturo, 2003), and levels of perceived stress (Thornton, Perez & Meyerowitz, 2004).

Furthermore, the results from the current study suggest that the spousal caregiver still has a valuable influence on the PC survivor's physical quality of life, despite the lower than norm levels of significant other support that were reported by the PC survivor. The simple idea that the significant other's support can influence physical outcomes is particularly salient for the medical team, as they seek to find any avenue by which to maintain the PC survivor's level of physical functioning. Thus, it becomes critically important to evaluate what aspects of her support play the key roles in this relationship. The existing research has proposed the ideas that the impact of good social support may be through an increased use of positive coping strategies, improved health behaviors, and improvements in immune functioning via reductions in perceived stress (Dunkel-Schetter et al., 1992; Wilkinson & Kitzinger, 2000; Lewis et al., 2006; Helgeson et al., 2004; Carlson et al., 2007).

One promising aspect of the findings from the current study is the levels of support reported by the PC survivor from his family and friends. Prior evidence has suggested that men are less likely than women to be able to access social resources beyond their significant other (Schwarzer & Gutiérrez-Doña, 2005; Hann et al., 2002).



However, in PC specific populations, research has shown that PC survivors believe they receive a significant amount of support from a number of support providers (Ptacek et al., 1999). Given that the current study findings concur with this notion that PC survivors perceive quality support from members of their social network outside of their significant other, it would be advisable for professionals who come in contact with them to encourage the men to continue to pursue these avenues of support. Results from the current study indicate that one particular area where the support of friends may be of significant benefit for the PC survivor is in influencing their mental quality of life. This may provide evidence of a gender effect wherein men may feel more comfortable disclosing to other men the challenges that they experience with facets of the PC experience, such as the sexual dysfunction resulting from treatment, rather than with women, such as their spouse. Thus, a clear benefit can be accrued from encouraging PC survivors to attempt to recruit as many sources of support as possible, with a particular focus on enhancing the relationships they have with the friends in their social networks. Both clinicians and researchers would be remiss to not capitalize on such a sound resource for the PC survivor during their adjustment process, particularly if one of their goals was to ensure the mental functioning of the survivor.

Despite the poor social support reported by participants in the current study, they appear to be a resilient group, reporting higher than normative levels of physical and mental quality of life. Prior literature has documented samples of high functioning localized PC survivors, suggesting that they are a group that can successfully navigate the cancer experience (Zhou, Penedo & Bustillo, 2010; Zhou, Penedo & Lewis, 2010). For the PC survivors, it would appear that they were able to receive quality of life benefits as



a result of support of their significant other and their friends. These are noteworthy resources that PC survivors benefit from and are members of their support network that require further attention.

Although psychosocial interventions exist to enhance the relationship between PC survivors and their significant others, no interventions are targeted toward specifically improving the ability of a PC survivor to seek and benefit from the support of his friends. The more general nature of the social support components in existing psychosocial work (e.g., Lepore et al., 2003) does not appear to provide sufficient informational depth to fully educate the survivor with respect to how they can benefit from the support of their friends. The findings in the current study that suggest that family support does not significantly influence quality of life also deserve attention, when considering implications for clinical work.

Beyond the importance of further research to understand what aspects of family support are hindering it from positively affecting survivor functioning, it is crucial to ensure that PC survivors are aware that aspects of family support may be perceived as negative. This initial understanding of less than desirable forms of support were critical in allowing PC survivors the ability to fully benefit from the positive aspects of support that they receive.

In terms of spousal caregiver support, it appears that the support she receives from her friends is vital to her mental quality of life. Thus, it would be sensible to consider dedicating a greater amount of time in any psychosocial intervention work conducted with spousal caregivers to the role that her friends play in her ability to cope with the challenges in her life. As with PC survivors, the greater part of time during a



psychosocial intervention is dedicated to improving relationships with her significant other and a lesser role is given to support from other resources, including friends. Furthermore, as significant other and family support did not appear to have a significant effect on quality of life, it would be prudent to consider educating the spousal caregiver as to the potential negative aspects of her relationships with her significant other and family and how this may detrimentally affect her quality of life.

Finally, the results from the current study indicate that the introduction of medical co-morbidities to the Study Model impacts the relationship between sources of support and quality of life outcomes with the PC survivor and his spousal caregiver. More than half of the sample of PC survivors (51.7%) and spousal caregivers (53.0%) reported at least one medical co-morbidity. This high prevalence indicates that clinicians and researchers must establish a broader biomedical picture, when evaluating PC survivor and spousal caregiver functioning. The stressors associated with needing to take care of another chronic medical condition, while concomitantly either living with PC or caregiving for a PC survivor, are tremendous and have major implications for not only their health care, but also for how clinicians can intervene (Ogle et al., 2000). Previous clinical interventions designed to improve psychosocial functioning in PC survivors or with their caregivers provide little information on how to simultaneously manage multiple medical conditions (e.g., Lepore et al., 2003; Northouse et al., 2007). Although general coping skills are taught during such intervention work, inadequate attention is paid to how medical co-morbidities may interact with cancer and how patients can best adjust to managing multiple medical regimens. The need is clear and pressing to ensure that all professionals active in the health care process for PC survivors and their spousal



caregivers are aware of the consequences of medical co-morbidities in their treatment of cancer itself.



## Tables

	PC Survivors	Caregivers
Age (years)	63.5 (SD=9.3)	60.6 (SD=8.9)
Range	45.3-84.3	40.9-78.7
Ethnicity		
Non Hispanic White	88.2%	93.5%
African-American	4.3%	4.3%
Other	7.5%	2.2%
Education		
$\leq 12^{\text{th}}$ grade	32.1%	35.9%
Some college	24.7%	28.3%
College degree	21.5%	20.7%
Professional/graduate degree	21.5%	15.2%
Income (\$)		
<19,999	5.4%	6.5%
20,000-39,999	25.8%	18.3%
40,000-74,999	30.1%	29.0%
>75,000	32.3%	25.8%
Prefer Not to Answer	6.4%	20.4%
Employment status		
Employed	57.0%	63.4%
Not employed	41.9%	34.4%
Caregiving duration (months)		13.4 (SD=12.1)
Time since diagnosis (months)	27.8 (SD=3.9)	

<u>Table 1</u>. Demographic characteristics of the study sample (N=93 dyads composed of PC survivors and their spousal caregivers).



	PC Survivors	Caregivers	$\chi^2$
Medical co-morbidities			
No medical co-morbidities	48.4%	41.9%	4.1*
1 medical co-morbidities	28.0%	31.2%	2.3
$\geq 2$ medical co-morbidities	23.7%	11.8%	9.9**
Most common co-			
morbidities			
High blood pressure	37.6%	35.5%	.34
Heart condition	11.8%	10.8%	1.1
Diabetes	9.7%	5.4%	1.2
Circulatory problems	9.7%	1.1%	3.9*
Arthritis	4.3%	17.2%	6.9**
Osteoporosis	1.4%	9.7%	1.9
			*p<.05 **p<.01

<u>Table 2</u>. Medical co-morbidity information for PC survivors and their spousal caregivers (N=93 dyads) and  $\chi^2$ -test.



PC Survivors	Caregivers	r	t
21.6 (SD=4.5)	22.9 (SD=4.5)	13	
25.7 (SD=3.8)	22.3 (SD=4.0)	.01	
24.1 (SD=4.1)	21.7 (SD=4.1)	.09	
26.4	26.4		
25.2	25.2		
25.6	25.6		
53.7 (SD=8.4)	51.9 (SD=10.8)		
		.41**	
53.2	50.2		
49.6 (SD=10.2)	48.1 (SD=9.9)		
		.47**	
47.2	46.3		
Family			11.2**
Friends			-7.9**
Family			6.8**
Physical			-3.0**
Family			1.5
Friends			2.7**
Family			1.7
Physical			
	24.1 (SD=4.1) 26.4 25.2 25.6 53.7 (SD=8.4) 53.2 49.6 (SD=10.2) 47.2 Family Friends Family Physical Family Friends	25.7 (SD=3.8) 24.1 (SD=4.1) 26.4 25.2 25.6 53.7 (SD=8.4) 51.9 (SD=10.8) 21.7 (SD=4.1) 26.4 25.2 25.6 53.7 (SD=8.4) 51.9 (SD=10.8) 49.6 (SD=10.2) 48.1 (SD=9.9) 47.2 46.3 Family Friends Family Physical Family Friends	$\begin{array}{cccccccccccccccccccccccccccccccccccc$

<u>Table 3</u>. Descriptives of sources of social support and quality of life, and relationships among study variables. (N=93 dyads).



models.	Modification Index	Relative $\chi^2$	CFI	NFI	RMSEA
Model 1		18.8	.01	.07	.44
Model 2	65.7	17.5	.13	.18	.42
Model 3	49.2	18.1	.14	.20	.43
Model 4	45.7	16.3	.28	.32	.41
Model 5	37.3	13.2	.46	.49	.36
Model 6	33.4	9.3	.66	.66	.30
Model 7	30.0	1.3	.99	.96	.06

<u>Table 4</u>. Addition of covariances among predictor variables (sources of support) to study models.

Model 1: No covariances.

Model 2: Model 1 with addition of covariance between spousal caregiver significant other support with spousal caregiver family support.

Model 3: Model 2 with addition of covariance between spousal caregiver significant other support with spousal caregiver friend support.

Model 4: Model 3 with addition of covariance between PC survivor significant other support with PC survivor family support.

Model 5: Model 4 with addition of covariance between spousal caregiver friend support with spousal caregiver family support.

Model 6: Model 5 with addition of covariance between PC survivor friend support with PC survivor family support.

Model 7: Model 6 with addition of covariance between PC survivor significant other support with PC survivor friend support.



Caregivers		
Mental Health	Physical Health	
r=.17	r=24	
F=1.10	F=.36	
F=.36	F=.47	
F=2.13	F=1.73	
r=02	r=.22	
F=1.35	F=1.70	
r=.05	r=05	
r=.25*	r=15	
F=.16	F=.52	
F=.62	F=1.54	
F=.43	F=.21	
r=.04	r=30	
F=2.87*	F=7.63**	
r=.11	r=04	

<u>Table 5</u>. Pearson correlation (r-statistic) and one way analysis of variance (F-statistic) relationships between potential covariates and study outcome variables.

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	PC Survivors		Caregivers	
Sources of support	Mental Health	Physical Health	Mental Health	Physical Health
Study Model: No covariates				
PC Survivor				
Significant other	.10	.33*	.08	.03
Family	19	28	01	11
Friend	.43*	.13	.12	.08
Spousal Caregiver				
Significant other	.08	01	.13	23
Family	.24	.12	22	.07
Friend	26	26	.38*	.24
Study Model Including Age as a				
<u>Covariate</u>				
PC Survivor				
Significant other	.09	.30*	14	.08
Family	18	38	.20	03
Friend	.42*	.14	.32	20
Age	.08	.10**		
Spousal Caregiver				
Significant other	03	23	02	31
Family	.41	.01	23	.21
Friend	15	39	.41*	.11
Age			.12*	.11**
<u>Study Model Including Age and</u> <u>Co-morbidity as Covariates</u>				
PC Survivor				
Significant other	.10	.26	.03	.03
Family	39	31	.05	08
Friend	.42*	.11	.24	35
Age	.08*	.09**		
Co-morbidity	.17*	.36**		

<u>Table 6</u>. Path coefficients (standardized  $\beta$ ) between unique sources of social support and mental and physical health among PC survivors and their spousal caregivers.



Spousal Caregiver				
Significant other	03	21	02	31
Family	.40	.41	23	.21
Friend	14	15	.41*	.11
Age			.11*	.10*
Co-morbidity			.06	.25**
Study Model Including Full				
Covariates				
PC Survivor				
Significant other	.09	.30*	14	.08
Family	18	38	.20	03
Friend	.42*	.14	.32	20
Age	.08*	.04		
Education	.06	03		
Co-morbidities	.14	40**		
Spousal Caregiver				
Significant other	03	23	02	31
Family	.41	.01	23	.21
Friend	15	39	.41*	.11
Age			.06*	.02
Income			04	01
Co-morbidities			.30*	.27**

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



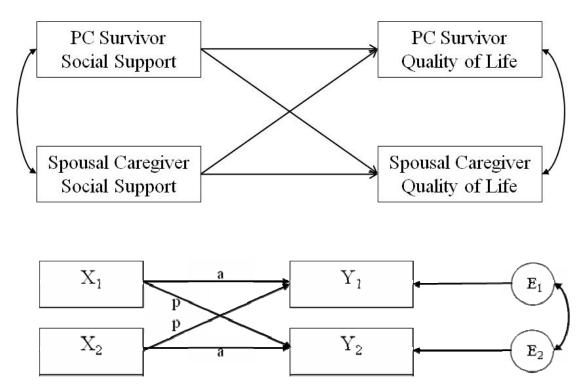
	No Covariates	Age as Covariate	Age & Co- morbidity as Covariates
Model Fit			
Relative $\chi^2$	1.3	1.0	1.4
CFI	.99	.99	.96
NFI	.96	.95	.92
RMSEA	.06	.01	.06
PC Survivor Actor Effects			
Sig. Other $\rightarrow$ Physical QoL	.33*	.30*	.26
Friend $\rightarrow$ Mental QoL	.43*	.42*	.42*
<b>Caregiver Actor Effects</b>			
Friend $\rightarrow$ Mental QoL	.38*	.40*	.41*
			* <i>p</i> <.05

<u>Table 7</u>. Comparison between 3 study models evaluated, including significant study effects identified.

# Figures

Figure 1

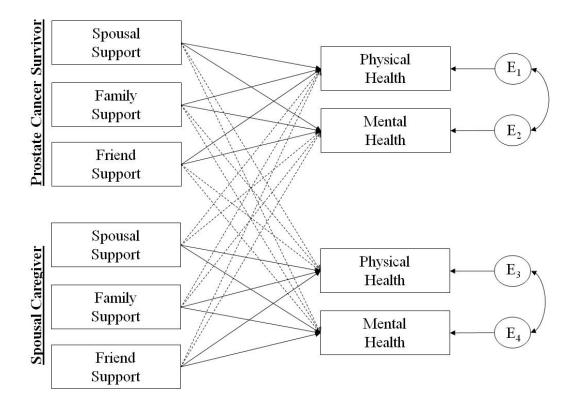
Model of dyadic influences of social support resources, and actor-partner interdependence model (a=actor effect, p=partner effect).





# Figure 2

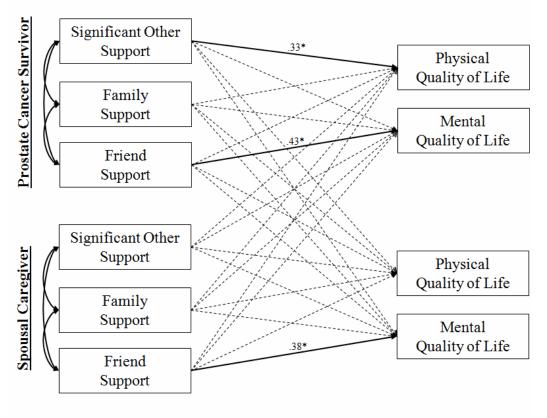
Initial proposed model for Specific Aim 1. Solid lines represent actor effects, dashed lines represent partner effects.





## Figure 3

Revised model for Specific Aim 2. Model provided good fit (relative  $\chi^2$ =1.3, CFI=.99, NFI=.96, RMSEA=.06). Solid lines represent statistically significant paths, dashed lines represent statistically non-significant paths.

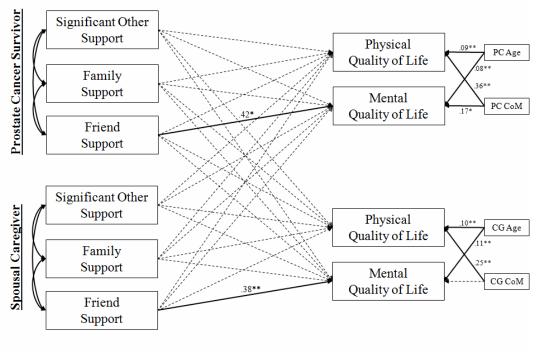


\**p*<.05, \*\**p*<.01



## Figure 4

Revised model including age and number of medical co-morbidities as covariates. Model provided good fit (relative  $\chi^2$ =1.4, CFI=.96, NFI=.92, RMSEA=.06). Solid lines represent statistically significant paths, dashed lines represent statistically non-significant paths. CoM=medical co-morbidities.



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



## Appendices

## Appendix 1

Items from the Multidimensional Scale of Perceived Social Support (MSPSS). Significant Other

- 1. There is a special person who is around when I am in need.
- 2. There is a special person with whom I can share my joys and sorrows.
- 3. I have a special person who is a real source of comfort to me.
- 4. There is a special person in my life who cares about my feelings

## Family

- 1. My family really tries to help me.
- 2. I get the emotional help and support I need from my family.
- 3. I can talk about my problems with my family.
- 4. My family is willing to help me make decisions

## Friends

- 1. My friends really try to help me.
- 2. I can count on my friends when things go wrong.
- 3. I have friends with whom I can share my joys and sorrows.
- 4. I can talk about my problems with my friends.



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