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The Influence of Stigma on Quality of Life and Relationship Satisfaction for Prostate Cancer Survivors and Their Partners

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THE INFLUENCE OF STIGMA ON QUALITY OF LIFE AND RELATIONSHIP
SATISFACTION FOR PROSTATE CANCER SURVIVORS AND THEIR PARTNERS

by

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A dissertation submitted in partial fulfillment of the requirements
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ABSTRACT

The purpose of this study was to examine the relationships between stigma, quality of life (QoL), and relationships satisfaction for prostate cancer (PCa) survivors and their intimate and/or romantic partners. The investigator tested a theoretical model that stigma (as measured by the *Social Impact Scale* [SIS; Fife & Wright, 2000]) influenced QoL (as measured by the *Functional Assessment of Cancer Therapy – Prostate* [FACT-P; Esper et al., 1997] and the *Functional Assessment of Cancer Therapy – General Population* [FACT-GP; Cella et al., 1993]) and relationship satisfaction (as measured by the *Couples Satisfaction Index* [CSI; Funk & Rogge, 2007]) for both PCa survivors and their partners ($N = 72$ couples). The investigator hypothesized that stigma would have a negative influence on both QoL and relationship satisfaction. Further, exploratory research questions pertained to the influence of race on stigma, QoL, and relationship satisfaction, as well as examining difference in experiences of stigma based on demographic variables (e.g., age and income).

The results of the structural equation model analyses identified that stigma negatively influenced QoL ($R^2 = .84, p < .05$) and relationship satisfaction ($R^2 = .19, p < .05$) for both PCa survivors and their partners. Race did not have statistically significant ($p > .05$) relationships with stigma, QoL, or relationship satisfaction and stigma was not found to be statistically different ($p > .05$) based on demographic variables. Implications of the results of the study include (a) practical implications for PCa survivors and their partners; (b) strategies for effective individual, group, and couples-based counseling; (c) need for counselor educators to prepare counselors to work with medically ill populations and cancer survivors; (d) PCa stigma

instrument development; and (e) the necessity to examine research with couples in a dyadic fashion.

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CHAPTER ONE: INTRODUCTION

Prostate cancer is the most common and second deadliest type of cancer for men (National Cancer Institute [NCI], 2011; Walsh & Worthington, 2012). Prostate cancer (PCa), a cancer found in prostate glands in individuals born biologically male (Walsh & Worthington, 2012), affects one in seven men. There are an estimated 233,000 new cases of PCa each year and 29,480 deaths were estimated in 2014 (NCI, 2011). However, PCa incidence and mortality rates have been declining over the past 20 years, with 98.9% of individuals diagnosed surviving for more than five years (NCI, 2011).

Men living with PCa report experiencing decreased quality of life (QoL) due to multiple physical and psychosocial symptoms including difficulty urinating, erectile dysfunction, shame, lower emotional functioning, and stigma (Else-Quest, LoConte, Schiller, & Hyde, 2009; Walsh & Worthington, 2012; Zenger et al., 2010). Prostate cancer survivors experience stigma, but the effects of stigma on QoL have yet to be fully explored (Else-Quest et al., 2009; Fergus, Gray, & Fitch, 2002). Further, the effects of PCa can extend into couples, affecting partners of survivors (Couper et al., 2006). In addition, racial health disparities exist and can further affect QoL (Penedo, Dahn, Shen, Schneiderman, and Antoni, 2006).

Therefore, the aims of this study were to examine relationships between stigma and QoL, and between stigma and relationship satisfaction, for PCa survivors and their partners. The investigator examined if stigma predicts QoL and relationship satisfaction for PCa survivors and their partners. The occurrence of stigma based on race and demographic variables was also examined.

Background of the Study

Quality of life for PCa survivors has received considerable attention in empirical research for more than 15 years (Fergus et al., 2002; Letts, Tamlyn, & Byers, 2010; Maliski, Rivera, Connor, Lopez, & Litwin, 2008; Pedersen, Armes, & Ream, 2012). Specifically, mental health researchers focus on the influence of PCa on individuals' thoughts and feelings upon diagnosis, and also on relationships between physical problems such as incontinence (Kopp et al., 2013), impotence (Letts et al., 2010), and overall masculine identity (Maliski et al., 2008). Recently, researchers (Cho et al., 2013a; Else-Quest et al., 2009; Lebel et al., 2013a) discovered that individuals with cancer experience stigma. However, few empirical studies exist examining PCa stigma (Else-Quest & Jackson, 2014).

PCa also has a considerable influence on partners' QoL and is qualified as a "relationship disease" (Gray Fitch, Phillips, Labrecque, & Klotz, 1999; Green, Wells, & Laakso, 2010; Merz et al., 2011; Rivers et al., 2012; Song et al., 2011). Researchers (Merz et al., 2011; Segrin, Badger, & Harrington, 2012) have found that QoL for PCa survivors and their partners are interrelated and influence one another. In addition, stigma has negative influences on intimate relationships (Doyle & Molix, 2014). Thus, it can be inferred that PCa stigma can affect survivors and their partners.

Understanding how stigma influences QoL affords practitioners and researchers opportunities to develop effective interventions to reduce possible PCa stigma (Crocker & Quinn, 2000). However, researchers have not integrated two substantial findings: the influence of PCa on individuals' lives (Jayadevappa Malkowicz, Chhatre, Johnson, & Gallo, 2012; Letts et al., 2010; Mickeviciene et al., 2012; Torvinen et al., 2013) and the influence of stigma on

individuals' lives (Livingston & Boyd, 2010; Mak, Poon, Pun, & Cheung, 2007). Integration of these findings can aid in understanding how stigma influences QoL for PCa survivors and their partners. In addition, the extent to which PCa affects couples' relationships has been examined (Zhou et al., 2011), but the extent to which PCa stigma affects relationships is non-existent unfound in current literature. This study examined how stigma influences QoL for PCa survivors and their partners.

While PCa affects survivors and their partners, racial health disparities concurrently affect those of non-majority races, Black survivors in particular (NCI, 2011). While examining the struggles inherent in PCa, it is important to remember that racial health disparities contribute to greater incidence and mortality rates for non-majority races. Due to racial health disparities and noted cultural issues (Pedersen et al., 2012), this study also examined how stigma can differ based on race, as well as other demographic variables (e.g., education or treatment).

A point of clarification is required in reading this study. The investigator recognizes that PCa can affect individuals that do not identify as male but were born biologically male (e.g., transgender individuals). For the purposes of the study, the terms "males" or "men" are used for ease and clarity of language, while remaining aware that PCa can affect individuals who do not identify as "males" or "men." For similar ease of reading, the term "partner" is used for the romantic or intimate partners of PCa survivors. In the study, a partner could refer to anyone with whom PCa survivors were currently engaged in romantic or intimate relationships. Finally, the term "race" is used in order to reflect language used in NCI's reporting on PCa incidence and mortality rates and to account for inclusion of multiple ethnicities (e.g., use of the term African American may exclude Caribbean Americans).

Theoretical Foundations

Social exchange theory (Levinger, 1965; 1976) and modified labeling theory (Link, Cullen, Struening, Shrout, & Dohrenwend, 1989), provide a framework for conceptualizing and understanding the influence of stigma on PCa survivors and their partners. The examination of QoL, relationship satisfaction, and stigma from a counseling viewpoint reveals their connections to one another in regards to the issues PCa survivors and their partners face. The addition of racial health disparities provides another layer of examination for under-researched populations.

Social Exchange Theory

Social exchange theory (Levinger, 1965; 1976) aids in conceptualizing the experiences of PCa survivors and their partners. Social exchange theory conceptualizes the quality and strain of relationships based on couples': 1) attraction to a relationship; 2) barriers to leaving relationships; 3) and attraction to alternatives. Healthy couples mutually exchange costs and rewards in their relationships, making the attractions of relationships high (e.g., equal balance between rewards and costs); barriers to leaving relationships at a moderate level (e.g., needs are being met and partners are content in relationships); and attraction to alternatives lower (e.g., other potential partners do not provide what the current partner provides). The burden of PCa on survivors and their partners may cause attractions to the relationship (e.g., sexual satisfaction) to weaken, but also increase the barriers to leaving the relationship (e.g., perception of leaving a person with a chronic illness), creating problems for couples. Lewis and Spanier (1982) qualify this type of relationship as unsatisfied but stable. Attractions to a relationships and barriers to leaving a relationship could endure for PCa couples who have built strong and healthy

relationships prior to diagnosis, resulting in satisfied and stable relationships. In sum, social exchange theory (Levinger, 1965; 1976) highlights the influence of the disease on both survivors and their partners.

Modified Labeling Theory

Modified labeling theory (Link et al., 1989) conceptualizes how individuals encounter stigma (Link & Phelan, 2001). Originally, labeling theory (Scheff, 1984) viewed a label as the cause of physical or mental distress. Labeling theory and modified labeling theory are most applied to mental health issues (e.g., schizophrenia or depression), but the concept applies to other stigmatizing issues as well. According to labeling theory, a person labeled as suffering from PCa would experience physiological symptoms of the disease due to labeling rather than any biological cause. Modified labeling theory allows for pre-existing psychological and biological history and explains that labels exacerbate symptoms. In the case of PCa stigma, modified labeling theory suggests that individuals labeled with the disease endorse pre-existing symptoms of the disease (e.g., blood in urine) and labeling can lead to increased symptomatology (e.g., depression and sexual dysfunction). Without a diagnosis of PCa, survivors may not experience stigma. This trend prevails in multiple studies on stigma (Drapalski et al., 2013; Vogel, Bitman, Hammer, & Wade, 2013; Waugh, Byrne, & Nicholas, 2014).

Theoretically, PCa stigma affects partners as well as survivors. Researchers have often found that emotions between PCa survivors and their partners are inter-related (Lafaye et al., 2014; Regan et al., 2014; Zhou et al., 2011), with partners being more affected by the disease emotionally than survivors (Northouse et al., 2007). Partners can witness internalization of

stigma that results in lower QoL for survivors and then, lower QoL for partners. The social and emotional cost of PCa stigma can decrease partners' attraction to survivors and increase attraction to alternatives (Levinger, 1965; 1976), thus effecting relationship satisfaction. In healthy couples, previously established costs and rewards build attractive relationships with moderate burdens to leaving and low attraction to alternatives. Further, the culturally-specific PCa beliefs that individuals of different races endorse (e.g., thoughts pertaining to masculinity and digital rectal examinations) could change relationships between stigma, QoL, and relationship satisfaction for survivors and their partners (Pedersen et al., 2012; Rivers et al., 2011; Rivers et al., 2012).

Both theories conceptualized the study and hypotheses in that the experience of living with PCa can cause a strain on couples, leaving an unbalanced exchange in relationships and causing them to suffer. Further, through the experience of PCa, stigma compounds the mental health effects of the disease and leads to increased strain on the relationship. Based on previous research, the constructs of QoL, relationship satisfaction, and stigma interrelate in PCa stigma's effect on survivors and their partners. Additionally, those relationships differ based on race.

Social Significance

Prostate cancer researchers (Taylor-Ford et al., 2013; Zhou et al., 2011) examine many causes and outcomes of suffering and pain for survivors and their partners. Quality of life is a common outcome variable in PCa studies (Torvinen et al., 2013). Racial health disparities are a consistent area of interest for PCa researchers due to increased incidence rate and unique experiences of racially diverse PCa survivors and their partners (Rivers et al., 2012; Taksler,

Keating, & Cutler, 2012). Relationship satisfaction is often researched (Regan et al., 2014; Zhou et al., 2011) in how it affects PCa survivors and their partners as well as how other variables effect relationship satisfaction. Stigma, however, is a relatively new concept in PCa research (Else-Quest & Jackson, 2014). An examination of these constructs highlights a need to investigate how they interrelate and cause issues for PCa survivors and their partners.

Quality of Life for Prostate Cancer Survivors

Quality of life is a multidimensional construct that represents the subjective positive and negative experiences in individuals' lives through a variety of domains (emotional, physical, and social) (The WHOQOL Group, 1998). Researchers (Mickeviciene et al., 2012; Song et al., 2011; Torvinen et al., 2013; Zhou et al., 2010) have focused considerable attention on increasing QoL for PCa survivors. Prostate cancer can cause individuals to experience physical, emotional, and cognitive discomfort, lowering QoL (Walsh & Worthington, 2012). Quality of life for PCa survivors changes dependent on physical and social variables, including disease stage (Vanagas, Mickeviciene, & Ulys, 2013), treatment (Chipperfield et al., 2013), age (Diefenbach, Mohamed, Horwitz, & Pollack, 2008), education (Mickeviciene et al., 2012), and socioeconomic status (Aarts et al., 2010). Prostate cancer survivors also encounter psychological factors that can influence their QoL, such as body image issues (Taylor-Ford et al., 2013), self-efficacy (Campbell et al., 2004), optimism (Thornton, Perez, Oh, & Crocitto, 2012), and social support (Mehnert, Lehmann, Graefen, Huland, & Koch, 2010). Individuals can often have high QoL and suffer from diseases, due to an assortment of buffers (e.g., resiliency) (Nelson, Balk, & Roth,

2010). Thus, survivors' QoL suffers for a variety of reasons. For some survivors, differences in QoL can be exacerbated due to racial health disparities.

Racial Health Disparities in Quality of Life.

Due to a variety of explained and unexplained biological and social factors, Black men develop PCa at a 76% greater incidence rate as compared to White men (Taksler et al., 2012). Along with a higher incidence rate of PCa, Black survivors encounter different psychosocial issues in regards to the disease and treatment (Pedersen et al., 2012; Rivers et al., 2011; Rivers et al., 2012). Outside of the purviews of the study, racial health disparities also extend to initial screening and diagnosis of PCa (Pedersen et al., 2012). Thus, PCa differs not only biologically for Black survivors, but also psychologically, making the experience of the disease different when compared to White survivors. There are consistent differences amongst other races as well (Namiki et al., 2011; Penedo, Dahn, Shen, Schneiderman, & Antoni, 2006). A consistent limitation of psychosocial PCa research is a lack of focus on the concerns of racial non-majority survivors (Parahoo et al., 2013). The racial health disparities that non-majority race survivors face can be due to cultural and institutional influences that deter survivors from earlier diagnosis and treatment of the disease (Jones & Corrigan, 2014; Walsh & Worthington, 2012). After initial diagnosis, however, racial health disparities can extend to thoughts and feelings about the disease and its treatment (Jenkins et al., 2004). In addition to PCa affecting survivors differently, the disease's effects can extend to partners of survivors (Couper et al., 2006). The quality of intimate relationships, including relationship satisfaction and dyadic consensus, can improve QoL for PCa survivors (Banthia et al., 2003; Maliski, Heilemann, & McCorkle, 2002).

Relationship Satisfaction and Prostate Cancer Survivors

Researchers studying the physical and mental effects of PCa on survivors often conduct their studies in dyadic formats, assessing viewpoints of survivors and their partners, as relationships with partners can alleviate disease issues that influence QoL for survivors (Badr & Taylor, 2009; Song et al., 2012). In addition to intrapersonal changes, interpersonal changes occur between PCa survivors and their partners. Quality of life for PCa survivors and their partners tends to be non-independent (Segrin et al., 2012). Essentially, the thoughts, feelings, and actions of PCa survivors or their partners affect one another.

The relationships of PCa survivors and their partners are integral to understand the effects of the disease (Couper, 2007). Links exist between psychosocial issues and QoL for PCa survivors and their partners in previous literature (Jayadevappa et al., 2012; Mehnert, Lehmann, Graefen, Huland, & Koch, 2010), but to the investigator's knowledge, there are no links established between stigma and QoL for PCa survivors and their partners, even though evidence exists that survivors experience stigma (Else-Quest et al., 2009). In addition, researchers (Banthia et al., 2003; Regan et al., 2014; Wootten et al., 2007; Zhou et al., 2011) found that relationship satisfaction predicted psychosocial issues and QoL for PCa survivors and their partners, but stigma's influence on relationship satisfaction has not been researched. This study aimed to further research on QoL and relationships satisfaction for PCa survivors and their partners by including stigma as a possible origin of some issues.

Stigma of Diseases

The concept of stigma refers to a socially constructed phenomenon wherein individuals with diseases or disabilities that differ from the majority of individuals are discredited (Goffman, 1963; Link & Phelan, 2001). A majority of stigma research over the past 20 years concerns stigma of mental health issues (Mak et al., 2007) and the Human Immunodeficiency Virus (HIV) (Herek, 1999; Fife & Wright, 2000; Varni, Miller, McCuin, & Solomon, 2012). However, stigma research is growing in other diseases and disabilities (Pearl & Lebowitz, 2014; Werner, Corrigan, Dichtman, & Sokol, 2012).

Stigma can inhibit individuals' ability and motivation to seek mental and physical health care (Chapple, Ziebland, & McPherson, 2004; Vogel, Wade, & Hackler, 2007). For many individuals, the possibility of labeling causes some to not seek screening or treatment for diseases (Jones & Corrigan, 2014). As a result, diseases could worsen due to stigmatization, as not seeking treatment can result in long-term ill-effects and mortality (Walsh & Worthington, 2012). Because cancer can be a fatal disease, it remains important for survivors to seek mental and physical health treatment to avoid long-term ill-effects and possible death (Else-Quest & Jackson, 2014).

Empirical research on how stigma affects cancer survivors is on the rise (Else-Quest & Jackson, 2014). Researchers (Cho et al., 2013; Else-Quest et al., 2009; Stahly, 1988) found that stigma affects individuals with cancer, but the majority of literature focuses on lung cancer. Stigma related to PCa lacks thorough investigation in extant literature (Else-Quest & Jackson, 2014). However, researchers studying PCa have linked the disease to many physical and mental health issues that could lead to stigmatization, including depression (Jayavadeppa et al., 2012),

sexual desire (Jenkins et al., 2004), self-esteem (Maliski et al., 2008; Rivers et al., 2011; Rivers et al., 2012), and relational issues (Harden et al., 2013).

Prostate cancer and its treatment affects individuals differently depending on stage and progression of the disease (Vanagas, Mickeviciene, & Ulys, 2013). Some treatments decrease libido and change moods (e.g., androgen deprivation therapy) while others involve removing prostates entirely, sometimes causing irreparable damage (Walsh & Worthington, 2012). The changes that PCa survivors face can change the ways they think about themselves and how others view them (Halbert et al., 2010; Maliski et al., 2008; Pedersen et al., 2012).

Prostate cancer exists as a “couples disease” (Gray et al., 1999) and numerous researchers (Garos, Kluck, & Aronoff, 2007; Kershaw et al., 2008; Northouse et al., 2007; Song et al., 2011; Song et al., 2012) find that to fully conceptualize the experiences of survivors, researchers must examine the quality of relationships between survivors and their partners. Thus, to holistically examine PCa stigma, the relationships between survivors and their partners should also be examined. Further, racial health disparity issues for couples necessitates investigation to understand how PCa’s influence differs based on race.

Statement of the Problem

Prostate cancer accounts for 14% of all new cancers in the United States, with a projected 233,000 individuals diagnosed in 2014, more than any other cancer (NCI, 2011). The National Institute of Health (NIH, 2014) estimates spending almost \$5.5 billion on cancer research in 2014, with \$294 million devoted to PCa research, second only behind breast cancer. Prostate cancer causes a financial burden for the United States government and for survivors (DiIorio et

al., 2010; Jayadevappa et al., 2012; Zenger et al., 2010). Researchers (e.g., Jayadevappa et al., 2012) have found that both QoL and experiences of stigma predict increased hospital visits, longer hospital stays, and increased time to diagnosis, which all can contribute to increased public and private costs. In order to best care for PCa survivors, healthcare and mental health professionals should look toward increasing QoL for survivors and their partners and to lessen the overall burden the disease causes. Even though PCa incidence and mortality rates are decreasing over time, with a five-year survival rate of 98.9%, there remains an importance to continue research on PCa and how it distresses survivors and partners. Further, stigma is a concern for mental and physical health at national levels (Link & Phelan, 2006; NIH, 2004; 2013). Thus at national and individual levels, both PCa and stigma are issues that deserve further examination, yet the connection between the two constructs is vague.

A problem in the current literature endures but is not receiving focus: PCa survivors and their partners experience stigma and face numerous physical and mental health issues (Campbell, Keefe, McKee, Waters, & Moul, 2012; Else-Quest et al., 2009; Jayadevappa et al., 2012; Nelson et al., 2010; Northouse et al., 2007; Rivers et al., 2012; Torvinen et al., 2013). Mental health issues for PCa survivors often lead to increased mortality and lower QoL (Jayavadeppa et al., 2012). However, stigma's influence on QoL for PCa survivors remains unmeasured in current literature. Thus, the growing population of PCa survivors remain untreated for stigma, which they may face on a constant basis. Further, because of racial health disparities non-majority races face, their experiences of stigma may differ from those of majority race survivors. Partners of PCa survivors may also experience the effects of stigma (Doyle & Molix, 2014; Gaines, 2001; Goffman, 1963), and their relationships may suffer because of it (Doyle & Molix, 2014; Talley

& Bettencourt, 2010). The investigator utilized the current study to investigate how stigma affects QoL for PCa survivors and their partners; how their relationship satisfaction was influenced by stigma; and how relationships between stigma, QoL, and relationship satisfaction differed based on race.

Professional Significance

The current study is the first study designed, to the investigator's knowledge, to examine how PCa stigma influences QoL and relationship satisfaction for survivors and their partners. Stigmas of other diseases (e.g., HIV) have been found to have substantial effects on individuals and their partners. However, there are gaps in empirical research on the relationship between stigma, relationship satisfaction, and QoL for PCa survivors and their partners. The investigator combined two areas of federal research initiatives to conduct basic research that provides data to better QoL for PCa survivors and their partners in future studies.

The investigation aimed to aid counselors in recognizing not only mental health stigma, but also PCa stigma for survivors and their partners. The investigator looked to examine the influence of stigma on couples experiencing PCa in order to provide information to counselors and other mental health professionals. The information gathered in this study can aid counselors and other mental health professionals in gauging the need, or lack thereof, to address issues related to PCa stigma when providing services to couples experiencing the disease. Further, contributions of this study include novelty, in that the study is the first to examine how stigma affects QoL for survivors and their partners.

Research Question and Hypothesis

The purpose of this study was to assess the influence of stigma on PCa survivors and their partners' QoL and relationship satisfaction. The primary research hypothesis which guided the study, and exploratory research questions, are in the following section.

Research Hypothesis

The research hypothesis for the study was: Stigma (as measured by the Social Impact Scale; Fife & Wright, 2000) has a negative influence on QoL (as measured by the Functional Assessment of Cancer Therapy - Prostate; Esper et al., 1997 and the Functional Assessment of Cancer Therapy – General Population; Cella et al., 1993) and relationship satisfaction (as measured by the Couples Satisfaction Index; Funk & Rogge, 2007) of PCa survivors and their partners (Figure 1).

Exploratory Research Questions

1. Are there statistically significant relationships between stigma (as measured by the SIS; Fife & Wright, 2000), QoL (as measured by the FACT-P; Esper et al., 1997 and the FACT-GP; Cella et al., 1993), relationship satisfaction (as measured by the CSI; Funk & Rogge, 2007), and race for PCa survivors and their partners?
2. Are there statistically significant differences in experiences of stigma (as measured by the SIS; Fife & Wright, 2000) based on demographic variables (e.g., age and income) for PCa survivors?

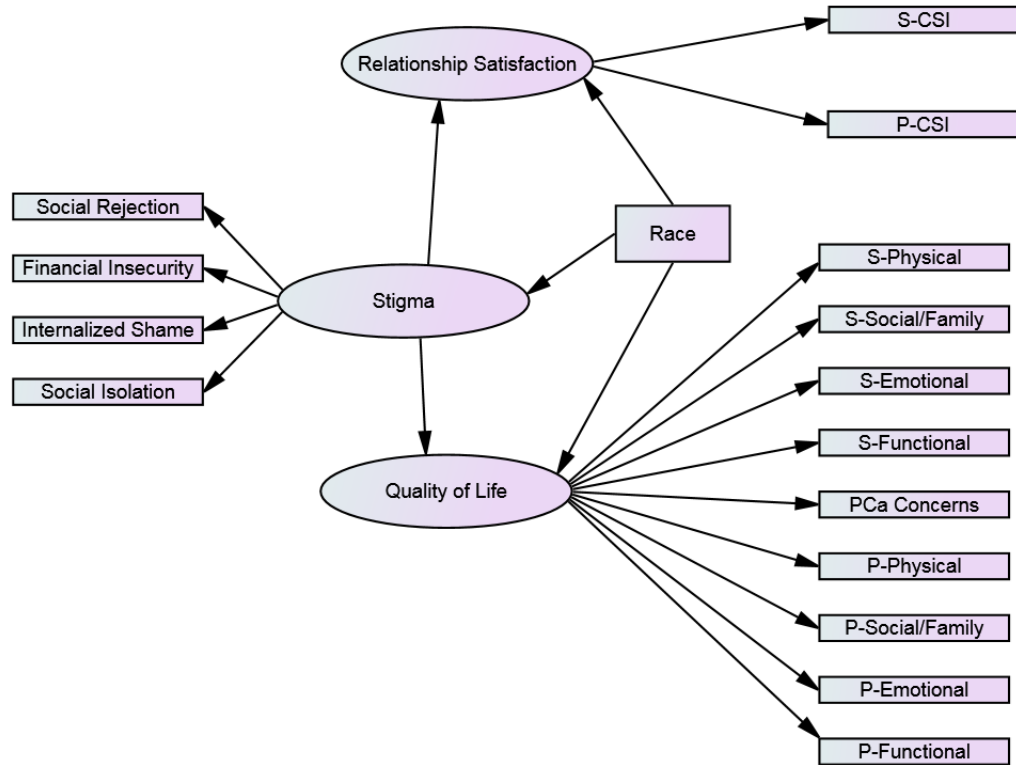


Figure 1 Hypothesized Path Model

Methodology

A correlational design was employed in this study, as the purpose of the study was based on relationships between QoL, relationship satisfaction, and stigma (Gall, Gall, & Borg, 2007). Sampling in the study utilized a convenience sample (Gall et al., 2007) and data collection measures relating to QoL, relationship satisfaction, stigma, and demographic variables. Data collection consisted of obtaining a sample from oncology centers and PCa support groups. Data was collected from multiple sites in order to obtain an adequate and robust sample to control for

issues related to statistical power (Cohen, 1992; Kline, 2010). An overview of the methodology follows.

Research Design

The investigator employed a correlational, quantitative research design to assess the influence of stigma and relationship satisfaction on QoL for PCa survivors and their partners (Gall et al., 2007). The research utilized dyadic data obtained from PCa survivors and their partners (Kenny, Kashy, & Cook, 2006) to measure stigma's influence on QoL and relationship satisfaction. The combination of a correlational research design with dyadic data was used in previous literature to address research hypotheses similar to the current study's primary hypothesis (e.g., Kershaw et al., 2008; Zhou et al., 2011).

Sampling and Instrumentation

The sample for the study was composed of PCa survivors and their partners. A convenience sample consisting of PCa survivors receiving treatment or consultation from oncology centers or attending PCa support groups in the southeastern US and their partners were eligible to participate in the study. In order to accrue a large number of participants who meet the inclusion criteria for the study, the investigator used a convenience sample. The dyads for the study (i.e., PCa survivors and their partners) were paired together for data analysis to establish and evaluate relationships between stigma, QoL, and relationship satisfaction.

To answer the research question, the study necessitated a sample of approximately 150 dyads (300 individual participants). A priori power estimations for structural equation modeling (SEM) yielded information on appropriate sample sizes for the study, with a sample of 150 dyads

ensuring appropriate power estimations ($\alpha = .8$; Cohen, 1992) with a 95% confidence interval. Using an SEM sample size calculator suggested by Schumacker and Lomax (2012), www.danielsoper.com yielded a recommended minimum sample size of 200 to detect an anticipated effect size of 0.2 and a desired power level of 0.8 with three latent variables (e.g., stigma, QoL, and relationship satisfaction) and 15 observed variables (e.g., four subscale totals of the survivor's stigma, one total score of survivor relationship satisfaction, one total score of partner relationship satisfaction, five subscale totals of survivor QoL, and four subscale totals of partner QoL). An anticipated effect size of 0.2 was chosen to account for smaller sample sizes in researching couples (Kenny et al., 2006) and common correlations between QoL and relationship satisfaction measures for PCa survivors and their partners (Segrin et al., 2012; Song et al., 2011). A sample of 150 dyads meets the commonly held standard minimum of 200 individual participants for SEM (Kline, 2010). However, previous researchers note that small samples suffice for SEM (Bentler & Yuan, 1999) and other studies utilizing dyadic data to assess QoL for PCa survivors and their partners have used smaller sample size, similar to the sample size in the present study. The achieved sample of 72 dyads was sufficient based on previous studies despite seeking to obtain a sample of 150 dyads in the present study.

Data collection

Institutional Review Board approval was required for the study to ensure ethical research practices and the safety of participants. The Institutional Review Board protocol included a request for participants to receive a waiver of informed consent in order to limit any possible identifying information and in order to use PCa survivors and their partners in online support

groups. For the study, the investigator sought partnerships with oncology centers within Florida to have access to their patients to gather data. Face to face support groups (e.g., Us TOO) were contacted and asked for permission to collect data from support group members. Also, online support groups (e.g., You Are Not Alone [YANA]) were contacted for permission to post advertisements on their websites or listservs.

Face-to-face data collection consisted of asking individuals in either oncology centers or in support groups to volunteer for the study. Individuals were asked to participate at any time in support groups. However, in oncology centers, individuals were not asked to participate if it was their first visit to the cancer center, in order to lessen stress on individuals who may be facing an initial cancer diagnosis or weighing treatment options. Individuals were approached with options to either a) take the assessment packet and complete it with their partner (if the partner was also present), b) take the assessment packet home and complete it with their partner and bring it back at their next appointment, or c) take a pre-addressed and stamped assessment packet home and complete it with their partner to send to the investigator. The mail-in assessment packets were created for the support groups, as the majority meet monthly and there was a possibility of support group members not bringing back assessment packets to the following group, or not attending the following group at all. However, the mail-in assessment packets were also used to collect data from PCa survivors who came in for check-up appointments at oncology centers, as they would not be able to return the packets personally in a timely fashion.

Online data collection consisted of posting advertisements to online PCa support groups. Measures used in the study were adapted from paper/pencil formats to online formats, following survey construction guidelines suggested by Dillman, Smyth, and Christian (2009). The

Qualtrics website and software was used to collect online data. Participants were asked to complete the assessments sequentially, with the ability for either partner to initiate the assessments.

The investigator sought permission from the authors of the measures used in the study. Permission was granted to use the SIS (personal communication with Dr. Fife; June 9th, 2014). The FACT-P and FACT-GP were allowed to be used once registered through the FACIT website (completed June 20th, 2014). To use the CSI, the measure is available for free on Dr. Rogge's website in 32, 16, and 4 item versions.

Incentives were provided to participants. For each individual who participated in the study, a \$1 donation was made to the Prostate Cancer Foundation, an organization that supports PCa research and awareness. The donation was made through the Safeway Foundation, which matched donations to the Prostate Cancer Foundation (up to one million dollars until December 31, 2014).

Instruments

The investigator collected demographic information to assess the characteristics of participants, such as number of years since PCa diagnosis, treatment information, disease stage, age, and race. Demographic information of partners included non-disease specific questions (e.g., age and race). The *Functional Assessment of Cancer Therapy for Patients with Prostate Cancer* (for PCa survivors) (Esper et al., 1997), and the *Functional Assessment of Cancer Therapy – General Population* (for PCa survivors' partners) (Cella et al., 1993) measured QoL;

the *Couples Satisfaction Index* (Funk & Rogge, 2007) measured relationship satisfaction; and the *Social Impact Scale* (Fife & Wright, 2000) measured stigma in the study.

Functional Assessment of Cancer Therapy - Prostate Cancer and General Population

The *Functional Assessment of Cancer Therapy - Prostate* (for PCa survivors) (FACT-P; Esper et al., 1997) and the *Functional Assessment of Cancer Therapy – General Population* (for PCa survivors' partners) (FACT-GP; Cella et al., 1993) assessed QoL. The FACT-P and the FACT-GP were similar items to one another, except that the FACT-P's questions were geared toward PCa and has a separate subscale for PCa-specific functioning. The FACT-P and the FACT-GP were 39-item and 21-item scales, respectively, assessing QoL on five subscales: physical well-being, social/family well-being, emotional well-being, functional well-being, and additional concerns (relating to PCa symptoms). The fifth subscale exists only on the FACT-P. Items on both the FACT-P and the FACT-GP utilize similar wording and were mostly identical. Both scales use five-point Likert-type response formats (e.g., *not at all*, *a little bit*, *somewhat*, *quite a bit*, and *very much*). The FACT-P has shown internal consistency levels ranging from .61 to .90 for its subscales and .89 overall (Esper et al., 1997). The FACT-GP has internal consistency levels ranging from .71 to .83 and .88 overall (Victorson, Barocas, Song, & Cella, 2008).

Couples Satisfaction Index

The *Couples Satisfaction Index* (CSI; Funk & Rogge, 2007), a 16-item scale, assessed relationship satisfaction based on current romantic relationships. Each item followed a six-point (15 items) or seven-point (1 item) Likert-style response format based on satisfaction in

relationships. The CSI did not contain subscales and its items exist to measure relationship satisfaction (e.g., I have a warm and comfortable relationship with my partner). The creators of the CSI used item-response theory in constructing the instrument. The creators of the CSI took items from other relational measures (e.g., Marital Adjustment Test [Locke & Wallace, 1959] and Dyadic Adjustment Scale [Spanier, 1976]) and researcher-created relationship satisfaction items to construct the measure. The CSI shows convergent validity with other relational measures and high internal consistency ($\alpha = .98$). The CSI had strong, but minimal, empirical support (Graham, Diebels, & Barnow, 2011) due to the limited amount of studies that have utilized the measure.

Social Impact Scale

The *Social Impact Scale* (SIS; Fife & Wright, 2000), a 24-item scale, assessed stigma. The SIS measures general stigma, in that the items did not relate to any particular stigmatizing issue (e.g., mental health or HIV). The SIS consisted of four subscales: two assessed social stigma and two assessed self-stigma. The first social stigma subscale assessed social rejection and consisted of nine items (e.g., I feel others avoid me because of my illness). The second social stigma subscale assessed financial insecurity and consisted of three items (e.g., I have experienced financial hardship that has affected how I feel about myself). The first self-stigma subscale assessed internalized shame and consisted of five items (e.g., I feel I need to keep my illness a secret). The second self-stigma subscale assessed social isolation and consisted of seven items (e.g., Due to my illness, I sometimes feel useless). Each item followed a four-point Likert-style response format (e.g., *strongly agree*, *agree*, *disagree*, and *strongly disagree*). The SIS was

normed with a sample of individuals with HIV and cancer. The SIS had internal consistency ranging between .85 and .90, and validity (Pan, Chung, Fife, & Hsiung, 2007).

Analysis

The investigator utilized SEM with dyadic data to interpret data collected for the study (Kline, 2010; Peugh, DiLillo, & Panuzio, 2013). The use of SEM allowed the investigator to examine each research question concurrently, as well as account for measurement error with the chosen measures. Structural equation modeling, a second-generation multivariate analysis, combines multiple regression, path analysis, and confirmatory factor analysis (Kline, 2010). Structural equation modeling allows the investigator to test the theoretical models of the study with sample data. The use of SEM also aided in examination of item-based error measurement, thus creating a less distorted picture of results. Structural equation modeling allows for confirmatory factor analysis during model testing, ensuring that all measures fit the sample of PCa survivors and their partners appropriately. Confirmatory factor analysis is of particular importance for the SIS and the CSI, as neither has been used in a sample with PCa survivors and their partners.

In the study, the investigator followed the five steps of SEM: model specification, model identification, model estimation, model testing, and model modification. Structural equation modeling and dyadic data worked together to answer the research question (Kenny et al., 2006; Peugh et al., 2013). Previous researchers (e.g., Kershaw et al., 2008) studying PCa couples utilized similar methods. In estimating the fit of the model, the investigator uses maximum likelihood estimation and multiple recommended fit indices (Kline, 2010), including chi-square,

the root mean square error of approximation (Steiger, 1990), the standardized root mean square residual (Bentler, 1995), the Tucker-Lewis Index (Kenny, 2014), and the comparative fit index (Bentler, 1990) to ensure a model fit to the sample data.

The data for the study was dyadic in nature (Kenny et al., 2006). Similar assessments were collected from both PCa survivors and their partners. Both PCa survivors and their partners received the CSI (Funk & Rogge, 2007) and versions of the FACT (Cella et al., 1993; Esper et al., 1997) such that the investigator could analyze the influence on not just the individuals, but the couple as a unit. In order to analyze data, the common fate model (Ledermann & Kenny, 2012) for modeling dyadic data was used. Thus, creating dyadic data sets and measuring for nonindependence was necessary for analysis.

Potential Limitations

In the design and analysis of the study, efforts were made to minimize limitations. However, as with all studies, there were some limitations to the study.

1. Self-report measures were used in the study and were subject to participant bias.

Therefore, the participants' responses on self-report measures may influence study results

2. The types of individuals who participated in the study may influence the results. There may be inherent differences between individuals who choose to participate in research and those who do not. Thus, there may be limited variance within the data when not accounting for those who choose not to participate in research.

3. All measures used in counseling research have some amount of measurement error, regardless of psychometric properties. Thus, the measures chosen for the study may have influenced the results of the study.
4. Finally, research bias may have occurred due to use of nonprobability (i.e., convenience) sampling.

Definition of Terms

Modified Labeling Theory

Modified labeling theory is a theory of stigma that details how individuals are stigmatized. In the theory, individuals exhibit symptoms of a disease or ailment, and once labeled, those symptoms become worse due to labeling and endorsing societal attitudes about the disease or ailment (i.e., stigma).

Quality of Life

Quality of life is a multi-dimensional concept describing individuals' physical, social, emotional, spiritual, and/or cognitive functioning (The WHOQOL Group, 1998). Quality of life is commonly linked to both health-related quality of life as well as a more general and overall well-being for individuals.

Partners

Partners in the study are individuals who are intimately or romantically connected to PCa survivors.

Prostate Cancer (PCa)

Prostate cancer is a type of cancer found in prostate glands in individuals born biologically male (Walsh & Worthington, 2012).

Prostate Cancer Survivors

Prostate cancer survivors are individuals who have had a diagnosis of PCa and are living.

Race

Race is a socially constructed designation based on physical characteristics. Difficult to operationalize, the use of the term “race” in the study is in place of commonly used terms regarding ethnicity that may not be inclusive to those assumed to be of that group (e.g., African American), yet are still effected by PCa in similar ways.

Relationship Satisfaction

Relationship satisfaction is the extent to which individuals in a relationship are satisfied with a relationship, or, “one’s subjective global evaluation of one’s relationship” (Graham, Diebels, & Barnow, 2011).

Social Exchange Theory

Social exchange theory suggests that the relationship quality that exists in couples is due to an equal balance of costs and benefits. The theory conceptualizes the quality and strain of relationships based on couples’: 1) attractions to relationships; 2) barriers to leaving relationships; 3) and attraction to alternatives.

Stigma

Stigma is a socially constructed phenomenon wherein individuals with diseases or disabilities that differ from the majority of individuals are discredited (Jones & Corrigan, 2014; Goffman, 1963).

Chapter Summary

In Chapter One, the background to the study, constructs to be measured, and methodology were discussed to assess stigma's influence on QoL and relationship satisfaction for PCa survivors and their partners. Throughout the research, the focus has been on the conceptualization and reduction of stigma, and an increase of QoL for individuals who experience stigma. Stigma of physical and mental health illnesses results in individuals suffering from an overall lower QoL than non-stigmatized individuals. Prostate cancer is a disease many men face in their lives that causes psychosocial problems for survivors and their partners. Prostate cancer does not affect everyone equally, as individuals from non-majority races suffer from the disease at much higher rates than individuals from majority races. The present study aimed to test the following research hypothesis: Stigma (as measured by the Social Impact Scale; Fife & Wright, 2000) has a negative influence on QoL (as measured by the Functional Assessment of Cancer Therapy - Prostate; Esper et al., 1997 and the Functional Assessment of Cancer Therapy – General Population; Cella et al., 1993) and relationship satisfaction (as measured by the Couples Satisfaction Index; Funk & Rogge, 2007) of PCa survivors and their partners. The present study aimed to answer the following exploratory research questions:

1. Are there statistically significant relationships between stigma (as measured by the SIS; Fife & Wright, 2000), QoL (as measured by the FACT-P; Esper et al., 1997 and the FACT-GP; Cella et al., 1993), relationship satisfaction (as measured by the CSI; Funk & Rogge, 2007) and race for PCa survivors and their partners?

2. Are there statistically significant differences in experiences of stigma (as measured by the SIS; Fife & Wright, 2000) based on demographic variables (e.g., age and income) for PCa survivors?

With the use of measures assessing stigma, relationship satisfaction, and QoL, the study aimed to examine how stigma affects PCa survivors and their partners. The use of dyadic data and SEM allowed the investigator to conduct meaningful and statistically thorough analyses of the results. There were multiple limitations to the study in gathering data from dyads and in using a correlational research design. The contributions of the study to the counseling field are numerous and aim to help counselors in supporting PCa survivors and their partners to live well.

CHAPTER TWO: REVIEW OF THE LITERATURE

Chapter Two consists of a review of the literature pertinent to the current study. Chapter Two begins with an overview of the selected constructs for the current study: (a) quality of life (QoL), (b) relationship satisfaction, and (c) stigma. In addition, racial health disparities are emphasized to illustrate how they relate to the selected constructs. Theoretical frameworks for relationship satisfaction (social exchange theory) and stigma (modified labeling theory) are also detailed to provide context for those constructs. Next, a review of the literature supports rationale to investigate the influence of stigma on QoL and relationship satisfaction for prostate cancer (PCa) survivors and their partners. Further, a literature review highlights gaps in current literature. A concluding integration of all three constructs, along with racial health disparities, illustrates how the current study fills those gaps.

Quality of Life for Cancer Survivors

Quality of life for cancer survivors is an important issue for mental health professionals wanting to provide the best care for survivors. Quality of life is a multi-dimensional concept describing individuals' physical, social, emotional, spiritual, and/or cognitive functioning (The WHOQOL Group, 1998). Quality of life is commonly linked to both health and a more general and overall well-being for individuals. For the purposes of this study, QoL refers to both health-related QoL and general QoL.

Variations in QoL depend on numerous issues including types and stages of cancer (Torvinen et al., 2013), physical symptoms (Kopp et al., 2013), and psychosocial factors such as relationship satisfaction (Segrin et al., 2012). Relationship satisfaction is a positive factor in

increasing QoL, whereas stigma has negative effects (Cataldo, Jahan, & Pongquan, 2012). The aim of the current study is to examine the relationships between QoL, relationship satisfaction, and stigma for PCa survivors and their partners. In addition, the investigator aims to examine how race and other demographic variables influence QoL, relationship satisfaction, and stigma. The following sections detail the background and empirical foundations of QoL, relationship satisfaction, and stigma.

Background on Quality of Life for Prostate Cancer Survivors

Cancer researchers (Bottomley, 2002; Farkkila et al., 2014; Pasetto et al., 2007) often focus on QoL for cancer survivors and individuals with whom they have immediate contact (Salonen, Kellokumpu-Lehtinen, Huhtala, & Kaunonen, 2014). Quality of life is an important construct to measure in order for healthcare workers to maximize the well-being of cancer survivors (Schirm, 2006). The focus of the current study is partially to investigate the influence of stigma on QoL for PCa survivors and their partners.

Prostate cancer, a type of cancer found only in men or individuals born biologically male, is the leading cancer for men in incidence and the second leading cancer for men in mortality (Walsh & Worthington, 2012). The investigator recognizes that PCa can affect individuals who do not identify as male but were born biologically male (e.g., transgender individuals). For the purposes of the current study, the terms “males” or “men” are used for ease and clarity of language, while remaining aware that PCa can affect individuals who do not identify as “males” or “men.”

Risk factors for PCa include age and race (Walsh & Worthington, 2012). There is a direct relationship between age and enlarged prostates, with PCa affecting one in seven men by the age of 70. PCa also tends to affect Black men at much higher rates than White men (Taksler et al., 2012), with Black men having a 78% higher incidence rate. Depending on contextual issues like age at diagnosis and metastasis, PCa can be a life threatening and debilitating disease with numerous effects on QoL (Vanagas, Mickeviciene, & Ulys, 2013). However, mortality rates are decreasing due to advances in PCa treatment (NCI, 2011), meaning both that fewer men are dying from PCa, but also that more men continue to live with PCa.

Quality of life for PCa survivors has been researched for nearly 35 years (Leibel, Pino y Torres, & Order, 1980). Symptoms and treatments of PCa can cause problems that other cancers do not, such as incontinence, blood in urine, and loss of sexual desire (Walsh & Worthington, 2012). Symptoms and treatments of PCa establish QoL as a unique concern compared to survivors of other cancers. The problems that PCa causes manifest in psychological effects on survivors in other types of cancers (Maliski et al., 2008). To illustrate the ways in which PCa can affect QoL, the empirical research is explored with emphases on diagnosis, treatment, and biological impacts on QoL (e.g., age); emotional and cognitive impacts on QoL (e.g., sadness); and issues that could contribute to affected QoL (e.g., masculine identity).

Quality of Life for Prostate Cancer Survivors

The empirical research on QoL for PCa survivors details the overall effects, including physical, functional, emotional, and social impairments. Researchers demonstrate that PCa survivors have lower QoL as compared to the general population (Zenger et al., 2010). In a 2010

study, Zenger and colleagues investigated relationships between QoL and distress in PCa patients ($n = 265$) and the general population ($n = 444$). Results indicated that PCa survivors had lower QoL in emotional and social domains, with increased physical symptoms (e.g., insomnia, constipation, and diarrhea) and financial difficulty. Limitations of the study included an international sample (with limited generalizability to the U.S. population), a lack of reported effect size, and use of a cancer-specific QoL measure, which may have made the scale invalid for a general population without cancer diagnoses.

Torvinen and colleagues (2013) examined differences between QoL for PCa survivors in multiple stages of the disease ($N = 522$) and with the general population. Contrary to Zenger et al.'s findings (2010), PCa survivors in more severe disease stages (e.g., metastatic disease and palliative care) were the only groups that experienced significantly decreased QoL ($R^2 = .49$ to $.71$) compared to the general population (Torvinen et al., 2013). Interestingly, PCa survivors in less severe disease stages had higher QoL than the general population, but scores decreased the longer they had the disease, with those in palliative care having the lowest scores across all measures. Limitations of the study included an international samples (with limited generalizability to the U.S. population), use of cancer-specific assessments which may not be valid for a general population, and limited descriptions of demographic characteristics of the samples. Torvinen and colleagues' results provide researchers with contrary data to previous findings, suggesting that PCa survivors in early stages may have QoL levels comparable to the general population and also that QoL decreases as exposure to the disease increases and the disease spreads.

Vanagas, Mickeviciene, and Ulys (2013) conducted a study on QoL for PCa survivors ($N = 514$) controlling for stage of disease and treatment. Similar to the findings of Zenger et al. (2010), Vanagas and colleagues (2013) found QoL was most affected in emotional and social functioning, being the only statistically significant areas that differed by disease stage. Prostate cancer survivors in stage IV had the lowest QoL compared to survivors in earlier disease stages. In regards to PCa treatment, there were significant differences for physical, role, emotional, and social functioning areas of QoL. Prostate cancer survivors undergoing chemotherapy treatment had the lowest QoL. Limitations for the study include lack of a reported effect size, use of an international sample that may limit generalizability, and large differences in disease stage samples; however, results from the study further support that QoL for PCa survivors differs by disease stage, and that treatment affects survivors.

Focusing on treatment for PCa, Chipperfield and colleagues (2013) studied the effects of androgen deprivation therapy (ADT) on depression, anxiety and QoL for PCa survivors ($N = 377$). Androgen deprivation therapy lowers the amount of testosterone produced in men's bodies in order to shrink the prostate. The study found that PCa survivors with longer treatment had the lowest QoL and highest level of depression in their sample ($R^2 = .2$). Chipperfield and colleagues note that ADT impacts physical and sexual functioning, including vitality, energy, and fatigue, leading to lower QoL. Limitations for the study include an international sample that may limit generalizability and a lack of demographic descriptors of participants. The study sheds a continued light on how not only PCa affects survivors, but also how treatment affects them.

Characteristics such as age can also contribute to QoL for PCa survivors. Diefenbach, Mohamed, Horwitz, and Pollack (2008) conducted a longitudinal investigation to examine how

age moderates relationships between distress, regret, worry, subjective life expectancy, and QoL for PCa survivors ($N = 391$). Predictor variables significantly predicted changes in each component of QoL. Age was a moderator variable between the predictor variables and QoL: younger PCa survivors had stronger relationships between the predictor variables and QoL (model explained 20% variance of functional well-being, 31% variance of emotional well-being, 10% variance of social well-being, and 18% of physical well-being) as compared to older survivors (model explained 13% variance of functional well-being, 40% variance of emotional well-being, 10% variance in social well-being, and 15% variance of physical well-being). The results of the study show that distress, regret, worry, and subjective life expectancy have stronger and more detrimental relationships with QoL for younger PCa survivors. Limitations to the study include a lack of diversity based on race, disease stages, and treatment. Diefenbach and colleagues' study provides researchers with knowledge that younger PCa survivors are at risk for lower QoL as compared to older survivors soon after early-stage diagnosis, leading to inferences about functionality in younger age compared to older age (e.g., sexual issues).

Based on the results of PCa studies (Diefenbach et al., 2008), one can infer that older PCa survivors face less emotional distress and better QoL as compared to younger PCa survivors. Nelson and colleagues (2009) examined emotional indicators of QoL to understand differences between older and younger PCa survivors ($N = 716$). The results of the study indicated that older PCa survivors experienced lower distress, lower anxiety, and higher scores in emotional QoL, but also experienced greater depression ($R^2 = .03 - .05$). Contrary to previous evidence and the general knowledge of relationships between anxiety and depression, older PCa survivors experienced higher QoL, yet had higher scores for depression as compared to younger PCa

survivors. Thus, emotional QoL and psychological issues are dependent upon age for many PCa survivors, but no age range is without significant emotional and psychological issues.

Limitations for the study include a lack of racial diversity in the sample and limited generalizability due to a cross-sectional design. Nelson and colleagues show that emotional and psychological issues are of concern to PCa survivors at any age.

The review of the previous six empirical articles highlight a need to examine QoL for PCa survivors. QoL for PCa survivors is significantly different from the general population (Zenger et al., 2010), decreases with exposure to the disease (Torvinen et al., 2013), and decreases by age, stage, and treatment (Chipperfield et al., 2013; Diefenbach et al., 2008; Nelson et al., 2009; Vanagas et al., 2013).

Psychosocial issues associated with prostate cancer

Various psychosocial issues affect PCa survivors, ranging from depression (Jayadevappa et al., 2012) to body image issues (Taylor-Ford et al., 2013). Social support is one area that is affected by PCa throughout multiple studies (Zenger et al., 2010). Zhou and colleagues (2010) conducted a study on how perceived stress mediated the effects of social support on QoL for PCa survivors ($N = 175$) treated for localized PCa. At two-year follow up, PCa survivors with strong social support had higher QoL than those with weak social support. In addition, perceived stress mediated relationships between social support and QoL. Zhou and colleagues reported several limitations to their study, including a sample with higher QoL compared to the general population, not including individuals with psychological impairments, and a lack of reported

effect size. The study demonstrated that a commonly known finding – that social support increases QoL – also applies to PCa survivors.

Other psychological factors, like body image, can also predict QoL for PCa survivors. In a sample of PCa survivors ($N = 74$), Taylor-Ford and colleagues (2013) found that changes in body image before treatment, to two years following treatment completion, predicted changes in QoL ($R^2 = .5$). Body image was hypothesized to predict changes in QoL as PCa treatment can often leave changes in a person's body (e.g., scars and gynecomastia). The researchers found that body image explained 11% of variance in QoL. Taylor-Ford and colleagues' study included several limitations, including racial homogeneity of the sample and psychometric issues with their body image measure. The findings of the study shed light on body image and masculinity issues found in PCa and treatment (Maliski et al., 2008).

Many researchers (Bill-Axelson et al., 2010; Jayadevappa et al., 2012) have found that some psychosocial issues impact and influence PCa survivors' lives by using measure-related constructs, such as depression or suicidality. Depression is an indicator of poor QoL, as evidenced by inclusion of items related to low-moods and sadness on multiple QoL measures (Aaronson et al., 1993; Cella et al., 1993). Numerous researchers have conducted studies on the relationship between PCa and depression (Bennett & Badger, 2005; Pirl, Greer, Goode, & Smith, 2008).

Jayadevappa and colleagues (2012) investigated the prevalence of depression in PCa survivors ($N = 50,147$). The researchers found that 8.5% of their sample had a diagnosis of depression either during or following PCa treatment. Further, PCa survivors with a diagnosis of depression had more hospital visits ($OR = 1.71 - 4.45$), longer hospital visits ($OR = 3.22$), and

spent more on medical care as compared to those without depression. Further, PCa survivors with depression had higher mortality rates ($HR = 2.06$). Limitations in the study include lack of diversity in race and age, as well as minimal clinical indicators of depression. Jayadevappa and colleagues show in their study that depression is a major burden for PCa survivors. Not only do 8.5% of PCa survivors face depression and the symptoms of depression, but also increased financial and health burdens as compared to those without depression.

Similar to Nelson and colleagues (2009), Bill-Axelsson and colleagues (2010) found in a Swedish population of PCa survivors ($N = 77,439$) that suicidality was linked to PCa ($n = 128$) for older survivors and those with greater severity of disease. Suicide incidence for PCa survivors was higher for those with advanced local and metastatic disease. In addition, suicide incidence was higher for those with higher Gleason scores and prostate-specific antigen levels, two indicators of PCa severity. A limitation for this study includes the use of an international sample that may limit generalizability, and lack of a reported effect size. The population-based study provides more information about suicidality for PCa survivors, specifically those with later-staged disease. It displays a need to increase QoL for those in later-staged disease to decrease suicidality.

In examining QoL for PCa survivors it is apparent they tend to have lower QoL, compared to the general population, due to a variety of disease-related and psychosocial issues. Although studies produce mixed findings about the QoL of PCa survivors, overall the results of empirical studies point to a need to address and improve it. Previous studies also indicate that psychological and psychosocial issues affect QoL, primarily the emotional and social domains. They also indicate the use of mental health services may increase QoL for PCa survivors.

However, one imperative psychosocial issue has not been discussed in how it affects QoL for PCa survivors: relationship satisfaction.

Researchers (Segrin et al., 2012; Zhou et al., 2011) have found that both PCa survivors and their partners are affected by the disease. Further, partners and family members of PCa survivors help survivors cope with disease-related stressors (Jones et al., 2008). For PCa survivors in romantic relationships, the struggles of their disease also fall onto their partners, whether due to caregiving activities, or watching their partner suffer while experiencing the disease and treatment. For PCa survivors in relationships, studying the QoL for only survivors is not sufficient to understand how the disease effects QoL. The study of both PCa survivors and their partners better illustrates how the disease effects individuals.

Relationship Satisfaction and Prostate Cancer

Quality of life for PCa survivors is interrelated with QoL for their partners (Merz et al., 2011; Segrin et al., 2012). Partners of PCa survivors often act as caregivers for their partners (Harden et al., 2013; Zhou et al., 2011). Partners experience psychological and societal effects of their partner's PCa diagnosis, whether they fill roles of caregivers or just as partners (Fergus, 2011). PCa is a "relationship disease" which affects the individual and the relationships between individuals, causing possible problems in relationships (Gray et al., 1999; Lafaye et al., 2014). Relationships can also effect QoL (Merz et al., 2011).

Theoretical Framework: Social Exchange Theory

To conceptualize relationship satisfaction for PCa survivors and their partners, social exchange theory (Levinger, 1965; 1976) helps illustrate the issues the disease can cause. As

Segrin and colleagues (2012) illustrate in their findings, the strains of PCa symptoms predict the QoL of partners, and the QoL of their partners predicts and mediates changes in QoL for survivors. The burden of PCa on survivors and their partners can cause the attractions to the relationship to weaken (e.g., decreased sexual satisfaction). The burden of PCa also increases the barriers to leaving the relationship (e.g., perception of leaving a person with a chronic illness), creating issues for couples. Lewis and Spanier (1982) qualify this type of relationship as unsatisfied but stable. Alternatively, attraction and barriers to leaving relationships could remain high for couples who have built strong ties throughout their relationship, resulting in satisfied and stable relationships. Banthia and colleagues (2003) found that relational issues lead to distress for both PCa survivors and their partners, and other researchers (McCubbin & Patterson, 1982) qualify the disease as a crisis for couples. How couples cope with PCa effects relationship satisfaction (Fergus, 2011) and has influence on QoL for survivors and their partners.

Relationship Satisfaction for Prostate Cancer Survivors and Their Partners

The effects of PCa on couples is vast and is evidenced in numerous studies. In order to truly understand the struggles PCa provides, researchers must consider the impact of the disease on partners of survivors (Couper, 2007). Much of the current PCa couples research shows they are both affected by the disease, and relationship satisfaction worsens when the disease is present.

Couper and colleagues (2006) conducted one of the earliest investigations of the impact of PCa on survivors and their partners ($N = 103$). In their sample, the researchers found that distress and relationship satisfaction did not differ for those diagnosed with localized PCa or

metastatic PCa. At the time of diagnosis, partners of PCa survivors were significantly more distressed, depressed, and anxious than PCa survivors. In a six-month follow-up, partners' distress decreased while PCa survivors' distress increased, leading to no overall differences in distress between survivors and their partners. In addition, relationship satisfaction declined after diagnosis for partners, but not for PCa survivors. PCa associated with lower relationship satisfaction in partners at the six-month follow-up. The study suggest PCa affects both survivors and their partners. Limitations to the study include use of an international sample, limiting the sample to couples not experiencing a chronic illness, lack of diversity of cancer care, and lack of a reported effect size. The findings of the study demonstrate the impact that PCa causes on survivors and their partners, making the disease a legitimate concern for them.

Not only does PCa affect survivors and their partners, but the QoL of both partners tends to change at similar rates. Segrin and colleagues (2012) conducted a study on PCa survivors and their partners ($N = 70$). Partners in this study referred to a close person in the PCa survivors' social network, with 83% being intimate partners. The purpose of the research was to investigate psychological QoL, as defined by measures of depression, anxiety, fatigue, and positive affect. Segrin and colleagues found that QoL for survivors predicted their partners' results after controlling for survivors' QoL in depression ($T2 R^2 = .45$, $T3 R^2 = .48$), anxiety ($T2 R^2 = .19$, $T3 R^2 = .43$), and positive affect ($T2 R^2 = .19$, $T3 R^2 = .44$). At different points in the study, partner QoL predicted PCa survivors' levels of depression ($T2 R^2 = .54$, $T3 R^2 = .63$), anxiety ($T2 R^2 = .65$, $T3 R^2 = .63$), and positive affect ($T2 R^2 = .57$, $T3 R^2 = .6$), establishing that QoL is interdependent between survivors and their partners over time. In addition, partner QoL mediated the effects of PCa survivors' levels of depression ($R^2 = .06$) and anxiety ($R^2 = .01$). Limitations to

the study include a lack of racial and educational diversity, and complications generalizing the results to beyond just intimate partners. The study demonstrates the interdependence of QoL for PCa survivors and their partners; through various means, the QoL of one partner relies on the other in the relationship. Thus, to examine the QoL of partnered PCa survivors, researchers must examine the QoL of their partners to understand how the disease affects QoL.

Similar to Segrin and colleagues' study (2012), Song and colleagues (2011) found that PCa survivors' and partners' ($N = 134$) QoL tend to have small to moderate correlations, longitudinally. Further, couples' lower QoL was associated with lower social support, lower open dyadic communication, advanced disease stage, higher general symptoms, increased PCa symptoms, and higher uncertainty about the disease. Throughout the study, PCa survivors' QoL was consistently higher than their partners. Limitations to the study include lack of racial and economic diversity, changes in sample size throughout data collection, lack of treatment information, and lack of reported effect size. These findings further solidify the idea that PCa is a "couple's disease" (Gray et al., 1999).

As seen in PCa survivors (Torvinen et al., 2013; Vanagas et al., 2013), QoL for partners also differs based on disease stage and related issues. Northouse and colleagues (2007) studied PCa survivors and their partners ($N = 263$) to understand how disease stage affects couples. Overall QoL was lower in advanced stages of PCa for survivors and their partners as compared to newly diagnosed survivors and their partners. This applied to every QoL subscale except the social subscale. Prostate cancer survivors and their partners differed on physical and emotional subscales of QoL, with survivors experiencing more physical troubles and their partners experiencing more emotional troubles. Newly-diagnosed PCa survivors and their partners rated

more positive appraisal of illness, positive appraisal of caregiving, less uncertainty, and less hopelessness compared to the other two stages of disease studied. Self-efficacy was higher in newly-diagnosed PCa survivors and their partners, but partners had less self-efficacy than survivors regardless of disease stage. Limitations of the study include lack of diversity in race and disease stage, and lack of reported effect size. The findings of Northouse and colleagues point to inferences that PCa survivors and their partners are more similar than different, with disease stage indicating more differences in QoL, risk for distress, and appraisal of illness than differences between survivors and their partners.

Several demographic factors influence the experiences of PCa survivors and their partners. For example, similar to previous findings (Diefenbach et al., 2008; Nelson et al., 2009), age is a predictor of QoL for PCa survivors and their partners (Harden et al., 2008). Harden and colleagues studied the influence of age on PCa survivors and their partners ($N = 69$), splitting ages between late middle age (50-64), young-old (65-74), and old-old (75-84). The researchers found that PCa survivors in the late middle age and old-old groups tended to have worse QoL, less self-efficacy, and more perceived effects of the disease on them as compared to the young-old group. For partners, those in the late middle age and old-old groups experienced more effects of the disease through sexual and hormonal symptoms with PCa survivors than did those in the young-old group. Sexual bother due to PCa was found to be an issue for partners, but not PCa survivors. Limitations to the study include use of a convenient and non-diverse sample across socio-economic status, race, and education, as well as a lack of reported effect size. Harden and colleagues found that the experiences of partners do not change as much as PCa survivors

throughout time, but that the disease does affect differently aged PCa survivors and their partners in different ways.

Couples-based issues exacerbated by prostate cancer

In addition to demographic factors that contribute to QoL for PCa survivors and their partners, couples-based issues can also contribute to problems and varying QoL. In a qualitative study, Boehmer and Clark (2001) found that survivors with metastatic PCa ($n = 20$) and partners ($n = 7$) discussed little about emotions, worries, and fears related to the disease. Manne et al. (2010) found that when PCa couples ($N = 75$) communicated in relationship-enhancing ways (constructive communication), intimacy increased and levels of distress decreased ($R^2 = .28$). Relationship-compromising communication (avoidance) predicted lower levels of intimacy and higher levels of distress. Badr and Carmack Taylor (2009) found that as PCa symptoms arose for couples ($N = 116$), communication decreased, which was then linked to an increase in marital distress for partners ($R^2 = .04$). Communication was also related to poorer marital adjustment and greater sexual dissatisfaction ($R^2 = .04$). Song and colleagues (2012) conducted a longitudinal study on communication patterns between PCa survivors and their partners ($N = 134$). They found that open communication increased as time passed, with those with localized PCa had the lowest amount of open communication. Further, couples' communication increased as social support increased, uncertainty decreased, and hormonal symptoms reduced. In these studies, common limitations affect their results (e.g., lack of racial diversity or lack of reported effect size). However, the results of these studies indicate that communication within PCa couples is

related to the well-being and QoL of couples (Song et al., 2011), and relationship issues can also cause negative effects on survivors and their partners.

Differences between PCa survivors and their partners can affect QoL. Merz and colleagues (2011) studied dyadic concordance on issues related to PCa (e.g., urinary, bowel, and sexual problems) and QoL for survivors and their partners ($N = 164$). Overall, disagreement predicted lower PCa survivor QoL. Minimization and maximization of PCa symptoms affected QoL for survivors ($R^2 = .01 - .19$), while maximization of symptoms affected QoL for partners ($R^2 = .03 - .1$). The largest disagreement existed between PCa survivors and their partners for sexual bother, with partners minimizing the effects of sexual bother on survivors, yet disagreement on sexual bother did not predict QoL. Limitations to the study include lack of racial diversity and small ranges of QoL and marital adjustment scores. Merz and colleagues demonstrated that disagreements about PCa within couples can cause changes in QoL for both partners.

Ezer, Chachamovich, and Chachamovich (2011) examined differences in psychosocial adjustment within PCa couples ($N = 81$). Overtime, there were significant differences between PCa survivors and their partners in perception of health care (T1 $d = .32$, T2 $d = .22$), sexual relationships (T2 $d = .5$, T3 $d = .24$), social environment (T1 $d = .26$), and psychological distress (T1 $d = .56$, T2 $d = .28$, and T3 $d = .39$). Of particular importance, sexual relationships and psychological distress differed significantly at six-month and 12-month follow-ups. The researchers found that PCa survivors were more distressed sexually and psychologically than their partners. In further analyses, mood disturbance, urinary and sexual bother, social support, and coherence within the couple accounted for 63% of variance in psychological distress.

Limitations to the study include a declining sample size over time, an international sample, and a lack of available demographic data important to PCa research, such as race and socio-economic status. Ezer and colleagues' findings identify sexual relationships and psychological distress as areas of incongruence between couples, which can lead to lower QoL (Merz et al., 2011). These findings highlight that deteriorating sexual relationships is an issue concerning masculine identity, echoing findings of other studies (Burns & Mahalik, 2008; Campbell et al., 2012; Jenkins et al., 2004).

In addition to the mutual experiences of PCa survivors and their partners, the actions and beliefs of individuals within couples can cause changes in their partners. Zhou and colleagues (2011) investigated marital satisfaction, mental, and physical health for advanced disease-stage PCa survivors and their partners ($N = 29$). The researchers found that PCa survivors' mental and physical health predicted their ($\beta = .79, .64$) and their partners' marital satisfaction ($\beta = .33, .28$), but that partners' mental and physical health predicted only their own marital satisfaction ($\beta = .43, .67$). Zhou and colleagues found that the marital satisfaction of PCa couples can be predicted by survivors' mental and physical health, indicating the importance that both partners place on the survivors' health to increase marital satisfaction. Limitations to the study include a small and non-generalizable sample.

In a study on coping strategies for PCa couples ($N = 99$), Lafaye and colleagues (2014) found that coping by each partner affects the other. For PCa survivors, problem-focused coping and social support coping predicted their and their partners' lowered anxiety and depressive symptoms and increased QoL. However, partners' problem-focused coping predicted increased anxiety for themselves and lowered QoL in PCa survivors. Social support coping by partners

predicted their own lowered anxiety levels, lowered depressive symptoms, and increased QoL, but also predicted increased anxiety levels for PCa survivors. These mixed results raise questions about the effects of coping on PCa couples.

However, Regan and colleagues (2014) found different results for dyadic coping in PCa couples ($N = 42$). In their study, they found that supportive dyadic coping by each partner predicted lower anxiety and depression for the other partner, but not themselves. Further, perceptions about each other's involvement in supportive dyadic coping influenced their respective scores on relationship satisfaction. Negative dyadic coping was found to negatively influence anxiety, depression, and relationship satisfaction. The outcomes of these two studies indicate the coping strategies of each partner affects themselves and their partners. Dyadic coping tends to have more consistent and less-mixed results as compared to singular coping (Lafaye et al., 2014). Limitations to these studies (Lafaye et al., 2014; Regan et al., 2014) include limited sample size, lack of reported effect size, and reported selection bias.

Other researchers (Fagundes, Berg, & Wiebe, 2012; Soloway, Soloway, Kim, & Kava, 2005) have shown that PCa survivors and their partners tend to be more similar to one another (intradically) than other couples (interdyadically) in how the disease affects them. To examine differences between couples, researchers should include the experiences of couples of non-majority races (Black and Latino) that are not sufficiently represented in PCa research (Parahoo et al., 2013). Both racial minority individuals and couples experience PCa differently than racial majority (e.g., White) individuals and couples. The next section examines the available research concerning racial disparities, QoL, and relationship satisfaction for PCa survivors and their partners.

Racial Disparities, Quality of Life, and Relationship Satisfaction

Black men receive PCa diagnoses at a rate 76% higher than White men (Taksler et al., 2012). Further, mortality is nearly 50% higher in Black men as compared to White men (NCI, 2011). While Black men have the highest incidence and mortality rates of any racial group with PCa, there are cultural concerns that should be explored in research on the disease (Penedo et al., 2006). In reviewing the extant literature for the present study, the investigator found that a majority of PCa research focusing on racial and ethnic issues focused on differences between Black and White survivors, whereas few examined the experiences of Hispanic or Asian survivors (Namiki et al., 2011; Penedo et al., 2006). In addressing the racial disparities in PCa, it is necessary to address the concerns of Black survivors as well as White survivors. Not including the perspectives and experiences of Black men with the disease is the equivalent of withholding information about a group that experiences the disease more than any other group. This study will include an examination of racial issues and health disparities in PCa stigma and QoL, as well as the influences of those issues on partners.

Despite the contributions of the previously reviewed studies, a consistent limitation in PCa research is a lack of racial diversity in samples. The following review of literature will emphasize the racial disparities existing in PCa, QoL, and QoL-related issues in the extant literature. Considering the alarming rate at which Black individuals are diagnosed with PCa (Taksler et al., 2012), the review reflects this in a focus on the concerns of Black PCa survivors.

Taksler and colleagues (2012) examined differences in PCa mortality between Black ($n = 6,899$) and White ($n = 70,139$) survivors. The researchers found that PCa risk and incidence was higher for Black survivors than White survivors at all disease stages. For local and regional PCa,

mortality was 24% greater for Black survivors than White survivors. Treatment and socioeconomic status contributed to the racial gap in PCa mortality, with tumor characteristics accounting for the largest portion of the racial gap. Limitations to the study include a lack of diversity in age, lack of knowledge of other illness factors, and not measuring tumor aggressiveness. Taksler and colleagues demonstrate the wide gap in incidence and mortality across disease stages between Black and White PCa survivors. Other researchers have also indicated racial disparities between Black and White PCa survivors in the area of perceived access to care, both in physician bias, and with financial issues (DiIorio et al., 2011).

In exploring Asian populations more closely, Robbins, Koppie, Gomez, Parikh-Patel, and Mills (2007) found that the majority of Asian individuals recently immigrated to the US (those from China, the Philippines, Japan, Korea, and Vietnam) had equal survival rates when compared with White individuals ($N = 116,916$) ($HR = 0.66 - 0.94$). However, South Asian sample (those from India, Pakistan, Bangladesh, Sri Lanka, Nepal, and Bhutan) tended to have lower overall survival rates when compared with other Asian samples and White samples ($HR = 1.4$). Limitations to the study include lack of information regarding Gleason scores and PSA levels, as well as possible misclassification of race. In addition to incidence and mortality, health disparities take a toll on QoL issues for racial and ethnic minority PCa survivors.

Penedo and colleagues (2006) investigated race and other determinants of QoL for PCa survivors ($N = 204$) after disease treatment. Penedo and colleagues examined White ($n = 85$), Black ($n = 37$), and Hispanic ($n = 82$) PCa survivors. Results indicated that Black and Hispanic PCa survivors experienced lower QoL as compared to White survivors. Race accounted for 11% of total variance in predicting QoL for PCa survivors in the study. Penedo and colleagues

concluded that differences in QoL between White and Black PCa survivors were accounted for by other variables (e.g., sleep functioning), while differences between White and Hispanic survivors remained through the full analysis. Limitations for the study include an 18-month window after treatment to participate in the study and limited sampling to those with localized PCa. Penedo and colleagues provide important information for how different races experience PCa and how their QoL is affected.

Black and White PCa survivors tend to view the disease differently. DiIorio and colleagues (2011) studied treatment-based beliefs and coping between Black and White PCa survivors ($N = 320$). In addition to the larger financial difficulties that Black PCa survivors faced compared to White survivors, Black survivors were 12 times more likely to think doctors treated White survivors better ($R^2 = .16$). Limitations to the study include a sample from a small geographical area and issues in analyzing secondary data. The findings of DiIorio and colleagues illustrate common ideas in racial health disparities relating to unfair financial burden based on race. Similar to previous studies (Halbert et al., 2010), there is a theme of racial discrimination and mistrust in healthcare settings for Black PCa survivors, creating racial health disparities. With a higher incidence rate than White PCa survivors (Taksler et al., 2012) and a mistrust of medical treatment (DiIorio et al., 2011; Halbert et al., 2010), Black survivors are at a disadvantage in disease care. In addition to the racial health disparities issues discussed so far, the general experiences of Black and White PCa survivors tend to differ.

There are some cultural issues that have not been examined that could lead to psychosocial problems and lead to decreased QoL, such as stigma. Stigma is addressed in the third section of this literature review, but a brief review of cultural issues provides rationale for

how the current research on QoL does not provide a comprehensive view on QoL for survivors who are racial minorities.

Pedersen, Armes, and Ream (2012) conducted a systematic review of literature on perceptions of PCa for Black men ($k = 33$). Pedersen and colleagues' review aimed to identify themes across studies that inhibit PCa screening. One of their major consistent findings can inform how the disease affects Black survivors differently than White survivors: screening and treatment of PCa was seen as a threat to masculinity. Threats to masculinity include fear of erectile dysfunction, loss of sex drive, and sterility. The theme of masculine identity arose in 12 of the 33 studies reviewed, which indicated it was a prevalent issue for Black PCa survivors. A closer look at masculinity and sexuality in Black PCa survivors provides detail of how cultural variables can affect survivors.

Sexual functioning issues related to PCa and treatment affect most survivors regardless of race or ethnicity. Jenkins and colleagues (2004) examined the role of sexuality and its relationship to QoL in PCa survivors treated for localized disease ($N = 1230$). The researchers found that Black PCa survivors had lower physical health, mental health, and were more likely to report problems with sexual desire, as compared to White survivors. Jenkins and colleagues indicated there was a significant correlation between Black PCa survivors' importance of erection score and self-perception of being powerful and aggressive on a measure of sexual self-schema ($R^2 = .17$), which led the authors to conclude there was a connection between Black survivors' self-concept and ability to maintain erections for sexual activity. The findings indicate sexual functioning and sexual identity are more important to Black PCa survivors than White survivors. Because PCa and its treatment cause many sexual issues (Walsh & Worthington,

2012), PCa can be a particularly debilitating disease for Black survivors' sexuality. One limitation of the study is a lack of racial and disease-stage diversity in the sample. Overall, the findings of the study provide culturally relevant conclusions about sexual functioning for PCa survivors, and how they affect QoL.

Extending the findings of Jenkins and colleagues (2004), Campbell, Keefe, McKee, Waters, and Moul (2012) examined masculinity beliefs' influence on psychosocial functioning for Black PCa survivors ($N = 59$). They found that holding traditional masculine identities predicted higher depressed moods ($R^2 = .18$) and tension scores ($R^2 = .17$), and lower functional ($R^2 = .16$) and social ($R^2 = .27$) well-being for Black PCa survivors. The study had limitations, including a small sample size and psychometric issues with the authors' chosen measures (e.g., weak internal consistency). The majority of the findings reflect those of other authors (Burns & Mahalik, 2008; Jenkins et al., 2004) about the important effect of sexuality and masculinity affecting QoL for PCa survivors. In addition to individual PCa concerns, racial minority survivors' relationships can also be affected. Racial minority couples are affected by similar relational issues racial majority PCa survivors and their partners, as well as race and ethnicity-specific concerns which will now be detailed.

The influence of racial disparities on PCa couples' relationship satisfaction is a growing area of study (Parahoo et al., 2013). Nonetheless, it is still very small compared to the number of studies focused on couples without specific attention to race. In this growing body of literature, the largest focus has been on Black PCa couples, partially due to the increased incidence and mortality previously discussed (Taksler et al., 2012; NCI, 2011). Thus, in the following review of literature on racial disparities in PCa and relationship satisfaction, the majority of studies

reviewed pertain to Black couples. Couples of other racial minorities are rarely discussed in extant literature, but a pertinent study is included in the following section.

Rivers and colleagues (2012) conducted a qualitative study on psychosocial issues on Black PCa couples ($N = 12$). Couples reported feeling fear, anxiety, and stress about PCa metastasis and mortality. Prostate cancer survivors reported wanting to distance themselves from their partners, whereas their partners wanted to open up communication with survivors. Both felt their communication suffered because of the disease. Social support was also an important topic for both partners, as they sought support from family and community members. However, some community members treated PCa survivors differently, causing social isolation of survivors. Overall, survivors reported feeling that impaired sexual functioning was the most detrimental issue related to PCa, and it was linked to their ideas about masculinity. Survivors with supportive partners did not report this same trend in the study. Survivors also reported feelings of depression and self-consciousness related to sexual dysfunction, incontinence, and fatigue, whereas their partners reported changes in overall emotional well-being changes. Limitations to the study include a lack of information on qualitative framework, data analysis guidelines, and measures to ensure trustworthiness. Rivers and colleagues' study helps highlight the unique challenges some Black PCa couples experience.

As found in previous literature (Boehmer and Clark, 2000; Badr & Carmack Taylor, 2009; Manne, Badr, Zaider, Nelson, & Kissane, 2010; Song et al., 2012), communication within PCa couples is important. In one study, Friedman, Thomas, Owens, and Hebert (2012) interviewed Black PCa survivors ($n = 43$) and their partners or female relatives ($n = 38$) on issues of communication. Friedman and colleagues found Black PCa couples have varying levels of

comfort about discussing the disease; the barriers to discussing it related to fear and shame of the disease and its effects (e.g., impotence). Limitations to the study include using a mix of intimate partners and female relatives and only one type of data collection.

The research that does exist points to specific cultural issues that impact the lives of Black PCa couples, including sexual functioning, masculinity, and a cautiousness to discuss these matters within couples. Research concerning other racial minority couples is even more limited. To summarize, the QoL for PCa survivors and their partners is a complex issue. The QoL of both partners is interdependent (Segrin et al., 2012), yet communication issues and disagreement about PCa can cause problems (Badr & Carmack Taylor, 2009; Manne et al., 2010; Merz et al., 2011; Song et al., 2012).

The impact of PCa affects not only survivors, but their partners as well. Issues that affect couples can be magnified in Black or other racial minority PCa couples (Jones et al., 2004). With PCa causing a strain on individuals and relationships (Couper, 2007), some factors can predict the severity of strain, such as the stage and treatments of the disease. One construct that has not been thoroughly measured in PCa literature is stigma, which may be related to strain caused by the disease, both individually and in couples. Due to fear experienced by survivors and partners (Pedersen et al., 2012), the effects of the disease (Torvinen et al., 2013), and treatment of the disease (Vanagas et al., 2013), PCa causes a burden in peoples' lives, and stigma could be a contributor to that burden.

Stigma of Diseases

Researchers have been studying stigma and stigma of diseases for a number of years (Ablon, 2002; Jones & Corrigan, 2014). Some (Link & Phelan, 2001) have also discussed how to conceptualize and define stigma. Stigma is an intriguing and multi-faceted construct; in discussing it, it is beneficial to follow a conceptual framework and define what types of stigma are examined. For the purposes of the current study, modified labeling theory helps to conceptualize stigma (Link et al., 1989), and two types of stigma are highlighted: social stigma and self-stigma. Further, clarifications between related constructs, such as prejudice and discrimination, are made.

Theoretical Framework: Modified Labeling Theory

Modified labeling theory (Link et al., 1989) is a common theoretical framework for understanding stigma. Originally conceptualized to understand how stigma affects those with mental health disorders, the concepts aligned with modified labeling theory apply to individuals experiencing disease stigma. First, individuals are born with or develop an identity that has no intrinsic value, but does have a societal value. An identity that relates to a disease or disability (e.g., development of PCa) is seen as less valuable in society than what could be considered a normal identity (e.g., free of disease). Second, information is gathered about different stigmatized identities. Individuals who may one day be diagnosed with PCa discover information about the disease from a variety of sources, including media representations of PCa survivors who are incontinent, and stigma is attached to the disease (e.g., all PCa survivors have to wear diapers). Third, individuals are made aware of their own stigmatized identity through diagnosis.

The fear of possibly being aware of their own stigmatized identity can manifest in label avoidance, or not seeking screening or treatment for a disease. Fourth, individuals assume societal information targets them in regards to their stigmatized identity. Prostate cancer survivors at this point understand their own stigmatizing beliefs and many assume the larger society has those same opinions. Fifth, individuals have possible experiences of stigmatization. Receiving pity due to PCa diagnosis, or jokes made about decline in sexual functioning, can be experiences of stigmatization for survivors. Sixth, individuals internalize social stigma and develop self-stigma (Vogel et al., 2013). Eventually, the stigma experienced or assumed becomes internalized, making stigma a belief existing both internally and externally, rather than only externally.

Definitions of Stigma

Social stigma

Social stigma, sometimes known as public stigma, is the alleged societal discrimination toward individuals with stigmatizing identities and is more widely studied than self-stigma (Jones & Corrigan, 2014). Social stigma is alleged societal discrimination. Social stigma is alleged in that it is an understanding that some individuals with stigmatized identities view the larger society as stigmatizing them, even though many individuals do not hold stigmatizing beliefs. Also, there are individuals with stigmatized identities who do not believe that stigma is an issue for them (Crocker & Quinn, 2000). Thus, in examining social stigma, researchers must work under several assumptions to understand the implications of social stigma (Link et al., 1989; Link & Phelan, 2001).

In the case of PCa survivors, social stigma is the public perception of those diagnosed with the disease as being “less-than” (Gannon, Glover, & Abel, 2004; Jones & Corrigan, 2014). Due to PCa, survivors can be seen as weak, sexually dysfunctional, or pitiable (Maliski et al., 2008). A common perception about cancer is that death is a certainty (Niederdeppe & Levy, 2007; Vrinten, van Jaarsveld, Waller, von Wagner, & Wardle, 2014), whereas PCa is a survivable disease (NCI, 2011). Thus, due to public perception and/or misinformation about the disease, stigmatizing attitudes can form about PCa survivors.

Researchers often assume that a group is stigmatized, and in need of stigma interventions (Crocker & Quinn, 2000). It is necessary, however, to understand the perceptions of both those who are expected to be stigmatized and those who stigmatize, an example of which was completed by Cho and colleagues (2013a; 2013b) in investigating cancer stigma in South Korea. Another type of stigma, self-stigma, forms when perception of public stigmatization issues becomes internalized.

Self-stigma

Self-stigma is the internalization of social stigma that impacts the mental health of individuals more than social stigma (Vogel et al., 2013). Essentially, individuals experience social stigma, and over time they begin to believe the messages that social stigma sends, including feelings of self-doubt, shame, and lack of self-efficacy (Corrigan & Rao, 2012). Self-stigma increases the negative attributes of stigma and can have long-lasting effects on stigmatized individuals (Vogel et al., 2013). Developing internalized beliefs can result in lowered self-esteem and depression (Vogel et al., 2007).

In the case of PCa survivors, too, self-stigma is the internalization of social stigma. Public beliefs about being weak, sexually dysfunctional, or pitiable can cause changes in mood and identity (Cushman, Phillips, & Wassersug, 2010; Letts et al., 2010), resulting in lowered QoL. The effects of self-stigma are more severe and individualized than social stigma, as it is no longer that all PCa survivors have a certain characteristic, but that the individual manifests those characteristic, which are now part of a belief system. Due to a variety of body image, masculine identity, and sexual functioning issues (Fergus et al., 2002; Maliski et al., 2008; Taylor-Ford et al., 2013), the beliefs about changes in these areas due to PCa and treatment become true for survivors.

As stigma research continues to develop, researchers continue to investigate other types of stigma (Jones & Corrigan, 2014). Stigma that is measured in the current study relate to social and self-stigma, but an understanding of other types of stigma is beneficial in conceptualizing the need for the current study.

Other types of stigma

Two additional constructs deal with fear of stigma: label avoidance and anticipated stigma. Label avoidance (Jones & Corrigan, 2014) is the avoidance of diagnosis or treatment for fear of stigmatization. For example, the treatment of PCa can result in a variety of sexual side effects, such as impotence. In order to avoid stigmatization (e.g., others being aware of decreased libido), PCa survivors may avoid treatment for the disease, or even diagnosis (Pedersen et al., 2012). Thus, label avoidance can lead to complications with PCa, or even death.

Anticipated stigma is the fear of impending stigma. Anticipated stigma occurs when individuals know they will be stigmatized and fear others finding out about their stigmatized identities (Newheiser & Barreto, 2014; Quinn et al., 2014). For PCa survivors, the concealable nature of sexual dysfunction leaves survivors in a state of not knowing if friends, family, or others will find out about their problems, resulting in anticipated stigma.

The concept of family stigma, a newer conceptualization of stigma, describes how individuals close to stigmatized individuals can be affected by stigma. Still in its infancy, the concept of family stigma has been hypothesized to result in overall lower QoL for families (Park & Park, 2014). In a study of family members of individuals with mental disorders ($N = 437$), Muralidharan, Luckstead, Medoff, Fang, and Dixon (2014) found that stigma was related to distress and family functioning, with many family members feeling as though they had to cover up the stigmatized individuals' ailments. Further, Doyle and Molix (2014) found that experiences of stigma diminished relationship quality for racial minorities ($n = 630$) and sexual minorities ($n = 47$). Based on limited empirical research, it can be inferred that PCa couples experience family stigma when survivors are stigmatized. That is, stigmatization effects both partners' QoL and relationship satisfaction.

Other concerns in defining stigma

As a point of clarification, stigma is closely related to prejudice and discrimination, as they all refer to mistreatment of social groups and individuals. However, stigma differs from prejudice and discrimination traditionally in terms of the target population. Often, prejudice and discrimination refer to larger and more broad features like race, gender, and age, whereas stigma

is focused on specialized features, such as disease, disfigurement, or abnormalities (Phelan, Link, & Dovidio, 2008; Stuber, Meyer, & Link, 2008). For the purposes of the current study, we are examining PCa stigma, as the development of a disease falls in line more with stigma, rather than prejudice or discrimination. In the current study, the investigator is also examining race, but relating it to stigma as it pertains to PCa.

Research on Stigma of Diseases

In previous years, stigma researchers mainly investigated issues like HIV and mental health disorders (Herek, 1999; Fife & Wright, 2000; Mak et al., 2007; Varni et al., 2012). Recently, topics such as obesity (Pearl & Lebowitz, 2014; Puhl & Heuer, 2010), disability (Ali, Hassiotis, Strydom, & King, 2012; Werner et al., 2012), and lung cancer (Bresnahan, Silk, & Zhuang, 2013; Brown & Cataldo, 2013; Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011; Else-Quest et al., 2009; Gonzalez & Jacobsen, 2012) have gained exposure in stigma research. To illustrate the probable impact of stigma on PCa survivors and their partners, a review of stigma related to other cancers is necessary.

Cancer-related stigma

Empirical research on how stigma affects cancer survivors has been steadily growing in recent years (Else-Quest & Jackson, 2014). Some researchers have started to find that stigma affects those with cancer (Cho et al., 2013a; Cho et al., 2013b; Fife & Wright, 2000; Else-Quest et al., 2009; Stahly, 1988). In two Korean population studies, Cho and colleagues (2013a; 2013b) found that wide-scale social stigma exists for cancer survivors among individuals without cancer (2013b), and that 30% of cancer survivors experienced social or self-stigma related to the disease

(2013a). In the study (2013a), experiences of stigma were significantly associated with depressive symptoms. While these results examined stigma in Korea, some generalizations can be made that an American sample would yield similar results. Cho and colleagues highlight an important finding in stigma research.

A current problem with some of the empirical research on cancer stigma is that researchers rarely differentiate between different types of cancer stigma. However, researchers (Cataldo et al., 2012; Gonzalez & Jacobsen, 2012) have begun to account for cancer-specific stigma. Of cancer-specific stigmas, lung cancer is the most researched (Else-Quest & Jackson, 2014). In order to understand the influence of stigma on QoL for PCa survivors and their partners, it is helpful to look into a research on lung cancer stigma.

In a qualitative study on stigma, shame, and blame experienced by lung cancer survivors ($N = 45$), Chapple, Ziebland, and McPherson (2004) found that survivors felt stigmatized by social implications of their diagnosis. Lung cancer survivors reported feeling that other individuals in their lives avoided them because of their diagnosis, felt others did not know how to talk to them about their diagnosis, were told that contact with them would “dirty” another person, and would often not seek treatment or support groups to avoid being seen as having lung cancer. Results from this study highlight the significance of lung cancer stigma on physical and mental health. Limitations to the study include lack of diversity in the sample and absence of a qualitative framework to guide data analysis. Chapple and colleagues gave an early insight into the experiences of lung cancer stigma.

The studies of Bresnahan and colleagues (2013) and Knapp-Oliver and Moyer (2009) provide knowledge of how ideas about lung cancer can cause stigmatization. In Bresnahan and

colleagues' study (2013), a sample of undergraduate students ($N = 224$) were provided with four different vignettes describing the father of a student undergoing chemotherapy for lung cancer wherein the father was a heavy smoker, a moderate smoker, a light smoker, or a nonsmoker. Nonsmokers in the study ($n = 113$) held stigmatizing views about individuals with lung cancer, even if the person in the vignette was a nonsmoker ($\eta^2 = .08$). Both smokers and nonsmokers in the sample blamed those in the vignettes who smoked for their disease more so than nonsmokers. Similar to Bresnahan and colleagues, Knapp-Oliver and Moyer (2009) sampled undergraduate students ($N = 299$) in a vignette-based study. Knapp-Oliver and Moyer studied individuals' willingness to help others with a visual cancer (e.g., facial melanoma). Participants were less likely to help an individual with a visible cancer as compared to those without visible cancers. Limitations to both studies include convenience samples, lack of reported effect sizes (Knapp-Oliver & Moyer, 2009), and the use of vignettes rather than field experiments. The results of both studies show that social stigma exists for lung cancer survivors, and the level of stigma changes based on both the perceived ability to prevent the disease, and the visibility of the disease.

In another study, Gonzalez and Jacobsen (2012) examined the role of stigma in depression for lung cancer survivors ($N = 95$). Results indicated positive relationships between stigma and depressive symptomatology. Although the contributed effect size was small ($R^2 = .03$), it was a statistically significant contribution to the overall model. Gonzalez and Jacobsen found that different types of stigma (e.g., social isolation) contributed to the final model greater ($R^2 = .07$) than stigma as a unidimensional concept. Similar to Gonzalez and Jacobsen's study, Cataldo, Jahan, and Pongquan (2012) found that in a sample of smokers ($n = 151$) and non-

smokers ($n = 39$), lung cancer stigma was positively correlated with depression ($R^2 = .47, .47$) and negatively correlated with QoL ($R^2 = .45, .25$). In addition to depression, lung cancer stigma predicted decreased QoL regardless if individuals in the sample had ever smoked ($R^2 = .02$). Brown, Brodsky, and Cataldo (2014) extended the study of lung cancer stigma's effects on survivors by including anxiety in their study. Lung cancer stigma was found to significantly correlate with anxiety and contributed to an overall decline of QoL ($R^2 = .01$). Limitations to the studies include small, unequal and non-diverse samples. These studies provide empirical quantitative evidence on how stigma affects lung cancer survivors and how it predicts increased depression, increased anxiety, and decreased QoL.

In looking at the seven previous studies (Bresnahan et al., 2013; Chapple et al., 2004; Cho et al., 2013a; Gonzalez & Jacobsen, 2012; Knapp-Oliver & Moyer, 2009), there is an established experience of lung cancer stigma. Research on lung cancer stigma continues to increase, with scales being created (Cataldo et al., 2011; Hamann et al., 2014) and findings of gender influence (Brown & Cataldo, 2013).

In addition, a recent finding details how stigma could lead to increased premature mortality. Carter-Harris, Hermann, Schreiber, Weaver, and Rawl (2014) investigated how stigma influences timing of medical help-seeking behavior in lung cancer survivors ($N = 93$). The study investigated multiple variables to predict delays in medical help-seeking behavior, including distrust of the healthcare system, smoking status, social desirability, ethnicity, annual income, and lung cancer stigma. Only lung cancer stigma was a significant predictor of timing of medical help-seeking behavior in the sample ($R^2 = .15$). Limitations to the study include a small sample size and low geographic variability in the sample. The findings of the study point to stigma being

a barrier to treatment after symptom onset, and being a risk to lung cancer becoming worse before treatment is sought. As described previously, it can be inferred from this study that label avoidance or anticipated stigma could contribute to not seeking medical help. How the findings of lung cancer stigma apply to other types of cancer is unknown.

One type of cancer that has been minimally linked to stigma in research is PCa. Researchers cannot assume that all stigmatization is equal (Greene & Banerjee, 2006; Switaj et al., 2011). However, researchers have begun to look at comparisons between cancer diagnoses.

Else-Quest and colleagues (2009) examined stigma, self-blame, and adjustment in lung cancer ($n = 96$), breast cancer ($n = 30$), and PCa ($n = 46$) survivors. Stigma and self-blame were found to be associated with poor psychological adjustment. An interesting finding in the study is that the stigma felt by individuals with any of these was not significantly different from one another. This implies the three sets of cancer survivors felt relatively similar amounts of stigma. Extrapolating these findings, researchers could infer that PCa survivors encounter levels of stigma similar to lung cancer survivors. A serious limitation of the study is that the measure of stigma was a single five-point likert-type response item of agreement to the question, “*People judge me for my type of cancer.*” Because the item used to measure stigma in Else-Quest and colleagues’ study is ambiguous and not reliable or valid, implications are tenuous. However, the self-report of judgment and possible stigma provides rationale that PCa survivors face stigma similar to individuals with other cancers.

Prostate cancer stigma

Stigma related to PCa has not been examined thoroughly in the extant literature (Else-Quest & Jackson, 2014). Many issues related to PCa and treatment can be stigmatizing and lead survivors to take on stigmatized identities (Elstad, Taubenberger, Botelho, & Tennstedt, 2010; Jackson, Botelho, Welch, Joseph, & Tennstedt, 2012). Prostate cancer has been linked to many physical and mental health issues, including decreased QoL (Torvinen et al., 2013; Zenger et al., 2010), relational issues (Harden et al., 2013), depression (Jayadevappa et al., 2012), sexual desire (Jenkins et al., 2004), self-esteem (Maliski et al., 2008; Rivers et al., 2011; Rivers et al., 2012) and incontinence (Kopp et al., 2013). The mental health issues PCa survivors experience are beginning to concern physicians as well (Matthew & Elterman, 2014).

The effects and treatments of PCa can leave individuals with new experiences that change their perception of themselves (Maliski et al., 2008; Taylor-Ford et al., 2013), depending on stage and progression of their disease (Vanagas et al., 2013). Some treatments can decrease libido and change moods, while others involve removing the prostate entirely, causing irreparable damage (Walsh & Worthington, 2012). For example, the effects of androgen-deprivation therapy include decreased levels of testosterone, and can lead to decreased sexual functioning in PCa survivors (Chipperfield et al., 2012; Walker & Robinson, 2012; 2011; 2010). The language used by the general public to describe PCa survivors who have gone through ADT can also lead to experiences of shame, powerlessness, and loss of control, stigmatizing survivors (Cushman et al., 2010). An examination of other pertinent empirical literature provides further rationale for investigating PCa stigma.

As demonstrated in numerous studies (Burns & Mahalik, 2008; Campbell et al., 2012; Green, Pakenham, Headley, & Gardiner, 2002; Jenkins et al., 2004; Robinson et al., 2002; Trinchieri, Nicola, Masini, & Mangiarotti, 2005), masculinity beliefs and sexual issues can cause problems for PCa survivors and their partners. Fergus et al. (2002) conducted a qualitative study of sexual dysfunction for PCa survivors ($N = 18$). An overarching theme in the study was “preservation of manhood” (2002, p. 307) in facing PCa. Many of the participants in the study voiced that sexual dysfunction made them feel like less of a man and that sexual performance was inherent to being a man. Participants discussed how a lack of libido was linked to feelings of sadness and depression, and that the use of tools (e.g., vacuum pump) did not restore what was lost from PCa and treatment. Also, the participants reported feeling an “invisible stigma” (Fergus et al., 2002, p. 311), similar to the concept of internal, or discreditable, stigma (Goffman, 1963). The invisible stigma felt by participants (Fergus et al., 2002) related to hiding the fact that they could no longer sexually perform, and they feared admitting that to any friends or future sexual partners. Finally, participants also reported that incontinence was a worse experience than erectile dysfunction. Fergus and colleagues’ study had a diverse sample, including White, Black and Gay men endorsing similar themes throughout their interviews. Limitations to the study include possible investigator bias and lack of a specific qualitative framework in study construction. Fergus and colleagues’ study is one of the earliest mentions of stigma related to PCa.

Maliski and colleagues (2008) conducted a qualitative study on Black and Latino PCa survivors ($N = 95$) and found that the disease and its treatment posed threats to masculinity. The participants in the study found that concepts of masculinity were formed early in life, with men

being taught to take care of their family and to be leaders. Black and Latino PCa survivors discussed not being able to work; having a lack of control and strength; and issues with sexual performance. Many PCa survivors felt they could not work due to treatment weakening them and making them incontinent, and thus were not able to readily provide for their families. Lack of control and strength were felt by PCa survivors in trying to maintain their own emotional state, as well as the emotional states of others around them (e.g., partners). Also, incontinence and erectile dysfunction caused survivors to feel less in control of their own bodies. Finally, sexual performance was affected by erectile dysfunction, with PCa survivors feeling they could not sexually please their partners. More than just sex, PCa survivors felt they were less emotionally and intimately united with their partners, and could lose their partners due to erectile dysfunction caused by treatment. Prostate cancer and treatment can cause physical effects on survivors that translate into emotional problems, causing them to feel stigmatized for not being able to hold on to previously formed conceptions of what it is to be a “man.” The stigma felt by PCa survivors can then affect their partners (Muralidharan et al., 2014; Northouse et al., 2007; Rivers et al., 2011). Limitations to the study include a lack of information of factors (e.g., disease stage) that could inform the obtained data and subsequent analysis.

Contrary to Maliski and colleagues’ (2008) and Fergus and colleagues’ findings (2002), Letts and colleagues (2010) found that PCa survivors, 5-10 years post-treatment ($N = 19$), experienced few changes to their masculine identity, affection expressed toward their partner, sexual desire, and relationship quality from the disease and treatment. The physical effects of PCa and treatment did cause anger and frustration for survivors in their romantic relationships, yet the majority of participants did not discuss these issues with their partners. Prostate cancer

survivors in the study also mentioned that a lack of open conversations with their physicians contributed to anger and frustration with the disease and treatment. Throughout the study, it was found that survivors' sexual well-being was affected by PCa even though their sexual desire was reported to not decrease, leaving them frustrated and experiencing symptoms of depression. The limitations of the study include an entirely White sample, and issues with attrition. Similar to Jenkins and colleagues (2004), Letts and colleagues (2010) found that much of the sexual well-being impacted by PCa could be a result of specific ideas about sex and sexuality in men, with intercourse being paramount over other types of intimacy. Letts and colleagues' study contradicts some of the findings by Maliski and colleagues (2008), but similar aspects of sexual well-being were impacted and resulted in emotional problems that were consistent between both studies.

Burns and Mahalik (2008) conducted a study on sexual functioning, masculinity, and social, role, and mental health QoL for PCa survivors ($N = 234$). They found that PCa survivors with traditional masculine norms and poor sexual functioning had worse social ($R^2 = .017$), role ($R^2 = .021$), and mental health functioning ($R^2 = .018$) (taken from a larger QoL measure) than those with less traditional masculine norms. Similarly, PCa survivors with less traditional masculine norms and good sexual functioning had better social, role, and mental health functioning compared to those with less traditional masculine norms. In essence, the study found that sexual functioning moderates the relationships between masculine norms and social, emotional, and role functioning. Limitations to the study include a lack of racial diversity and small effect sizes for results. Burns and Mahalik's study can frame the detailed results of

previous studies (Fergus et al., 2002; Letts et al., 2010; Maliski et al., 2008) with quantitative findings.

For PCa survivors who adhere to traditional masculine roles, the concept of sexual functioning is integral to their identity. Regardless of stage or treatment, most PCa survivors face sexual bother (Benedict et al., 2014). When their identity is threatened, PCa survivors react with a variety of emotions, including anger, frustration, anxiety, and depression. Thus, stigma associated with PCa exists for those with the disease that hold onto traditional masculine norms, which could include a large portion of older men (e.g., 55 and older), which the disease mostly affects. Further, due to the inherent interdependence in the effects of PCa on partners, they are at risk for decreased QoL and relationship satisfaction due to the disease (Muralidharan et al., 2014; Park & Park, 2014).

Prostate cancer is referred to as a “couple’s disease” (Gray et al., 1999). Researchers (Garos et al., 2007; Kershaw et al., 2008; Northouse et al., 2007; Song et al., 2011; Song et al., 2012) have found that in order to fully conceptualize the experience of PCa survivors, it is important to examine the quality of the relationships for both survivors and their partners. Researchers (Harden et al., 2013; Merz et al., 2011) have found direct relationships between relationship satisfaction and QoL for PCa survivors. Not only does QoL for PCa survivors and their partners correlate, but also one partner influences the other emotionally in a variety of different ways (DiIorio et al., 2011; Lafaye et al., 2014; Regan et al., 2014). The unique research findings regarding relationships between PCa survivors and their partners highlights the need to continue exploration on the influence of the disease on couples.

Relationship Between Quality of Life, Relationship Satisfaction, Prostate Cancer Stigma, and Race

As demonstrated in this review of literature, there are many links between QoL, relationship satisfaction, and stigma for PCa survivors and their partners. The problem in the current research is that the links that currently exist are not connected to one another. There are studies that indicate that PCa is linked to decreased QoL for survivors (Zenger et al., 2010). There are also studies that indicate that PCa is a detriment to some relationships (Couper et al., 2006). Finally, there are limited studies that indicate that PCa survivors experience stigma (Else-Quest et al., 2009). Within each of these relationships, racial minority PCa survivors and their partners, overall, suffer more than White PCa survivors (Penedo et al., 2006). The combination of these variables has not been addressed in the current literature, even though the issues that cause stigmatization also decrease QoL and relational problems. The current study combines study on QoL, relationship satisfaction, and stigma for PCa survivors and their partners, with a focus on racial health disparities.

Quality of life for PCa survivors is affected by the disease. Treatment and the issues that affect survivors can be identified as stigmatizing, such as financial difficulties (Zenger et al., 2010), impotence (Fergus et al., 2002), and incontinence (Kopp et al., 2013). Stigmatizing issues for PCa survivors, such as beliefs about masculinity and sexual functioning, may affect racial minority PCa survivors more than White survivors due to cultural concerns related to those issues (Jones et al., 2004; Maliski et al., 2008; Rivers et al., 2011). Further, the disease and its impact on survivors also affect their partners, causing decreases in communication (Song et al., 2012), emotional functioning (Zhou et al., 2011), and relationship satisfaction (Couper et al., 2006). Prostate cancer can affect survivors' and their partners' QoL and relationship satisfaction,

and the stigmatizing issues related to the disease appear to play a large, but unexamined, role in these relationships.

Implications of the Current Study

Based on the literature review conducted for the current study, there are tremendous findings in the field of PCa research in how it affects survivors and partners. There is a lack of research regarding racial health disparities in PCa, but more studies are being completed to address this gap in the current literature. A large gap still exists in understanding how stigma affects PCa survivors and their partners. Some researchers (Else-Quest et al., 2009; Fergus et al., 2002) have found that PCa survivors face stigma, but how that stigma affects them and their partners' QoL and relationship satisfaction is unknown. Further, no studies exist, to the investigator's knowledge, that have examined differences in stigma between racial minority and White PCa survivors, even though the impact of the disease and treatment can affect them differently (Jenkins et al., 2004). The risk in not investigating PCa stigma could result in delays of treatment and possible mortality (Carter-Harris et al., 2014; Jones & Corrigan, 2014). Thus, the purpose of the current study is to further understand the impact of PCa stigma. The current study investigates the influence of PCa stigma on survivors and their partners' QoL and relationship satisfaction.

Chapter Summary

Chapter Two consisted of the review of literature of the current study. Theoretical and empirical research on PCa's effects on QoL for survivors and partners was addressed. In addition, the ways in which PCa affects the relationships of survivors and their partners was also

addressed. Racial disparities were highlighted in addressing QoL and relationship satisfaction. Finally, theoretical and empirical research on stigma and its relation to PCa was examined. Social exchange theory (Levinger, 1965; 1976) and modified labeling theory (Link et al., 1989) were used to conceptualize relationship satisfaction for PCa couples and stigma, respectively. Chapter Three includes the methodology for the current study used to examine the constructs discussed in Chapter Two.

CHAPTER THREE: METHODOLOGY

Chapter Three presents the research design, methods, and procedures for the study. The purpose of this research study was to investigate the influence of stigma (as measured by the *Social Impact Scale* [SIS; Fife & Wright, 2000]) on prostate cancer (PCa) survivors and partners' quality of life (QoL; as measured by the *Functional Assessment for Cancer Therapy for Patients with Prostate Cancer* [FACT-P; Esper et al., 1997] and the *Functional Assessment for Cancer Therapy – General Population* [FACT-GP; Cella et al., 1993]), and relationship satisfaction (as measured by the *Couples Satisfaction Index* [CSI; Funk & Rogge, 2007]). Specifically, the study tested the hypothesized directional relationship that PCa survivors and partners who indicate higher levels of stigma will indicate lower levels of QoL and relationship satisfaction. Relationships between race, stigma, QoL, and relationship satisfaction were also explored.

The study utilized a descriptive, correlational research design (Gall et al., 2007) to investigate the research questions. A correlational design was used in the study in order to understand the strength and influence of stigma on QoL and relationship satisfaction for PCa survivors and their partners. The purpose of this Chapter is to present the research methodology for the investigation, including: (a) population and sample; (b) data collection procedures; (c) instrumentation; (d) research design; (e) research question and hypothesis; (f) data analysis; (g) ethical considerations; and (h) limitations to the study.

Population and Sample

The target population for the study was individuals diagnosed with PCa and their partners. The accessible population for the study consisted of PCa survivors who took part in

treatment at the selected oncology centers for the study (and their partners), PCa support groups in the state of Florida, and those in web-based support groups. For the study, PCa survivors were defined as individuals who were diagnosed with PCa, and partners were defined as the individual who was intimately or romantically involved with the PCa survivor at the time of data collection. For the purposes of the study, PCa survivors and their partners of any race were included in the accessible population, as the effects of PCa tend to differ based on race (Hoffman et al., 2001; Jayadevappa, Johnson, Chhatre, Wein, & Malkowicz, 2007; Krupski et al., 2005; Namiki et al., 2011; Penedo, Dahn, Shen, Schneiderman, & Antoni, 2006). Mixed-race couples in the study were categorized by the race of the PCa survivor. PCa survivors and their partners were chosen for the study as PCa is a life-altering disease with considerable negative side effects for both survivors and partners; however, little is known related to the influence of stigma on QoL (Couper, 2007).

Close to three million PCa survivors live in the United States (American Cancer Society [ACS], 2014). It is difficult to calculate an appropriate sample size to ensure a 95% confidence level of generalizability (Krejcie & Morgan, 1970), as there are *no* accessible records of the number of PCa survivors with a partner. Thus, relying on the size of the population of PCa survivors (three million), a minimum sample size of 385 was calculated (Krejcie & Morgan, 1970). In addition, statistical power estimates are necessary to calculate prior to beginning a quantitative investigation. Statistical power is the probability of rejecting the null hypothesis given the effect size, sample size, and alpha level (Balkin & Sheperis, 2011). A power level of .8 is desired in the investigation as it is a commonly used level to minimize Type II error in social science research (Cohen, 1992). In order to ensure that all statistically significant relationships

are found in the study, an a priori sample size analysis was run for a sample of PCa survivors and their partners.

Sample Size Considerations for Structural Equation Modeling

In addition to using population estimates when considering desired sample size, researchers need to take into account data analytic methods. For the study, Structural Equation Modeling (SEM) was employed as the primary method of data analysis (Kline, 2010). To measure the theorized structural model of three latent variables (e.g., stigma, QoL, and relationship satisfaction) and 15 observed variables (e.g., subscales and total scores for measures), consideration was taken to appropriately analyze data. SEM is an analysis that requires larger sample sizes than other statistical analyses (e.g., multiple regression). The appropriate sample size for SEM analyses differ; 10 to 20 participants per parameter measured are typically viewed as ideal, and samples with 200 participants are widely seen as the minimum acceptable sample size to ensure proper model estimations and eliminate chances of Type II errors (Kline, 2010; MacCallum, Browne, & Sugawara, 1996; Schumacker & Lomax, 2012), yet smaller sample sizes have been used in SEM (Bentler, 1999). Power considerations in SEM requires sample sizes based on desired effect sizes, power level, number of latent variables, number of observed variables, and probability level. A sample size calculator from www.danielsoper.com was used, as suggested by Schumacker and Lomax (2012), to determine an appropriate sample size to reach a power level of .8. Based on the recommended website's sample size calculator, and to decrease chances of Type II error, an anticipated effect size of .1 was used with a .8 statistical power level, and an alpha of .05. In the study, three hypothesized

latent variables were assessed (e.g., stigma, QoL, and relationship satisfaction) and 15 hypothesized observed variables (e.g., subscales and total scores for measures) were assessed, yielding a minimum sample size of 290 individuals, or 145 couples.

Sample sizes for research with couples range widely (Kenny et al., 2006), from as low as 25 couples to as high as 411 couples. An analysis of sample sizes in psychological and mental health couples research by Kenny and colleagues (2006) yielded an average sample size of 101. Kenny and colleagues provide a table of suggested sample sizes given population correlations. At a population correlation of .2, the minimum suggested sample size to achieve power of .8 is 200 dyads. It is expected that a population correlation of .2 is reasonable as previous studies have found that PCa survivors and their partners tend to have similar QoL and relationship quality (Merz et al., 2011; Segrin et al., 2012). Based on the a priori sample size analysis for SEM, recommendations for dyadic data analysis, literature, and sample size equations, a minimum sample size of 150 couples was sought to ensure a power level of .8 at post-hoc power analyses and to appropriately conduct dyadic SEM analysis.

Given that 150 couples were sought for the study in order to appropriately carry out analysis, the investigator needed to contact a sample of 350 couples to ensure a minimum of 150 couples. Based on available response rates reported in previous studies, response rates for non-longitudinal quantitative studies with PCa survivors and their partners range from 76.8% (Harden et al., 2008) to 43% (Ezer et al., 2011). Some studies did *not* report response rates (e.g., Song et al., 2011). The investigator used the lowest reported response rate and anticipated a response rate of 43% (Ezer et al., 2011). One hundred fifty-eight couples were approached during data collection due to a more limited access to the population than what was expected.

Recruitment

The primary method of obtaining participants for the study was through convenience sampling (Gall et al., 2007). Convenience sampling is a sampling technique in which researchers choose volunteers from an easily obtainable, or convenient, source. Compared to random sampling, convenience sampling is a type of nonprobability sampling which is difficult to generalize to a population. While the validity of results are theoretically not as sound as studies using random sampling, convenience sampling is a commonly used sampling technique in social sciences (Ludbrook & Dudley, 1998). Convenience sampling is used in this study in order to amass a large enough sample to conduct analyses, and because the researcher did not already have existing access to a participant pool.

Participants were recruited from oncology centers in Florida (Terk Oncology and First Radiation and Oncology Group) and PCa support groups (UsTOO and You Are Not Alone [YANA]) via face-to-face and online. The investigator continued to establish collaborative relationships with oncologists in Florida through face-to-face and email communications. Prior to any collection of data, the investigator obtained permission from the University of Central Florida's Institutional Review Board (IRB) to conduct the study. Permission was sought for the investigator to survey PCa survivors and their partners before or after their scheduled appointments. In addition, PCa support groups as part of the UsTOO group in Florida were contacted for the investigator to attend the group and collect data from survivors and their partners. In addition, the owner of an online support group, You Are Not Alone, was contacted for permission to post advertisements inviting participation in the proposed study. Other online

PCa support groups (Prostate Pointers, Malecare, and WebMD Prostate Cancer Community) were contacted to grant permission to post advertisements for participation in the study.

Data Collection Procedures

Based on the previous sample size calculations, a sample of 150 couples was sought to explore the influence of stigma on QoL and relationship satisfaction for PCa survivors and their partners. In order to ensure a sample of a minimum 150 couples, multiple sites were used, including online and face to face samples. The following section details the recruitment for the study, including IRB concerns and sites of data collection.

Procedure

The study was submitted to the University of Central Florida IRB, prior to data collection, to ensure ethical research practices. Permission was obtained to use all instruments for the study, plus to adapt them to Qualtrics, a web-based survey service. Proper formatting and ease of completion of the paper/pencil and web-based measures were checked by the investigator's colleagues prior to collecting data. The study utilized both face to face data collection (i.e., in-person) and online data collection. The study also utilized an incentive for participants. For each individual who participated, a \$1 donation was made to the Prostate Cancer Foundation, an organization that supports PCa research and awareness. The donation was made through the Safeway Foundation, which matched donations to the Prostate Cancer Foundation up to one million dollars until December 31, 2014. Thus, each individual who participated in the study was effectively donating \$2 for their time in completing the

assessments. The Prostate Cancer Foundation is the leading global philanthropic organization dedicated to PCa.

Face-to-Face Data Collection

The investigator utilized face-to-face data collection with paper and pencil. Before data collection began, guidelines for visual representation of surveys (Dillman et al., 2009) were used to organize the SIS (Fife & Wright, 2000), as the SIS was only available in the original scale-development article. At oncology centers, the investigator visited one to two times weekly in order to recruit participants. Oncology center staff notified patients at check-in that they had the opportunity to take part in a study and were directed to the investigator's designated area (office in center section of the lobby). If patients came to their appointment with their partner and both wished to be a participant in the study, they were given pens and read the waiver of informed consent. Participants were informed of the purpose of the study and their rights as participants by the investigator. Participants were asked if they understood the informed consent and were given their individual packets. PCa survivors were provided with a blue-colored packet of assessments including the SIS (Fife & Wright, 2000), the FACT-P (Esper et al., 1997), the CSI (Funk & Rogge, 2007), and a demographics form created for PCa survivors. Partners of PCa survivors were provided with a pink-colored packet of assessments including the FACT-GP (Cella et al., 1993), the CSI (Funk & Rogge, 2007), and a demographics form created for partners. Each group of two packets was numbered to indicate that they should be entered together when creating the dyadic dataset (e.g., 1001-1 and 1001-2; 1002-1 and 1002-2). If participants were *not* able to read, the assessment packets were read to them by the investigator.

If patients showed up without a partner and were interested in participating in the study, the investigator gave the assessment packets to participants to take home so they and their partners could complete the packets and either return them to the investigator the following week or mail them to the investigator's university program office. If participants preferred to mail the packets, their envelope was pre-addressed and stamped for their convenience.

Flyers were placed in oncology centers advertising the study and providing the dates and times in which the investigator was present, as well as the investigator's contact information. Many PCa treatments are administered daily or multiple times a week (Walsh & Worthington, 2012); thus, the investigator had multiple chances to collect data from potential participants.

Recruitment at PCa support groups consisted of the investigator visiting the group and explaining the study to group members. If group members were eligible (are in a current romantic or intimate relationship), they were provided the informed consent and assessment packets to take home in an unsealed, pre-addressed and stamped envelope. Upon completion of the packets, participants sealed the envelopes and placed them in any mailbox for pickup. The investigator visited the support groups twice during the study, as they typically meet monthly (UsTOO and Man to Man). After data collection ended, the investigator posted flyers in oncology centers and notified group leaders of the final total amount of money donated to the Prostate Cancer Foundation from incentives in the study.

Online Data Collection

Online data collection with web-based methods was utilized by the investigator. Through online PCa support groups, online advertisements with clickable hyperlinks to the survey were

posted for PCa survivors and their partners to participate in the study. Participants were also emailed the link for the study if they would rather receive a direct link for the survey from the investigator. Guidelines for the preparation and presentation of web questionnaires (Dillman et al., 2009) were followed in adapting the FACT-P (Esper et al., 1997), the FACT-GP (Cella et al., 1993), the CSI (Funk & Rogge, 2007), and the SIS (Fife & Wright, 2000). The Qualtrics survey was consistent for each of the measures. Both PCa survivors and their partners completed the survey, one after the other, in order to fully complete the survey. A printable copy of the informed consent waiver was provided on the first page of the survey, followed by a question asking if the first person taking the survey was a PCa survivor or the partner of a survivor. Then, depending on their answer, they were taken to the online version of their assessment packet. Next, a page appeared thanking PCa survivors or partners for completing the assessments and asked for PCa survivors or their partners (whomever did not do the first section of assessments) to complete the next portion of assessments. The final page appeared with a thank you for PCa survivors or partners for completing the study and thanking both individuals for participating in the study.

The tailored design method (Dillman et al., 2009) was followed when posting announcements of the study on message boards and listservs. In line with the tailored design method, participants were first notified in a message that contained information about the study; they then received a link to participate in a follow-up message. The next message contained a link to the Qualtrics site to complete the measures. The third message was a friendly and brief reminder that the study was still open. The fourth message contained a final announcement that the study was open (offering three chances to participate). The final message contained a thank

you with the number of participants. The final message also listed the total amount of money donated to the Prostate Cancer Foundation from incentives in the study.

Instrumentation

The constructs and data collection instruments in the study included: (a) QoL (FACT-P; Esper et al., 1997; FACT-GP; Cella et al., 1993), (b) relationship satisfaction (CSI; Funk & Rogge, 2007), and (c) stigma (SIS; Fife & Wright, 2000). A demographics questionnaire was used to obtain information pertaining to age, race, income, and other cancer specific characteristics. PCa survivors in the study received a paper/pencil packet or an online form containing the SIS, FACT-P, CSI, and the demographics form. Partners in the study received a paper/pencil pack or an online form containing the FACT-GP, CSI, and the demographics form. Because not all of the instruments were available in a variety of languages, only English versions of the instruments were provided to participants. Details on instrumentation follow.

Demographics Form

A demographics form was created by the investigator. The demographics form is a self-report form of general information about participants, including gender, age, race, relationship status, educational status, income, and geographic location. In addition to general variables, other items on the demographic form for PCa survivors included length of time since diagnosis, current stage of the disease, types of treatment (if any), and information on additional chronic illnesses. These variables were important to the study based on previous PCa research (Chipperfield et al., 2013; Diefenbach et al., 2008; Obertova, Brown, Holmes, & Lawrenson, 2012; Vanagas et al., 2013; Zenger et al., 2010). Additional demographic items were specific for

partners to inquire about chronic illnesses, as this variable may influence results (Couper et al., 2006). The demographics form was reviewed by a panel of experts (e.g., committee members and Counselor Education faculty), and was administered to colleagues of the investigator to check for ease of readability and clarity.

Stigma

Stigma in the study was measured by the *Social Impact Scale* (Fife & Wright, 2000). The SIS was chosen because it is one of the few available stigma measures that does *not* assess a stigma of a specific concern (Cataldo et al., 2011). In lieu of constructing a PCa stigma measure, the SIS was also chosen because it is a generalized measure of stigma, shown to measure multiple types of stigma in its development.

Social Impact Scale

The SIS is a 24-item measure of stigma that was originally developed to measure differences in stigma based on two different types of diseases (HIV and cancer). The SIS uses a four-point Likert response option for each question. The SIS consists of four subscales: two assessing social stigma and two assessing self-stigma. The first social stigma subscale assesses social rejection and consists of nine items (e.g., I feel others avoid me because of my illness). The second social stigma subscale assesses financial insecurity and consists of three items (e.g., I have experienced financial hardship that has affected how I feel about myself). The first self-stigma subscale assesses internalized shame and consists of five items (e.g., I feel I need to keep my illness a secret). The second self-stigma subscale assesses social isolation and consists of seven items (e.g., Due to my illness, I sometimes feel useless). Each item follows a four-point

Likert-style response format (e.g., *strongly agree*, *agree*, *disagree*, and *strongly disagree*). The SIS is a general stigma scale in that the items are not worded to relate to a particular stigmatizing issue, such as HIV. The SIS can be used to measure four factors of stigma, as well as a unidimensional measure for overall stigma. For the purposes of the study, and based on previous cancer stigma literature, the SIS was used multidimensionally (Gonzalez & Jacobsen, 2012).

The SIS was originally developed by Fife and Wright (2000) to measure differences in stigma between illnesses and differences in impact on individuals based on types of stigma encountered. Items were created to measure both social stigma and self-stigma. The norming group used by Fife and Wright was a sample of individuals with HIV ($n = 130$) and cancer ($n = 76$). The demographics of the cancer sample were evenly split between gender, and race was not reported. After an exploratory factor analysis (EFA) utilizing principal component extraction with varimax rotation, the social stigma and self-stigma categories yielded two subscales each: social rejection, financial insecurity, internalized shame, and social isolation. The internal consistency for each subscale was adequate at .903 (social rejection), .859 (financial insecurity), .85 (internalized shame), and .857 (social isolation). Further, correlations between the subscales ranged from .26 to .66, indicating that the scales are related, but distinct from one another. In their analysis, Fife and Wright (2000) found that individuals with HIV consistently experienced more stigma compared to individuals with cancer on each subscale and item, indicating construct validity.

Pan, Chung, Fife, and Liu (2007) investigated psychometric properties of the SIS in a sample of individuals with HIV ($n = 224$), schizophrenia ($n = 119$), and depression ($n = 237$). Using a Rasch measurement model, the overall separation reliability (similar to internal

consistency) was .99. Pan and colleagues also found, through using the Rasch measurement model, that the SIS can be used as a unidimensional measure of stigma, spanning different types of stigma. Construct validity was found again in measuring differences between types of illnesses. In addition to HIV, cancer, depression, and schizophrenia, the SIS has been used to measure stigma for other possibly stigmatizing issues. Burgener and Berger (2008) studied stigma of Alzheimer's disease ($n = 26$) and Parkinson's disease ($n = 14$). The SIS exhibited acceptable levels of reliability overall when measuring stigma of both diseases ($\alpha = .89$). Burgener and Berger found validity for the SIS through its correlations with mental status, self-esteem, depression, and personal control. The SIS has exhibited poor reliability in some studies (Woith & Larson, 2008) that could be contributed to issues outside of the scale, such as issues with translating scales and non-applicability of some items due to retirement or unemployment (e.g., my job security has been affected by my illness). To the investigator's knowledge, the SIS was not used to measure stigma in a sample of PCa survivors. Due to the research of Pan and colleagues (2007), it is possible that the SIS will load only on one factor of stigma, but other studies (Burgender & Berger, 2008) have shown that the SIS loads on the four original factors found by Fife and Wright (2000). Thus, precaution was taken in interpreting the confirmatory factor analysis (CFA) for the SIS.

Quality of Life

The Functional Assessment of Chronic Illness Therapy (FACIT; Webster, Cella, & Yost, 2003) publishes QoL measures for general cancer and site specific cancer. The measures selected for the proposed investigation are specific to PCa survivors and are adapted from the original

FACIT scale, the Functional Assessment of Cancer Therapy – General (FACT-G). Because both of the measures chosen for the proposed study are based on the core of the FACT-G, much of the psychometric information that is available is on the FACT-G.

Functional Assessment of Cancer Therapy for Patients with Prostate Cancer

The FACT-P is a 39-item measurement that assesses QoL of PCa survivors. The FACT-P consists of the *Functional Assessment of Cancer Therapy – General* (FACT-G; Cella et al., 1993), four subscales, and an additional PCa-specific subscale. Each item on the FACT-P follows a five-point Likert-style response format (e.g., *not at all*, *a little bit*, *somewhat*, *quite a bit*, and *very much*). Quality of life is assessed on the FACT-P based on five subscales: (a) physical well-being, (b) social/family well-being, (c) emotional well-being, (d) functional well-being, and (e) PCa concerns. The physical well-being subscale consists of seven items concerning physical illness symptoms (e.g., I have nausea). The social/family well-being subscale consists of seven items concerning social and familial support (e.g., I feel close to my friends), with one item being optional (e.g., I am satisfied with my sex life). The emotional well-being subscale consists of five items concerning negative emotions (e.g., I feel sad) and one item concerning positive coping (e.g., I am satisfied with how I am coping with my illness). The functional well-being subscale consists of seven items concerning enjoyment and fulfillment in life (e.g., I am able to enjoy my life). The final subscale on the FACT-P is the additional concerns subscale, a 12-item subscale concerning PCa-specific physical and emotional issues (e.g., I am losing weight; I am able to feel like a man).

Functional Assessment of Cancer Therapy – General Population

The FACT-GP is a 21-item measurement that assesses QoL for a general population. The FACT-GP is a version of the FACT-G, with items related to having an illness removed (e.g., because of my physical condition, I have trouble meeting the needs of my family) and the items not relating to an illness maintained (e.g., I have pain). The removal of illness-related items allows the FACT-GP to be given to individuals without cancer, such as the partners of PCa survivors. Each item on the FACT-GP follows a five-point Likert-style response format (e.g., *not at all, a little bit, somewhat, quite a bit, and very much*). The FACT-GP assesses QoL based on four subscales: (a) physical well-being, (b) social/family well-being, (c) emotional well-being, and (d) functional well-being. The physical well-being subscale consists of six items concerning physical illness symptoms (e.g., I have a lack of energy). The social/family well-being subscale consists of five items concerning social and familial support (e.g., I get emotional support from my family), with one item being optional but encouraged (e.g., I am satisfied with my sex life). The emotional well-being subscale consists of four items concerning negative emotions (e.g., I feel sad). The functional well-being subscale consists of six items concerning enjoyment and fulfillment in life (e.g., I am sleeping well). Items on both the FACT-P and the FACT-GP have been found to consistently load on their five (FACT-P) and four (FACT-GP) originally conceived factors (Cella, 2012; Janda, DiSipio, Hurst, Cella, & Newman, 2009).

The FACT-P and the FACT-GP are both based on the original FACT-G. Therefore, psychometric information for both the FACT-P and the FACT-GP can be partially gathered by the psychometric information of the FACT-G. An overview of the FACT-G's psychometric information is provided and then followed with FACT-P and FACT-GP specific information.

The FACT-G was originally assessed for reliability and validity during its construction to measure QoL in cancer patients ($N = 545$; Cella et al., 1993). The norm group of the FACT-G consisted of a heterogeneous sample of different cancer types from four different facilities. In the original article, the FACT-G demonstrated acceptable reliability in each subscale, from .69 (social/family well-being) to .82 (physical well-being), with the overall measure having an internal consistency of .89. Test-retest correlation ($n = 60$) ranged from .82 (emotional well-being and social/family well-being) to .88 (physical well-being), with the overall measure having a test-retest reliability of .92. The FACT-G showed evidence of construct validity in initial testing by correlating highly with other QoL and well-being measures, as well as low correlations with unrelated measures (e.g., social desirability). Further, the total FACT-G score was able to significantly differentiate between individuals in different stages of cancer ($n = 245$). In addition, Victorson, Barocas, Song, and Cella (2008) conducted a reliability generalization of the FACT-G across 78 studies and found that the subscales ranged in internal consistency from .71 (social/family well-being) to .83 (functional well-being), with the overall measure having an internal consistency of .88.

The FACT-G has been used in and adapted for multiple studies. It has been used for more than 50 distinct illnesses and translated into over 60 languages. Thus, the FACT-G has been seen as reliable and valid in a multitude of different settings (e.g., Brady et al., 1997; Esper et al., 1997; Pandey, Thomas, Ramdas, Eremenco, & Nair, 2002; Smith, Cocks, Parry, & Taylor, 2014; Ward et al., 1999).

The FACT-P has been used in more than 100 studies since its creation (Esper et al., 1997), and is one of the most used PCa-specific QoL measures (Hamoen, Rooij, Witjes,

Barentsz, & Rovers, 2014). In a systematic review of questionnaires used to measure QoL for PCa survivors by Hamoen and colleagues (2013), the FACT-P was found to have good content validity and internal consistency, making it one of the two preferred PCa-specific QoL measures.

The reliability of the FACT-P was originally assessed by Esper and colleagues (1997) during its development with PCa survivors ($N = 173$). In addition to psychometric information specifically based on the FACT-P, psychometric information for the FACT-G can also apply to the FACT-P, as they share 27 items with a similar structure. Internal consistency for the total FACT-P between two samples was .87 and .89. The separated subscales yielded slightly lower internal consistency scores across three samples, with physical well-being ranging from .64 to .83; functional well-being ranging from .81 to .83; social/family well-being ranging from .69 to .72; and emotional well-being ranging from .62 to .75. The PCa concerns subscale internal consistency scores ranged from .65 to .69 in two samples. Further, validity for the FACT-P was demonstrated through concurrent validity, by discriminating PCa survivors by disease stage, performance status, and baseline PSA levels

In a study on pain questionnaire performance in advanced PCa ($N = 170$), Robinson, Zhao, Dawkins, Qi, and Revicki (2013) found that the FACT-P had acceptable internal consistency scores between two trials for its items regarding pain ($\alpha = .92, .94$), PCa concerns ($\alpha = .72, .82$), and total score ($\alpha = .78, .83$). Intraclass correlations yielded scores of .89, .86, and .90 for pain, PCa concerns, and total score, respectively. In demonstrating content validity, the FACT-P had significant, moderate correlations with the *Brief Pain Inventory*.

Cella (2012) provided three clinical trial programs that serve as examples of validity for the FACT-P (Ahles et al., 2004; Cella, Nichol, Eton, Nelson, & Mulani, 2009; Tannock et al.,

2004). In each trial, the FACT-P predicted disease indicators, treatment progression, survival rates, and depression. In addition to validity information provided in these trials, the FACT-P was found to have acceptable reliability consistent with previous studies.

However, the FACT-P has also been reported to have poor reliability, with some subscales falling under the .7 threshold (Esper et al., 1997; Schmidt et al., 2014). Schmidt and colleagues suggest other QoL measures, such as the *Expanded Prostate Cancer Index Composite* (Wei, Dunn, Litwin, Sandler, & Sanda, 2000). However, the FACT-P was used as it has the advantage of being a PCa-specific measure and it has a mostly equivalent measure to measure QoL for the general population, the FACT-GP (Cella et al., 1993).

Empirical support for the FACT-GP is limited, as the reliability and validity information from the FACT-G is used. Brucker, Yost, Cashy, Webster, and Cella (2005) conducted a normative sample study on the FACT-G and the FACT-GP with a general adult population sample ($N = 1,075$) similar to the 2000 United States Census. Janda and colleagues (2009) conducted a study for a normative sample in Australia and also conducted a CFA of the FACT-GP. The FACT-GP was found to have the same hypothesized subscales as the FACT-G, with each item loading on its subscale as hypothesized (Cella et al., 1993). Janda and colleagues (2009) conducted a study of individuals with brain tumors ($n = 75$) and their caretakers ($n = 70$) and found that the internal consistency of the FACT-GP was .88. To the investigator's knowledge, the FACT-GP has *not* been used with a sample of partners of PCa survivors.

Relationship Satisfaction

Relationship satisfaction in the study was measured by the *Couples Satisfaction Index* (CSI; Funk & Rogge, 2007). A variety of different measures reliably measure relationship satisfaction (Graham, Diebels, & Barnow, 2011), but the CSI was chosen for multiple reasons detailed below. Essentially, the CSI is a new type of relationship satisfaction measure that was constructed using item-response theory (Harvey & Hammer, 1999) and may yield more reliable and valid results than older relationship satisfaction scales.

Couples Satisfaction Index

The CSI (Funk & Rogge, 2007) assesses relationship satisfaction based on current romantic relationships. The CSI is offered in multiple formats, including 32, 16, and 4 items. The 16-item form was used in the study in order to limit respondent fatigue (Ben-Nun, 2008) and to appropriately measure relationship satisfaction as a latent variable in SEM (Kline, 2010). Each item follows a six-point (15 items) or seven-point (one item) Likert-style response format based on satisfaction in relationships. The CSI measures relationship satisfaction unidimensionally. The creators of the CSI used item-response theory in constructing the instrument, and took items from other relational measures (e.g., *Marital Adjustment Test* [Locke & Wallace, 1959] and *Dyadic Adjustment Scale* [Spanier, 1976]) and researcher-created relationship satisfaction items.

The CSI has strong, but minimal, empirical support (Graham et al., 2011). Funk and Rogge (2007) originally designed the CSI using item-response theory, a way of constructing psychosocial measures that allows for lower numbers of items while retaining reliability and validity. The norming group in Funk and Rogge's study consisted of 5,315 participants who were

mostly White college-aged female participants. Funk and Rogge (2007) reported that the majority of participants were in serious relationships and were happy with their relationships. The authors found that the CSI had convergent validity with other relational measures and high internal consistency ($\alpha = .98$). In particular, the CSI was shown to have convergent validity, based on scale intercorrelations, with the *Dyadic Adjustment Scale* (.89; Spanier, 1976), the *Marital Adjustment Test* (.90; Lock & Wallace, 1959), the *Quality of Marriage Index* (.96; Norton, 1983), the *Relationship Assessment Scale* (.95; Hendrick, 1988), and *Semantic Differential* (.98; Karney & Bradbury, 1997; Funk & Rogge, 2007).

Graham, Diebels, & Barnow (2011) investigated reliabilities of multiple relationship satisfaction measures (e.g., the *Dyadic Adjustment Scale* and the *Marital Adjustment Test*) in a generalization meta-analysis ($k = 639$). The CSI demonstrated an average internal consistency of .94, based on five studies. Graham and colleagues note that the CSI had a higher amount of variance in internal consistencies reported between studies, between .9 and .98. However, due to the item-response construction of the measure, Graham and colleagues suggest that the CSI could be a more useful measure than traditionally constructed measures, such as the *Relationship Adjustment Scale* (Hendrick, 1988) and the *Quality of Marriage Index* (Norton, 1983).

While the CSI has limited use as compared to assessments like the *Dyadic Adjustment Scale* or the *Marital Adjustment Test*, it is a recommended measure of relationship satisfaction due its reliability and global nature (Mitnick, Heyman, & Smith Slep, 2009). Braithwaite, Selby, and Fincham (2011) found high internal consistencies with the four-item CSI ($\alpha > .90$) through multiple phases of their study, and a .87 correlation with the *Dyadic Adjustment Scale* (Spanier, 1976). With the four-item CSI, Lambert, Clark, Durtschi, Fincham, and Graham (2010) found

high internal consistencies ($\alpha > .90$) through multiple phases of their study. To the investigator's knowledge, the CSI has not been used in a sample of PCa survivors and their partners.

Research Design

The research design for the study was a descriptive correlational design (Gall et al., 2007). This allowed the investigator to examine relationships between stigma, QoL, and relationship satisfaction for both PCa survivors and their partners. Correlational research allows researchers to examine relationships between variables without manipulation. Because correlational research allows researchers to examine relationships between constructs, the investigator can measure the strength and direction of relationships between stigma, QoL, and relationship satisfaction (Tabachnick & Fidell, 2013). However, causality is *not* accounted for in correlational research. Although limited in explanation of causality, the correlational approach to the study was appropriate for the exploratory research questions.

Threats to Validity

Although there are several strengths of using a correlational research design in the study, there were certain threats to construct, internal, and external validity that needed to be addressed (Gall et al., 2007). Construct validity “concerns how well the variables chosen to represent a hypothetical construct actually capture the essence of the hypothetical construct” (Heppner, Wampold, & Kivlighan, p. 86). In supporting construct validity, the constructs for the study have been detailed in Chapter One, and the theoretical and empirical support for those constructs provided in Chapter Two. Also, using SEM allows researchers to simultaneously measure the

constructs and conduct CFA on the measures to ensure that they are appropriate for the sample of PCa survivors and their partners.

Threats to Internal Validity

The study was designed to address threats of internal validity to the study, but some threats were unavoidable. Threats to validity in the study included (a) characteristic correlations (Fraenkel, Wallen, & Hyun, 2011), (b) differential selection of participants, (c) testing, (d) mortality, (e) evaluation anxiety, and (f) reactive arrangements (Onwuegbuzie & McLean, 2003). In addition to common threats to internal validity for experimental studies (Shadish, Cook, & Campbell, 2002), Onwuegbuzie and McLean (2003) noted the importance of threats to validity for non-experimental quantitative research, and added threats to internal and external validity that were overshadowed in previous research.

- Characteristic correlations (Fraenkel et al., 2011) are threats to internal validity that occur when correlations between variables are explained by variables not being measured. In order to attempt to control for characteristic correlations, probable causes of differences in QoL (e.g., age, types of treatment, time since diagnosis) will be assessed for through the demographics form. However, there are variables unknown to the investigator that could influence the relationships in the study.
- Different selection of participants (Onwuegbuzie & McLean, 2003) is a selection bias in which two or more pre-existing groups are chosen from for the sample. In the study, the sample consisted of PCa survivors and their partners from different settings, including oncology centers and support groups. These groups may differ

- from one another (e.g., PCa survivors and their partners in support groups have higher social/family QoL than those in oncology centers). The investigator controlled for this threat to internal validity by noting the site from which a participant came, and by conducting a multivariate analysis of variance (MANOVA) to examine mean differences between the groups. If no differences existed, the data could be used together. If significant differences existed, adjustments to the analysis were made.
- Testing effects are a threat to internal validity in the study, as the answers on one scale might change the ways in which individuals answer items on another scale (e.g., the SIS could trigger feelings of social isolation and influence participants' ratings of QoL and relationship satisfaction). Testing effects were controlled for in the study by structuring the assessments in a way as to limit influences of the measures.
 - Mortality was a threat to internal validity in the study, as participation was voluntary and participants may quit the assessment at any time. The investigator controlled for this by employing pro-social techniques throughout data collection (e.g., letting the participants know that they are contributing to research on PCa to eventually help others, making the assessments easy to read and complete, use of official university emblems on informed consent to increase trust, and thanking participants for their participation before and after the assessments were completed) (Dillman, 1991; Dillman et al., 2009).
 - Evaluation anxiety was another threat to internal validity of the study. Participants may have evaluation anxiety, as they feel they need to respond or perform at a certain level, causing errors in self-report. While the study was not cognitively taxing,

feelings of having to answer quickly may have impacted responses, especially if the reading was difficult for participants.

- Reactive arrangements may occurred as a threat to internal validity as a reaction to being a participant in a study. Because individuals were taking part in a study, they might respond in socially desirable ways (to appear to have, for example, a high QoL when in fact their QoL is low). Reactive arrangements were controlled for in the study by asking participants to answer with the first thoughts or reactions that come to mind when they see the items on the measures.

Threats to external validity

Threats to external validity for the study included (a) population, (b) ecological, and (c) temporal.

- Population validity is a threat to external validity in that the findings in the study may *not* apply to all PCa survivors and their partners.
- Ecological validity is another threat in that the results of the study may *not* apply to PCa survivors and their partners from different settings and locations.
- Temporal validity is the final threat in that the results of the study may *not* generalize over time. Particularly, if PCa becomes less stigmatized over time, the influence of stigma on QoL may weaken. Though threats to validity are common in correlational research, the investigator has attempted to minimize them.

Research Hypothesis and Exploratory Research Questions

The purpose of the study was to assess the influence of stigma on PCa survivors and their partners' QoL and relationship satisfaction. The primary research hypothesis guiding the study is in the following section.

Research Hypothesis

The research hypothesis for the study was: Stigma (as measured by the SIS; Fife & Wright, 2000) will have a negative influence on QoL (as measured by the FACT-P; Esper et al., 1997 and the FACT-GP; Cella et al., 1993) and relationship satisfaction (as measured by the CSI; Funk & Rogge, 2007) of PCa survivors and their partners.

Exploratory Research Questions

1. Are there statistically significant relationships between stigma (as measured by the SIS; Fife & Wright, 2000), QoL (as measured by the FACT-P; Esper et al., 1997 and the FACT-GP; Cella et al., 1993), relationship satisfaction (as measured by the CSI; Funk & Rogge, 2007) and race for PCa survivors and their partners?

2. Are there statistically significant differences between stigma (as measured by the SIS; Fife & Wright, 2000) based on demographic variables (e.g., age and income) for PCa survivors? The hypothesized path model (Figure 2) and measurement models (Figures 3, 4, 5, and 6) visually represent the research hypothesis and chosen measures used to answer the research questions.

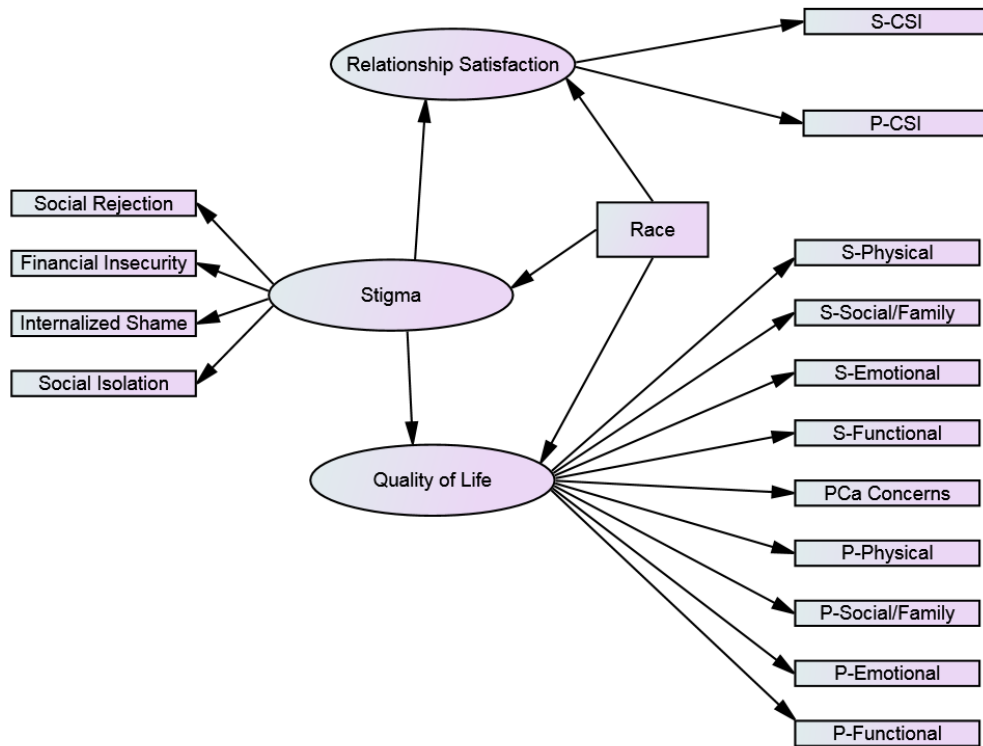


Figure 2 Hypothesized Structural Model

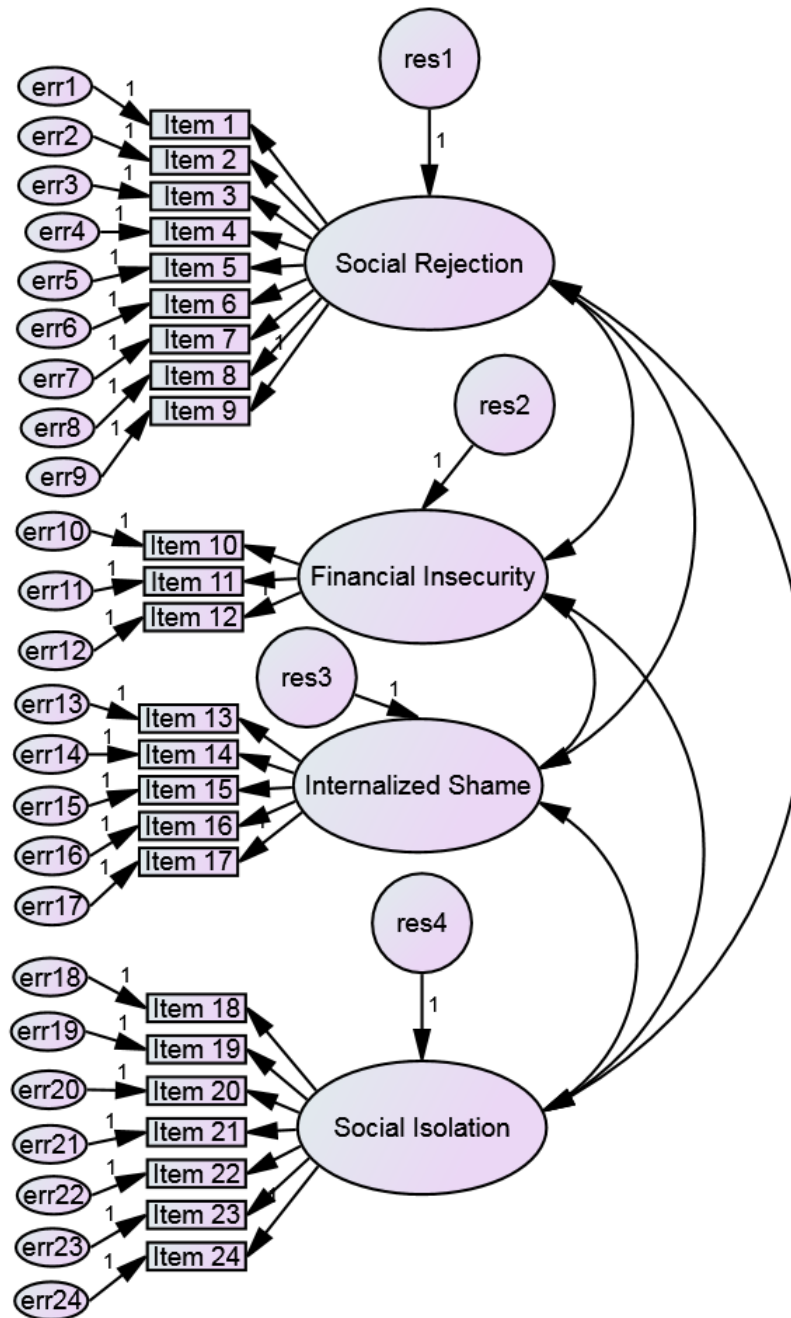


Figure 3 Hypothesized *Social Impact Scale* (SIS) Measurement Model Path Diagram

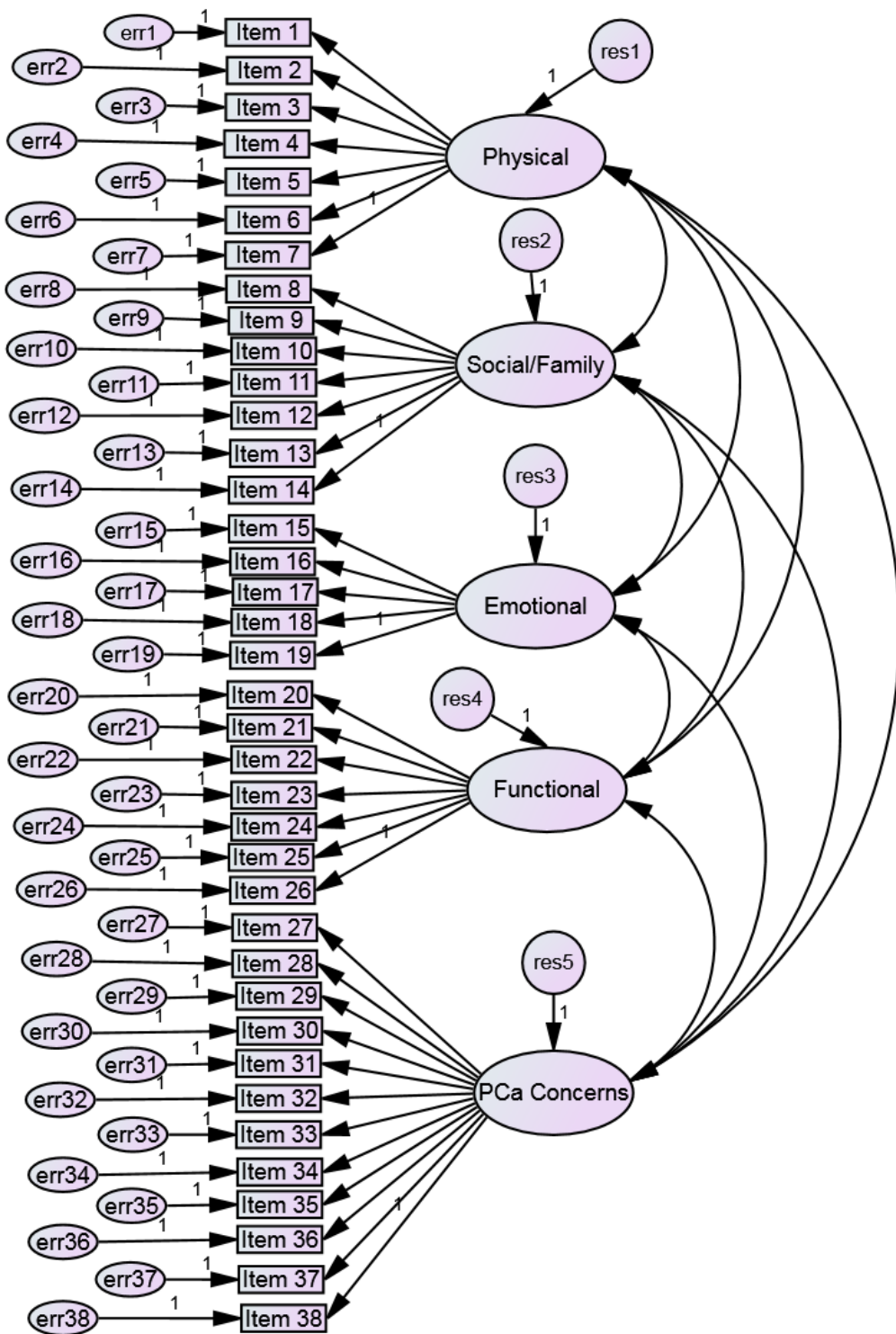


Figure 4 Hypothesized *Functional Assessment of Cancer Therapy for Patients with Prostate Cancer (FACT-P)* Measurement Model Path Diagram

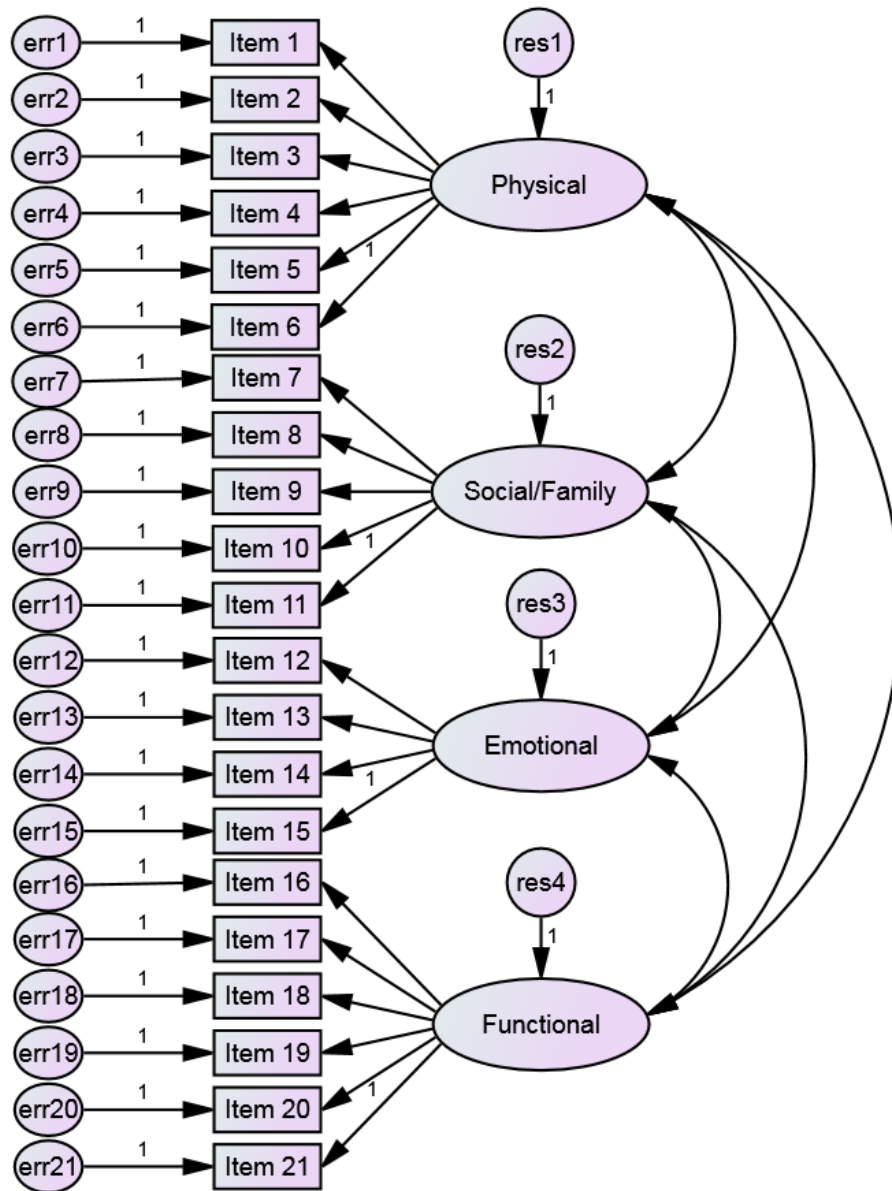


Figure 5 Hypothesized *Functional Assessment of Cancer Therapy – General Population* (FACT-GP) Measurement Model Path Diagram

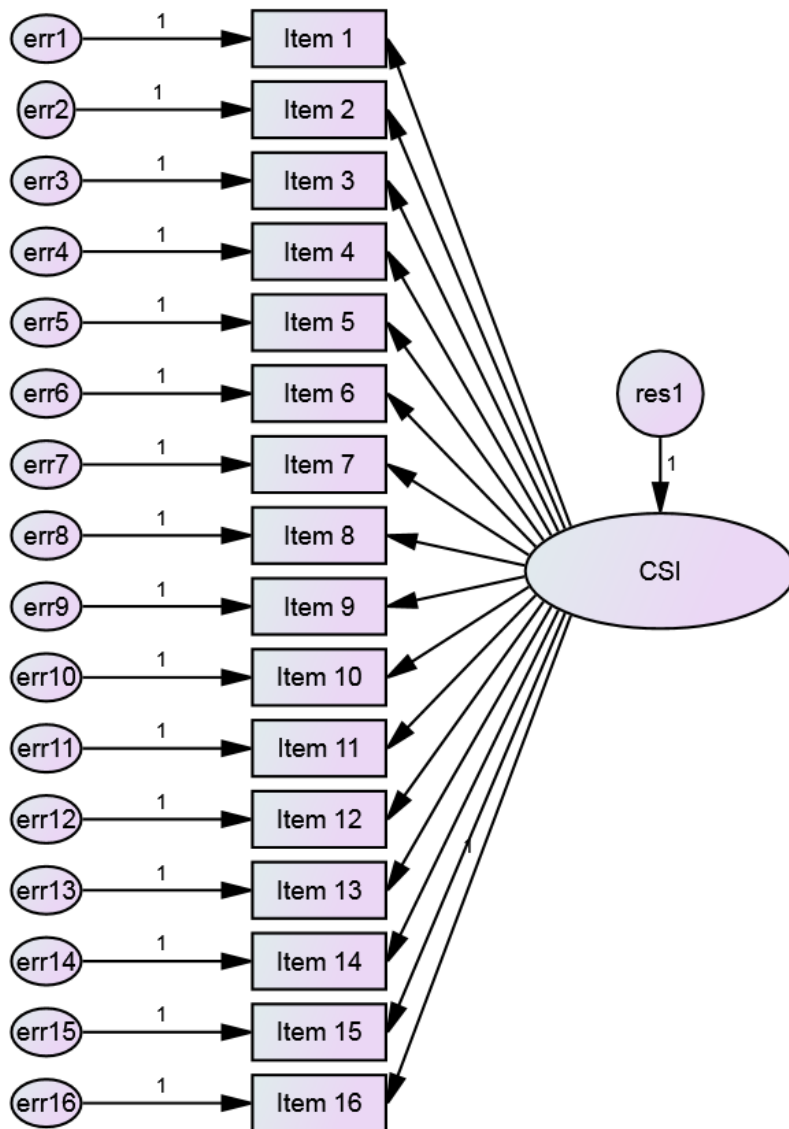


Figure 6 Hypothesized *Couples Satisfaction Index* (CSI) Measurement Model Path Diagram

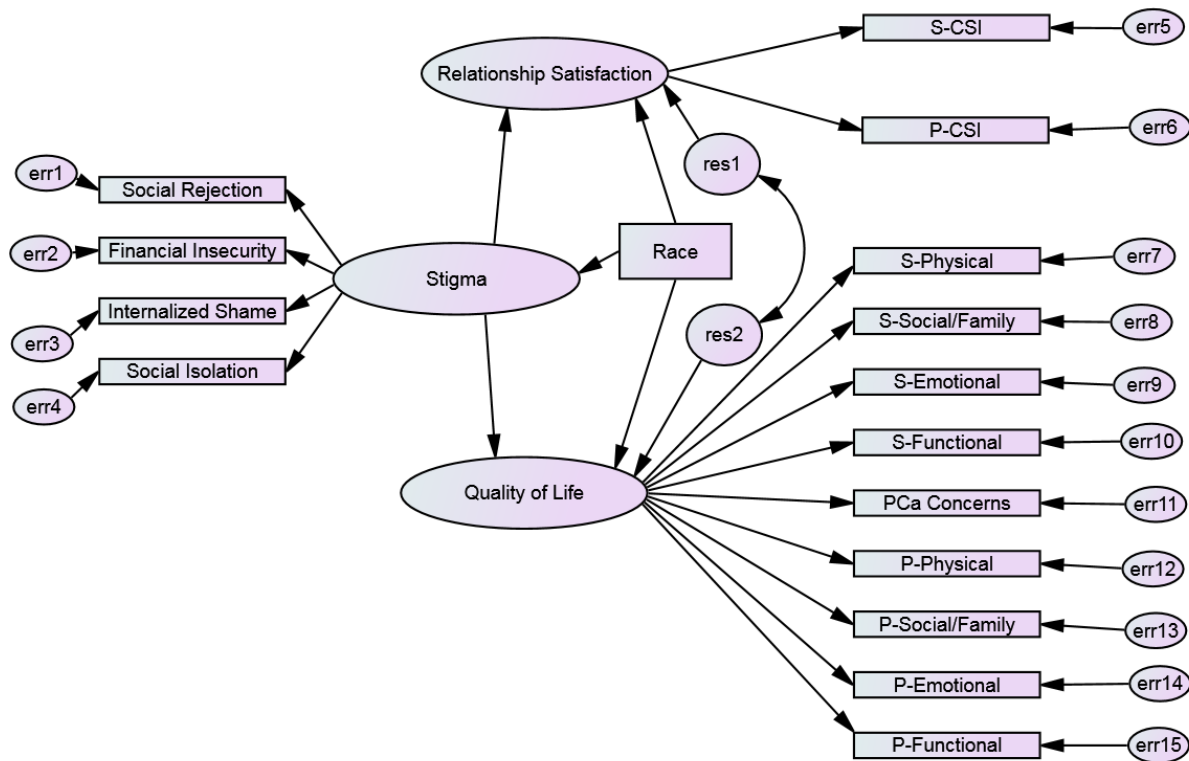


Figure 7 Hypothesized Structural Model

Data Analysis

The study utilized dyadic SEM (Kenny et al., 2006) to investigate the influence of stigma on QoL and relationship satisfaction for PCa survivors and their partners. Dyadic SEM is often used to study dyads (Kenny et al., 2006; Peugh, DiLillo, & Panuzio, 2013), and allows the investigator to examine the relationships between constructs. Data analysis for the study consisted of data collected from the demographics form created for the study, the SIS (Fife & Wright, 2000), the FACT-P (Esper et al., 1997), the FACT-GP (Cella et al., 1993), and the CSI

(Funk & Rogge, 2007). All data was inputted into the *Statistical Program Systems Software* (SPSS) 21st edition (2011). Data was analyzed with SPSS and the *Analysis of Moment Structure* (AMOS) 21st edition (2012). In using SPSS and AMOS, guidelines provided by Byrne (2010) were followed to create SEM. In order to use dyadic SEM, it is necessary to follow appropriate steps in preparing dyadic data and in conducting SEM. Descriptions of both of those issues follow.

Dyadic Data

The study utilized dyadic data (Kenny et al., 2006) to investigate the influence of stigma on QoL and relationship satisfaction for PCa survivors and their partners. In analyses with individual subjects, researchers examine assumptions of independence, which is, ensuring that the participants' data are unique and not influenced by other observations or participants. Assumptions of independence are tested in statistical analyses (e.g., Levene's Test of Independence; Tabachnick & Fidell, 2013). An alpha of less than .05 indicates a violation of independence.

Within dyadic data, the assumption of independence is frequently violated. Dyadic data is collected from two (or more) individuals in a relationship (e.g., supervisor-supervisee, parent-child, romantic relationship) with shared experiences. Thus, individuals within dyads influence each other's observations or measures. Therefore, the question researchers must ask is, to what extent do individuals in the same dyad influence one another? This question is answered by measuring the level of nonindependence (Kenny et al., 2006). Nonindependence is "the extent to

which two variables are related and how much the variables' relatedness is explained by the individuals' shared experiences" (Munyon, 2012, p. 106).

Measuring nonindependence is accomplished by creating pairwise datasets, conducting a bivariate correlation between multiple pairs of variables, and calculating the intraclass correlation. In this study, the paired variable sets included: (a) FACT-P and FACT-GP, (b) FACT-P and CSI, and (c) FACT-GP and CSI. Kenny, Kashy, and Bolger (1998) have determined that a correlation of .45 or higher denotes the level of consequential nonindependence. That is, when 45% or more of the nonindependence is explained by shared experiences, researchers increase the risk of committing a Type I error (i.e., finding statistical significance where there is none). Thus, certain steps must be taken to account for this, including dataset conversion and choice of analyses (e.g., SEM or hierarchical linear modeling). In previous PCa couples studies, observations of QoL and relationship satisfaction have been correlated with one another (Song et al., 2011). However, those correlations are small to medium correlations. Therefore, screening the data for nonindependence at the end of data collection is important to the validity of the study.

In the present study, there were three instances of consequential nonindependence (Kenny et al., 1998). Scores on the CSI correlated within dyads ($r = .67, p < .01$), as well as scores on the FACT-P social subscale and the FACT-GP social subscale ($r = .55, p < .01$) and scores between the FACT-P functional subscale and the FACT-GP social subscale ($r = .48, p < .01$). By not accounting for the shared relationship with these correlations, traditional (i.e., individual) data analysis would be done with measurement error that could be avoided by utilizing dyadic data. Thus, in order to reduce measurement error and to appropriately measure

data, dyadic data analysis was used in this study as consequential nonindependence was found. One way to account for nonindependence is to use appropriate analytic techniques, such as SEM.

Due to the choice of data analysis for the present study (i.e., SEM), measurements of nonindependence did not influence the analysis. Further, the common fate model (Ledermann & Kenny, 2012) was used as a means to measure the influence of an external or internal event on a dyad. In the present study, stigma was the internal event measured to assess its influence on PCa survivors' and partners' QoL and relationship satisfaction. A pure common fate model would consist of dyad-level variables influencing other dyad-level variables (e.g., child-rearing attitudes influencing marital satisfaction). The present study is a mixed common fate model as the model (Figure 7) uses a mixture of independent-level variables (i.e., stigma) and dyadic-level variables (i.e., QoL and relationship satisfaction). The common fate model differs from the more popular actor-partner interdependence model (Kenny et al., 2006), as in the actor-partner interdependence model, the influence of actors (e.g., PCa survivors) on partners (e.g., partners of survivors) is measured to understand the influence of one member of the dyad on another. Use of the actor-partner interdependence model in previous research has demonstrated how PCa survivors' QoL influences their partners' QoL and relationship satisfaction (Zhou et al., 2011). In using the common fate model, latent variables are used to measure influence on dyads to understand the influence of constructs on dyads. The common fate model allows for researchers to assess either individual-level or dyadic-level variables' influence on dyads as a unit. Use of the common fate model in the current study allows the investigator to analyze the shared influence that stigma has on couples facing PCa.

Creating dyadic datasets

In order to appropriately analyze PCa couples, dyadic datasets must be created (Kenny et al., 2006). Classic ways of inputting data into statistical software, like SPSS, for individuals (e.g., participant 1, participant 2, and participant 3) will not suffice for understanding differences within and between couples (Figure 8). Thus, each dyad was entered together, with variables for PCa survivors and variables for partners entered separately (see Figure 9). Compared to a traditional dataset, each individual participant was seen as a dyad. Thus, to account for all points of data, each dyad has more variables than if the dataset was created traditionally. Dyadic datasets are typically used in SEM analysis, whereas pairwise datasets (used to measure for consequential nonindependence in the study) are used with hierarchical linear modeling. In Figure 9, the variables with S (e.g., StigmaS, RelSatS, QoLS) represent scores from PCa survivors, and variables with P (e.g., StigmaP, RelSatP, QoLP) represent scores from partners. For the study, PCa survivors' scores on the SIS were inputted twice, once for survivors and once for partners, with identical data (variables StigmaS and StigmaP in Table 9). Scores on the CSI, FACT-P, and FACT-GP were entered separately.

| | Dyad | Person | Stigma | RelSat | QoL | var |
|---|------|--------|--------|--------|-------|-----|
| 1 | 1.00 | 1.00 | 5.00 | 21.00 | 41.00 | |
| 2 | 1.00 | 2.00 | 5.00 | 19.00 | 26.00 | |
| 3 | 2.00 | 1.00 | 15.00 | 15.00 | 55.00 | |
| 4 | 2.00 | 2.00 | 15.00 | 15.00 | 51.00 | |
| 5 | 3.00 | 1.00 | 2.00 | 22.00 | 37.00 | |
| 6 | 3.00 | 2.00 | 2.00 | 24.00 | 38.00 | |
| 7 | | | | | | |
| 8 | | | | | | |

Figure 8 Example of traditional dataset (screenshot from SPSS)

| | Dyad | StigmaS | RelSatS | QoLS | StigmaP | RelSatP | QoLP | var |
|---|------|---------|---------|-------|---------|---------|-------|-----|
| 1 | 1.00 | 5.00 | 21.00 | 41.00 | 5.00 | 19.00 | 26.00 | |
| 2 | 2.00 | 15.00 | 15.00 | 55.00 | 15.00 | 15.00 | 51.00 | |
| 3 | 3.00 | 2.00 | 22.00 | 37.00 | 2.00 | 24.00 | 38.00 | |
| 4 | - | - | - | - | - | - | - | |
| 5 | - | - | - | - | - | - | - | |

Figure 9 Example of dyadic dataset (screenshot from SPSS)

SEM is one of the two detailed methods for data analysis for research on dyads (Kenny et al., 2006; Peugh et al., 2013). In addition to hierarchical linear modeling, SEM allows researchers to investigate relationships within and between dyads. SEM can also be used to measure both the actor-partner interdependence model and the common fate model, two common approaches to measuring dyadic data. Previous researchers investigating dyadic data with PCa couples (e.g., Kershaw et al., 2008) have measured it using SEM. Based on the primary and exploratory research questions, SEM was an appropriate choice to analyze the dyadic data for the study.

Structural Equation Modeling

SEM is a second-generation multivariate technique that is a combination of multiple regression, path analysis, and CFA (Crockett, 2012; Tabachnick & Fidell, 2013). SEM allows researchers to test complex theoretical models and compare them to sample data. SEM is being used instead of first-generation multivariate techniques like multiple regression and path analysis as these types of analyses do *not* allow for item-based error measurement, thus creating a distorted picture of the results. It measures item-specific error in order to show a more accurate representation of the theoretical model and how it fits with sample data. Essentially, SEM allowed the investigator to investigate the primary research question of how stigma influences the QoL and relationship satisfaction of PCa survivors and their partners (Schumacker & Lomax, 2012). SEM also allowed the investigator to answer exploratory research question one, that is, were there statistically significant relationships between stigma, QoL, relationship satisfaction, and race for PCa survivors and their partners?

Utilizing SEM also allows researchers the opportunity to measure latent and manifest variables directly and indirectly, simultaneously (Crockett, 2012; Kline, 2010; Weston & Gore, 2006). Latent variables are variables that are *not* directly observed, such as stigma in the case of the study. Manifest variables are directly observed, such as a subscale of the SIS (Fife & Wright, 2000). Thus, SEM is a way to test theories derived from existing literature, by using measures that represent theoretical constructs. The latent variables in the study were stigma, QoL, and relationship satisfaction, represented by circles in the hypothesized path model (Figure 2). The manifest variables were the directly measured representations of latent variables, as well as race, which is a directly observed variable. For example, the concept of stigma is a latent variable that

is measured by the SIS (Fife & Wright, 2000), a scale used to measure stigma. As seen in the hypothesized path model (Figure 2), the subscale totals and scale totals are manifest variables and are represented by rectangles. There are two types of models in SEM: structural models and measurement models. Structural models display the latent and manifest variables for the analysis and the directions of their hypothesized relationships (Figure 7). The measurement models display individual measures used and items on those measures (Figures 3, 4, 5, and 6). One way arrows in the structural model represent directionality. For example, one arrow reaches from stigma to QoL in the structural model. The arrow from stigma to QoL indicates that stigma is predicting a relationship between itself and QoL. Two-way arrows in SEM indicate a correlation, as seen in the measurement model for the FACT-P (Esper et al., 1997; Figure 4). The subscales of the FACT-P correlate with one another, as the subscales measure distinct constructs that are related to one another. Error is estimated and removed in SEM, accounting for a lack of measurement error (Schumacker & Lomax, 2012).

The hypothesized path model for the study (Figure 2) contains circles that represent the latent variables and rectangles that represent manifest variables. Single-headed arrows represent a hypothesized direct effect, and absence of a line indicates a lack of hypothesized direct effects. For the study, a three-factor model of stigma, QoL, and relationship satisfaction was hypothesized. Stigma is a latent variable with four measured indicators (i.e., subscales on the SIS) and 24 measured items (Figure 3). Quality of life for PCa survivors is a latent variable with five measured indicators and 39 measured items. Quality of life for partners is a latent variable with four measured indicators and 21 measured items. Relationship satisfaction for PCa survivors and for their partners are two latent variables with one measured indicator and 16

measured items each. In the proposed study, it is hypothesized that higher levels of stigma will have negative relationships with QoL and relationship satisfaction.

Statistical assumptions need to be met in order to proceed with analysis once the data is collected (Kline, 2010). In using SEM, multivariate normality, linearity, multicollinearity, and residual assumptions need to be met (Ullman, 2007). Multivariate normality should exist in the data and can be checked by inspecting the data for possible outliers. If multivariate normality is not met, other estimation methods can be used. Linearity among variables should exist and can be checked through inspection of scatterplots. Multicollinearity should be addressed by inspection of variance inflation factors. Finally, residuals should be close to zero, and frequency distribution of residual covariances should be symmetrical (Ullman, 2007).

Steps of structural equation modeling

There are five steps to conducting SEM (Crockett, 2012) in the research: (a) model specification, (b) model identification, (c) model estimation, (d) model testing, and (e) model modification. *Model specification* is a process in which researchers specify two models that will create the full SEM: structural models and measurement models. The structural model is a model of the predicted relationship between latent and observed variables, without the selected measures displayed. The structural model shows the constructs being measured directly or indirectly (e.g., stigma, QOL, race, and geographic setting). The measurement model includes how the constructs are being measured (e.g., stigma being measured by the 24 items of the SIS).

The second step of SEM is *model identification* (Crockett, 2012), in which the researchers inspect the structural and measurement models to ensure that they can be measured.

Generally, identification can be measured with the equation $q(q+1)/2$, wherein q is the number of observed variables in the model. If the equation yields a number greater than the number of parameters in the model, then the model is said to be overidentified and researchers can then move on to the next step. The model is considered just-identified if the equation equals the number of parameters, and underidentified if the equation is less than the number of parameters. Just-identified and underidentified models are not sought in measuring models in SEM. The models must also be examined to ensure that they are recursive, that is, that no feedback loops exist in directionality (e.g., race \rightarrow stigma \rightarrow QOL \rightarrow race; Weston & Gore, 2006).

Data collection occurs between the model identification and model estimation steps of SEM. After data is cleaned, it must be screened for linearity, normality, outliers, and missing values, all of which could distort the results of the research (Kline, 2010).

Model estimation is the next step of SEM and requires researchers to use an estimation technique found in SEM software (e.g., AMOS). For the purposes of the study, Maximum Likelihood (ML) was used as an estimation technique; it is the most widely-used estimation technique (Kline, 2010). ML is robust to small sample sizes and moderate non-normality. If the data is highly non-normal and the sample size is large enough, researchers can use the Asymptotically Distribution Free estimation technique instead of ML. The purpose of model estimation is to estimate the closeness of a theoretical covariance to the sample covariance obtained during data collection.

The next step of SEM (Crockett, 2012) is *model testing*. In this step, the results are observed to see if the theoretical model fits the sample model. Numerous fit indices are used in SEM and there are no strict guidelines as to which to use to judge model fit. However, Weston

and Gore (2006) suggest the use of χ^2 as a global fit index, along with CFI (Bentler, 1990), RMSEA (Steiger, 1990), and SRMR (Bentler, 1995).

The final step of SEM (Crockett, 2012) is *model modification*, in which the model is adjusted and respecified (Kline, 2010) to better fit the sample data. Researchers should note that at this point they are using a data-driven model rather than a theoretically-driven model for their research. The use of SEM and the steps therein allow the research to be adequately measured, and spawns future research endeavors based on its results.

Along with SEM and dyadic data, a MANOVA was utilized to assess mean differences between participants from different sites (e.g., face to face versus online samples) in order to assess whether or not the data statistically differ from another. If differences do not exist between groups from different sites, then all of the data can be used in the analysis. A MANOVA analysis was also be used to answer exploratory research question two, by looking at differences in stigma as experienced by PCa survivors based on demographic variables (e.g., age and length of time since diagnosis).

Independent and Dependent Variables

In the study, independent and dependent variables were assessed to understand the influence of stigma on PCa survivors and their partners' QoL and relationship satisfaction. In SEM, variables can be both independent and dependent. Also, terminology in SEM calls for the use of the terms exogenous (similar to independent) and endogenous (similar to dependent) variables.

Independent/exogenous variables

For the study, stigma was the exogenous variable. Stigma was a latent variable and was measured by the SIS (Fife & Wright, 2000). Stigma is represented by four manifest variables: (a) social rejection, (b) financial insecurity, (c) internalized shame, and (d) social isolation. Stigma was chosen as an exogenous variable, since various aspects of PCa and treatment for the disease can lead to possibly stigmatizing identities for PCa survivors (Fergus et al., 2002; Maliski et al., 2008). In the analysis, it was expected that stigma influenced the endogenous variables.

Dependent/endogenous variables

For the study, QoL and relationship satisfaction were the endogenous variables. Quality of life for PCa survivors and their partners are two latent variables, measured by the FACT-P (Esper et al., 1997) and the FACT-GP (Cella et al., 1993). Quality of life for PCa survivors and their partners were represented by five and four manifest variables: (a) physical, (b) social/family, (c) emotional, (d) functional, and (e) PCa concerns. The PCa concerns variable was measured by the FACT-P only for survivors. Quality of life was chosen as an endogenous variable as it is a common outcome measure in PCa studies to assess overall well-being. Relationship satisfaction for PCa survivors and their partners were two latent variables, measured by the CSI (Funk & Rogge, 2007). Relationship satisfaction was represented by one manifest variable. Relationship satisfaction was chosen as an endogenous variable as the effects of stigma have been seen to affect couples (Doyle & Molix, 2014; Park & Park, 2014). In the analysis, it was expected that QoL and relationship satisfaction were influenced by the exogenous variable, stigma. In addition to QoL and relationship satisfaction, demographic

variables were entered as independent variables to account for possible differences between couples (e.g., age, income, and PCa treatment).

Ethical Considerations

In designing the study, ethical considerations were taken into consideration. The Institutional Review Board (IRB) application was in development and abided by common ethical guidelines (e.g., The Belmont Report, 1979). The American Counseling Association *Code of Ethics* recommendations for research and publication in counseling (ACA, 2014, Section G) also were followed to ensure ethical practices in collection, analysis, and presentation of data. Participants were provided with informed consent and were informed of their rights as participants in research.

The study necessitated ethical considerations concerning the well-being of participants. The participants of the study fell under three categories of special classes of subjects: elderly/aged persons, minorities, and terminally ill patients (IRB Guidebook, 1993). The study required participation from these populations, and thus, ethical considerations were made.

First, the majority of PCa survivors were over the age of 55 ($n = 70$). The IRB Guidebook does not indicate at what age individuals are elderly/aged persons, but because the majority of participants were above the age of 55, the investigator, when possible, ensured that consent was made with appropriate cognitive understanding. Also, the study did not require participants to physically exert themselves to participate in the study, as participants gathered at oncology centers and support groups, where they already had appointments.

The participation of minority PCa survivors and partners is integral to the study, as a majority of previously conducted PCa research has a lack of participation from minority groups (Parahoo, 2013). Also, because PCa affects more individuals of racial minorities than individuals of racial majorities (NCI, 2011), it was important to understand how the chosen constructs affect the majority of individuals diagnosed with the disease, and their partners. The IRB Guidebook (1993) notes that special consideration must be made to exclude participation of minority groups, whereas the proposed study looks for inclusion of minority groups. Thus, ethical considerations for minority groups were met for the study.

Finally, the inclusion of terminally ill patients needs to be addressed. The study was not used to investigate terminal illness, but a chronic illness. PCa is not necessarily a terminal illness, but can be for some individuals. For example, individuals diagnosed later in life, who have a variety of other health issues, may be terminally ill (Walsh & Worthington, 2012). The study did *not* target individuals with terminal illness specifically, but some participants may have been terminally ill. The study met all IRB considerations as described in chapter VI, section F.

The study posed minimal risk for participants. The risk pertained to the sensitive nature of some items on the chosen measures. For example, the PCa concerns subscale on the FACT-P contains the item “I am able to have and maintain an erection.” Some participants may have felt uncomfortable when answering questions of this nature. Concerns also exist for the CSI, as both partners were detailing their relationship satisfaction. In order to control for any issues post-assessment, participants were asked to not share their answers with one another. When possible, measures were given with participants within dyads separated and out of range of the

investigator; they were then asked to answer with their first impression, in order to limit socially desirable responses (Holtgraves, 2004; Nederhof, 1985).

Potential Limitations of the Study

Efforts were made to minimize limitations of the study. However, as with all studies, there are limitations to the study.

- Self-report measures were used in the study, but are not always valid and are subject to participant-bias. Therefore, the participants' responses on self-report measures may have influenced study results.
- The types of individuals who participated in the study may have influenced the results. There may be inherent differences between individuals who choose to participate in research and those who do not. Thus, there may have been limited variance within the data when not accounting for those who choose not to participate in research.
- All measures used in counseling research have some amount of measurement error, regardless of psychometric properties. Thus, the measures chosen for the proposed study may influence results of the study.
- Finally, research bias may occur due to use of nonprobability (i.e., convenience) sampling.

Chapter Summary

Chapter Three detailed the research methods used in the study to examine the influence of stigma (as measured by the SIS; Fife & Wright, 2000) on QoL (as measured by the FACT-P; Esper et al., 1997 and the FACT-GP; Cella et al., 1993) and relationship satisfaction (as measured by the CSI; Funk & Rogge, 2007) for PCa survivors and their partners. The population for the study included PCa survivors and their partners, but the sample was limited to individuals receiving care or consultation at oncology centers in Florida, attending PCa support groups in Florida, and attending online PCa support groups.

Data collection took place both face-to-face (in oncology centers and PCa support groups) and online (through online PCa support groups). PCa survivors and their partners each completed a packet of assessments with measures of stigma, QoL, relationship satisfaction, and demographic forms. The measures used were psychometrically and theoretically appropriate instruments for the study. The measures for the study included the SIS (Fife & Wright, 2000), the FACT-P (Esper et al., 1997), the FACT-GP (Cella et al., 1993), the CSI (Funk & Rogge, 2007), and investigator-constructed demographic forms.

The research design for the study was a descriptive quantitative correlational research design. This design was chosen as it can appropriately answer the primary research questions for the study: does stigma influence the QoL and relationship satisfaction of PCa survivors and their partners? The hypothesis for the primary research question was that stigma has a negative influence on QoL and relationship satisfaction of PCa survivors and their partners. Exploratory research for the study included: (a) Are there statistically significant relationships between stigma, QoL, and relationship satisfaction of PCa survivors and their partners and race? And (b)

are there statistically significant differences in levels of stigma between demographic variables (e.g., age and income)?

The data analysis for the study utilized dyadic SEM in order to answer the research questions. Dyadic SEM allowed the investigator to investigate relationships within and between dyads to assess the influence of stigma on PCa survivors and their partners' QoL and relationship satisfaction. Appropriate steps were taken to avoid violating statistical assumptions and to measure whether the theoretical model fits the achieved data or not.

Finally, ethical considerations and limitations to the study were discussed. Ethical considerations for the study include issues of informed consent and gathering participants from an older, medically ill population. Limitations to the study included the use of self-report measures, differential selection of participants, measurement error, and researcher bias. In Chapter Four, the results for study will be detailed.

CHAPTER FOUR: RESULTS

Chapter Four presents the results of the investigated research hypothesis and exploratory questions. The purpose of the study was to investigate the influence of stigma (as measured by the Social Impact Scale [SIS; Fife & Wright, 2000]) on prostate cancer (PCa) survivors and partners' quality of life (QoL; as measured by the Functional Assessment for Cancer Therapy for Patients with Prostate Cancer [FACT-P; Esper et al., 1997] and the Functional Assessment for Cancer Therapy – General Population [FACT-GP; Cella et al., 1993]), and relationship satisfaction (as measured by the Couples Satisfaction Index [CSI; Funk & Rogge, 2007]). The hypothesized relationships were that stigma would negatively influence QoL and relationship satisfaction for PCa survivors and their partners. In addition, exploratory research questions were investigated concerning the influence of race on stigma, QoL, and relationship satisfaction as well as differences in stigma between couples based on age and income.

The research hypothesis was analyzed using structural equation modeling (SEM), which is a statistical analysis that incorporates elements of multiple regression, path analysis, and confirmatory factor analysis (Kline, 2010). Multiple regression and multivariate analyses of variance (MANOVA) provided analysis of exploratory research questions (Tabachnick & Fidell, 2013). In Chapter Four, the results are presented first with information on (a) sampling and data collection, (b) descriptive statistics and description of participants, (c) data cleaning procedures and statistical assumptions, (d) data analysis of the research hypothesis, and (e) data analysis of the exploratory research questions.

Sampling and Data Collection

The population of interest for the study was PCa survivors and their partners. PCa survivors consisted of anyone who had received a diagnosis of PCa at any stage (e.g., directly after diagnosis, during treatment, or after treatment) and their partners were individuals with whom they were romantically or intimately involved. PCa survivors and their partners were chosen as the population of interest for this study due to previous research examining QoL (e.g., Northouse et al., 2007) and relational issues (e.g., Merz et al., 2011) of these couples and limited research pertaining to stigmatization of the disease (e.g., Else-Quest et al., 2009; Fergus et al., 2002). Stigma is not a well-defined experience in the current PCa literature; extant related literature pertains to issues surrounding treatment effects (e.g., erectile dysfunction), effects of the disease (e.g., incontinence), and how those relate to concepts of masculinity (e.g., Jenkins et al., 2004; Maliski et al., 2008).

There are an estimated three million PCa survivors currently living in the United States (NCI, 2011). The number of PCa survivors who are currently in a romantic or intimate relationship cannot be determined. Thus, to ensure a 95% confidence level of generalizability, the estimated number of PCa survivors in the United States (i.e., three million) was used to aid in determining an appropriate sample size. In order to access a variety of PCa survivors and their partners, individuals were recruited from an oncology center, six PCa support groups, and two online support groups. Participants from both face-to-face and online samples filled out identical assessments (face-to-face participants received paper and pencil packets; online participants received electronic packets).

Face-to-Face Data Collection

Data was collected at an oncology center located in northeast Florida, enabling the investigator to gain access to individuals beginning PCa treatment, during treatment, and after treatment (from one month to five years). PCa support groups, located throughout Florida, also helped the investigator gain access to survivors and their partners (either recently diagnosed, or many years past diagnosis and/or treatment).

The investigator distributed an assessment packet, which consisted of data collection instruments and demographic forms for the couple, in face-to-face data collection. Data collection instruments which had not been previously published in a consistent format (i.e., the SIS [Fife & Wright, 2000]) or that were new (e.g., the investigator-created demographic forms) were formatted following Dillman and colleagues' (2009) format for survey data collection in order to help increase participant response and to collect accurate data.

Online Data Collection

In the online data collection, assessment packets were distributed using the Qualtrics online survey creator. Each data collection instrument was adapted to conform to Dillman and colleagues' (2009) guidelines for formatting web-based surveys. Adaptation and formatting pertained only to the appearance of the instruments, rather than the content. The Tailored Design Method (TDM) was utilized to increase response rate through pro-social methods (e.g., letting participants know that they were helping other couples by participating in the survey). Although strict adherence to the TDM (e.g., five contact method) could have increased participant response

rate, the methods used for this study ensured anonymity of participants and decreased participant fatigue (Ben-Nun, 2008) by only being exposed to the study once.

The dissertation committee reviewed and approved the face-to-face data collection instruments and the online data collection instruments. Several of the investigator's colleagues also reviewed data collection instruments. All suggestions from the dissertation committee and colleagues were implemented related to the content of the demographic forms (e.g., including treatment variables) and readability of the online survey (e.g., font size).

Descriptive Data Results

The descriptive data for the achieved sample provides insight into the types of individuals who participated in the current study. Response rates and demographics for PCa survivors and their partners are included in the descriptive data results.

Response Rates

Based on the number of assessment packets given to couples and individuals in the face-to-face data collection, 158 couples were invited to participate in the study. The number of individuals in online PCa support groups was estimated to be 1,500 based on membership numbers provided by online support groups in February 2015. Because there is not a reliable way to estimate the number of individuals who encountered the advertisement to participate in the study, and we cannot calculate the number of eligible individuals in those groups, these individuals were not included in response rate calculations. In total, 80 assessment packets were returned either from face-to-face or online samples. Seventy assessment packets were returned in the face to face sample and 10 assessment packets were returned in the online sample. Out of the

70 assessment packets returned in the face-to-face sample, 4 were returned with only one packet in the envelope (i.e., either the PCa survivor or partner packet was returned), and one was returned with only the demographic form completed. Out of the 10 assessment packets returned in the online sample, 3 abandoned the assessment without providing any usable data (e.g., answered none of the items on the assessments). Due to these issues with the data, 72 of the 80 assessment packets were used in data analysis. Of the face-to-face couples included in the sample, 53 came from an oncology center and 15 came from support groups. The response rate for the face to face sample was 41%. Once data was collected, the investigator input the data into the Statistical Package for the Social Sciences (SPSS) 21 (2012) and participant characteristics, along with descriptive data, were analyzed.

Demographics

Participants provided demographic information through investigator-designed demographic forms. Demographic information included age, race, gender, income, and disease-related questions. Demographic information was collected because information from previous researchers discovered certain demographic information (e.g., age) has an impact on PCa survivors and their partners (e.g., Diefenbach et al., 2008). The following section contains information on demographics for participants in the present study (see Table 1).

The majority of PCa survivors in the study were between 66 and 75 years of age (47.2%), followed by those between 56 and 65 years of age (36.1%), between the ages of 76 and 85 (12%), between the ages of 46 and 55 (2.8%), and between the ages of 86 and 95 (1.4%). Partners followed similar trends, with 43.1% between the ages of 66 and 75, 33.3% between the

ages of 56 and 65, 12.5% between the ages of 46 and 55, 5.6% between the ages of 76 and 85, 2.8% between the ages of 36 and 45, and 2.8% between the ages of 86 and 95. In the sample collected for the study, the majority of PCa survivors indicated that they were “White” (79.2%), while smaller portions of the study described themselves as “Black” (16.7%), “Asian” (2.8%), and “American Indian/Alaska Native” (1.4%). Partners followed similar trends, with the majority describing themselves as “White” (79.2%) and smaller portions describing themselves as “Black” (16.7%), “Asian” (2.8%), and “Biracial/Multiracial” (1.4%).

In regards to sex identification, the majority of PCa survivors reported that they were male (98.6%), and a small portion indicated that they were female (1.4%). The majority of partners reported that they were female (97.2%); a small portion indicated that they were male (2.8%). The majority of couples were married (98.6%), and a smaller portion indicated that they were partnered (1.4%). Regarding sexual orientation, the vast majority of PCa survivors identified as heterosexual (97.2%), and a smaller portion identified “other” as being their sexual orientation (1.4%); both values were mirrored by partners. In regards to education, most PCa survivors (27.8%) had at least a Bachelor’s degree and most partners (30.6%) also had at least a Bachelor’s degree. Income for couples, as reported by PCa survivors (29.2%) and their partners (20.8%) was between \$60,000 and \$79,999. A few PCa survivors (9.7%) and partners (12.5%) did not report income.

Few items on the demographics forms for PCa survivors and partners were different from one another. PCa survivors answered questions related to diagnosis, severity of disease, and treatment. Both PCa survivors and partners then answered questions related to the presence of any chronic illnesses (excluding PCa). For PCa survivors, the majority of participants (44.4%)

did not know the stage of their cancer. Other PCa survivors indicated having stage zero cancer (26.4%), stage one cancer (6.9%), stage two cancer (5.6%), stage four cancer (2.8%), stage three cancer (1.4%), and 11.1% did not report cancer stage. The majority of PCa survivors indicated that it had been one to three years since they received their diagnosis (41.7%). Other PCa survivors had received diagnoses seven to nine months previous (9.7%), over six years previous (9.7%), four to six months previous (8.3%), zero to three months previous (7.7%), four to six years previous (6.9%), and 10-12 months previous (5.6%), with 9.7% not reporting the amount of time since diagnosis.

The majority of PCa survivors in the sample had been treated for PCa (94.4%). The types of treatment for PCa varied, with the majority having more than one type of treatment (40.3%), including a combination of hormone therapy, radiation therapy, and/or surgery. Approximately 47% of the sample had some type of radiation therapy, with 27.8% having external radiation, 9.7% having internal radiation, and 9.7% not specifying what type of radiation. Other PCa survivors reported having surgery (7%), or other types of treatment (1.4%), such as hormone treatment, with 4.2% not reporting type of treatment (possibly due to not being treated). Of those treated, over half (51.4%) had completed treatment. The reported demographics will be used in order to answer the exploratory research questions. Before moving to primary analyses, preliminary analyses were conducted on the data to check for missing values and statistical assumptions for dyadic data and SEM.

Table 1 Demographic Information for Participants

| Demographic | Total (<i>n</i>) | Percentage |
|-------------|--------------------|------------|
|-------------|--------------------|------------|

| Demographic | Total (n) | Percentage |
|-----------------------------------|-----------|------------|
| Age – PCa survivor | | |
| 46-55 | 2 | 2.8 |
| 56-65 | 26 | 36.1 |
| 66-75 | 34 | 47.2 |
| 76-85 | 9 | 12.5 |
| 86-95 | 1 | 1.4 |
| Age – Partner | | |
| 36-45 | 2 | 2.8 |
| 46-55 | 9 | 12.5 |
| 56-65 | 24 | 33.3 |
| 66-75 | 31 | 43.1 |
| 76-85 | 4 | 5.6 |
| 86-95 | 2 | 2.8 |
| Race – PCa survivor | | |
| American Indian/Alaska Native | 1 | 1.4 |
| Asian | 2 | 2.8 |
| Black | 12 | 16.7 |
| White | 57 | 79.2 |
| Race – Partner | | |
| Asian | 2 | 2.8 |
| Black | 12 | 16.7 |
| White | 57 | 79.2 |
| Biracial/Multiracial | 1 | 1.4 |
| Gender – PCa survivor | | |
| Male | 71 | 98.6 |
| Female | 1 | 1.4 |
| Gender – Partner | | |
| Male | 2 | 2.8 |
| Female | 70 | 97.2 |
| Relationship Status | | |
| Married | 71 | 98.6 |
| Partnered | 1 | 1.4 |
| Sexual Orientation – PCa survivor | | |
| Heterosexual | 70 | 97.2 |
| Other | 1 | 1.4 |
| Missing | 1 | 1.4 |

| Demographic | Total (<i>n</i>) | Percentage |
|------------------------------|--------------------|------------|
| Sexual Orientation – Partner | | |
| Heterosexual | 70 | 97.2 |
| Other | 1 | 1.4 |
| Missing | 1 | 1.4 |
| Education – PCa Survivor | | |
| Grammar School | 1 | 1.4 |
| High School or Equivalent | 14 | 19.4 |
| Vocational/Technical School | 5 | 6.9 |
| Associate’s Degree | 13 | 18.1 |
| Bachelor’s Degree | 20 | 27.8 |
| Master’s Degree | 12 | 16.7 |
| Doctoral Degree | 6 | 8.3 |
| Professional Degree | 1 | 1.4 |
| Education – Partner | | |
| High School or Equivalent | 22 | 30.6 |
| Vocational/Technical School | 9 | 12.5 |
| Associate’s Degree | 12 | 16.7 |
| Bachelor’s Degree | 22 | 30.6 |
| Master’s Degree | 6 | 8.3 |
| Professional Degree | 1 | 1.4 |
| Income – PCa Survivor | | |
| 10,000-19,999 | 2 | 2.8 |
| 20,000-39,999 | 11 | 15.3 |
| 40,000-59,999 | 7 | 9.7 |
| 60,000-79,999 | 21 | 29.2 |
| 80,000-99,999 | 10 | 13.9 |
| Over 100,000 | 14 | 19.4 |
| Missing | 7 | 9.7 |
| Income – Partner | | |
| 0-9,999 | 2 | 2.8 |
| 10,000-19,999 | 3 | 4.2 |
| 20,000-39,999 | 7 | 9.7 |
| 40,000-59,999 | 12 | 16.7 |
| 60,000-79,999 | 15 | 20.8 |
| 80,000-99,999 | 8 | 11.1 |
| Over 100,000 | 16 | 22.2 |

| Demographic | Total (n) | Percentage |
|--------------------------------------|-----------|------------|
| Missing | 9 | 12.5 |
| Time Since Diagnosis | | |
| 0-3 Months | 6 | 8.3 |
| 4-6 Months | 6 | 8.3 |
| 7-9 Months | 7 | 9.7 |
| 10-12 Months | 4 | 5.6 |
| 1-3 Years | 30 | 41.7 |
| 4-6 Years | 5 | 6.9 |
| Over 6 Years | 7 | 9.7 |
| Missing | 7 | 9.7 |
| Stage of Cancer | | |
| Zero | 20 | 27.8 |
| One | 5 | 6.9 |
| Two | 4 | 5.6 |
| Three | 1 | 1.4 |
| Four | 2 | 2.8 |
| I Don't Know | 32 | 44.4 |
| Missing | 8 | 11.1 |
| Treated for PCa | | |
| Yes | 68 | 94.4 |
| No | 4 | 5.6 |
| Type of Treatment | | |
| Surgery | 1 | 1.4 |
| Surgery – Prostatectomy | 4 | 5.6 |
| Radiation | 7 | 9.7 |
| Radiation – External | 20 | 27.8 |
| Radiation – Internal | 7 | 9.7 |
| Other | 1 | 1.44 |
| Multiple | 29 | 40.3 |
| Missing | 3 | 4.2 |
| Completed Treatment for PCa | | |
| Yes | 37 | 51.4 |
| No | 31 | 43.1 |
| Missing | 4 | 5.6 |
| Additional Diagnoses – PCa survivors | | |
| Cancer | 16 | 39.0 |

| Demographic | Total (<i>n</i>) | Percentage |
|---------------------------------|--------------------|------------|
| Diabetes | 7 | 17.1 |
| Heart Disease | 6 | 14.6 |
| Osteoporosis | 1 | 2.4 |
| Parkinson's Disease | 2 | 4.9 |
| Multiple Diagnoses | 9 | 22 |
| Additional Diagnoses – Partners | | |
| Cancer | 4 | 13.3 |
| COPD | 1 | 3.3 |
| Diabetes | 4 | 13.3 |
| Heart Disease | 1 | 3.3 |
| Osteoporosis | 2 | 6.7 |
| Other | 4 | 13.3 |
| Multiple Diagnoses | 14 | 46.7 |

Descriptive Data Analysis

In addition to the participant characteristics, each assessment instrument was analyzed. Descriptive data analysis provides a more detailed examination of those who participated in the study. In the analysis for each assessment instrument, the format of the instrument, subscale reliabilities, and measures of central tendency are described.

Stigma

The instrument used to measure stigma was the Social Impact Scale (Fife & Wright, 2000). There were 24 items on the SIS, each measuring stigma with four response options to each item (i.e., Strongly Disagree, Disagree, Agree, and Strongly Agree). The SIS was designed to measure stigma on four subscales: social rejection, financial insecurity, internalized shame,

and social isolation. The first two subscales measure social stigma and the other two measure self-stigma. Reliability analysis was conducted for each SIS subscale. Using Cronbach's α , the social rejection subscale ($\alpha = .865$), the financial insecurity subscale ($\alpha = .830$), the internalized shame subscale ($\alpha = .752$), and the social isolation subscale ($\alpha = .938$) indicated acceptable reliability. Measures of central tendency and dispersion for each subscale are listed in Table 2.

Table 2 Social Impact Scale Measures of Central Tendency and Dispersion

| Instrument | <i>M</i> | <i>SD</i> | <i>Mdn</i> | Mode | Range |
|----------------------|----------|-----------|------------|------|--------|
| Social Rejection | 11.02 | 3.15 | 9 | 9 | 9 - 22 |
| Financial Insecurity | 4.01 | 1.81 | 3 | 3 | 3 - 12 |
| Internalized Shame | 7.48 | 2.68 | 7 | 5 | 5 - 16 |
| Social Isolation | 10.28 | 4.52 | 7 | 7 | 7 - 23 |

Quality of Life

The instruments used to measure QoL were the Functional Assessment of Cancer Therapy – Prostate (Esper et al., 1997) for PCa survivors and the Functional Assessment of Cancer Therapy – General Population (Cella et al., 1993) for partners. There were 39 items on the FACT-P, and 24 items on the FACT-GP, with five response options to each item (i.e., Not at all, A little bit, Somewhat, Quite a bit, and Very much). The FACT-P and FACT-GP were designed to measure QoL on four subscales: physical well-being, social/family well-being, emotional well-being, and functional well-being. The FACT-P also contained PCa-specific additional concerns on another subscale (e.g., “*I have difficulty urinating*”). Reliability analysis was conducted for each of the FACT-P and FACT-GP subscales. Using Cronbach's α , the physical well-being subscale (FACT-P $\alpha = .869$, FACT-GP $\alpha = .830$), the social/family well-

being subscale (FACT-P $\alpha = .781$, FACT-GP $\alpha = .644$), the emotional well-being subscale (FACT-P $\alpha = .646$, FACT-GP $\alpha = .807$), and the functional well-being subscale (FACT-P $\alpha = .884$, FACT-GP $\alpha = .848$) indicated acceptable reliability and were in line with previous psychometric findings (Hamoen et al., 2014). The FACT-P additional concerns subscale yielded a very low alpha level ($\alpha = .123$; Tavakol & Dennick, 2011). However, this is not unexpected, as the subscale is not used to measure a specific domain, but rather an assortment of specific concerns. Based on the measurement model analysis later in Chapter Four, the FACT-P additional concerns subscale did not yield any statistical miscalculations, as items on the subscale were factored in with related items on the other remaining subscales or were used to create their own reliable factor. Measures of central tendency and dispersion for each subscale are listed in Table 3.

Table 3 Functional Assessment for Cancer Therapy – Prostate and Functional Assessment for Cancer Therapy – General Population Measures of Central Tendency and Dispersion

| Instrument | <i>M</i> | <i>SD</i> | <i>Mdn</i> | Mode | Range |
|----------------------------------|----------|-----------|------------|------|---------|
| FACT-P Physical Well-being | 22.77 | 5.48 | 24.5 | 26 | 0 - 28 |
| FACT-P Social/Family Well-being | 21.62 | 4.49 | 23 | 24 | 10 - 28 |
| FACT-P Emotional Well-being | 19.09 | 4.78 | 20 | 24 | 6 - 24 |
| FACT-P Functional Well-being | 21.59 | 5.75 | 23 | 28 | 6 - 28 |
| FACT-P Additional Concerns | 33.06 | 8.82 | 34 | 29 | 12 - 48 |
| FACT-GP Physical Well-being | 20.40 | 3.72 | 21 | 24 | 5 - 24 |
| FACT-GP Social/Family Well-being | 15.43 | 3.24 | 16 | 16 | 7 - 20 |
| FACT-GP Emotional Well-being | 13.16 | 3.10 | 14 | 16 | 4 - 16 |
| FACT-GP Functional Well-being | 18.23 | 4.55 | 19 | 22 | 5 - 24 |

Relationship Satisfaction

The instrument used to measure relationship satisfaction was the Couples Satisfaction Index (Funk & Rogge, 2007). There were 16 items on the CSI, each measuring relationship satisfaction as a unidimensional concept. Response options varied on the CSI, but all followed a Likert-scale style (e.g., Not at all, A little, Somewhat, Mostly, Almost Completely, and, Completely). Both PCa survivors and their partners completed the CSI. Reliability analysis was conducted for each CSI. Using Cronbach's α , both PCa survivors' CSI ($\alpha = .966$) and partners' CSI ($\alpha = .968$) indicated acceptable reliability and were in line with previous psychometric findings (Graham et al., 2011). Measures of central tendency and dispersion for each scale are listed in Table 4.

Table 4 Couples Satisfaction Index Measures of Central Tendency and Dispersion

| Instrument | <i>M</i> | <i>SD</i> | <i>Mdn</i> | Mode | Range |
|------------------------------------|----------|-----------|------------|------|---------|
| PCa Couples Satisfaction Index | 66.66 | 14.38 | 71 | 79 | 15 - 81 |
| Partner Couples Satisfaction Index | 64.76 | 15.17 | 68.5 | 71 | 12 - 81 |

The final descriptive analysis took place post-hoc to ensure that the face-to-face and online samples could be combined in a representative sample for the current study. An independent samples t-test was conducted to assess mean differences between the two groups. There was a significant difference, $t(70) = -4.08, p < .05$, between levels of self-stigma (as measured by the redefined factor structure detailed later in the chapter): PCa survivors in the face-to-face group ($M = 8.5$) measured lower than survivors in the online group ($M = 14.5$).

None of the other variables were different at a .05 level for either PCa survivors or their partners. Although there was a difference in self-stigma, the online sample was included in the analysis as it only accounted for a small portion of the sample (9.7%). However, interpretations of the findings of the study should be made with a caveat that the findings may not be representative of all PCa survivors and their partners.

Preliminary Analyses and Statistical Assumptions

Preliminary analyses of the data were conducted to ensure that the sample data were appropriate for primary analyses. Multiple preliminary analyses and statistical assumptions were checked, including (a) data-entry errors and missing values, (b) dyadic consequential nonindependence, and (c) SEM statistical assumptions.

Data-Entry Errors and Missing Values

First, the data was entered into SPSS (2012) and checked for any abnormal values (e.g., values higher than responses available on assessments) or any data-entry issues. Following entering data, missing values were noted. If missing data makes up for more than 5% of the dataset, further analyses must take place to adjust for missing data (Tabachnick & Fidell, 2013). In this study, less than 5% of data was missing. However, in order to ensure proper subscale and total assessment scores with the size of this dataset, missing data for continuous variables (e.g., non-demographic data) were addressed.

There are multiple methods for filling in missing data (e.g., mean replacement and expectation maximization). For the dataset in this study, multiple imputation (Rubin, 1987) was the most appropriate method for imputing data, as it is seen as the most respectable method for

addressing missing data (Tabachnick & Fidell, 2013). Expectation maximization was also considered to address missing data, as AMOS (Arbuckle, 2012) utilizes it for missing data automatically. However, based on analysis utilizing both SPSS (2012) and AMOS (Arbuckle, 2012), multiple imputation was used to utilize the same values in all analyses. Multiple imputation is a process wherein missing data points are estimated from participants' previous responses and other participants' responses for that same item (Tabachnick & Fidell, 2013). In multiple imputation, scores are predicted multiple times (Graham, Cumsille, & Elek-Fisk, 2003; Rubin, 1996). Data was imputed five times through the multiple imputation command on SPSS. Each imputed data point was then summed and averaged to create a new dataset with no missing continuous data. Following the missing values process, assumptions for dyadic data and SEM were checked.

Dyadic Consequential Nonindependence

In order to treat data as individual data, it is necessary for data to be independent (Kenny et al., 2006). However, with data from dyads, it is possible for data to be nonindependent. Thus, Kenny and colleagues (2006) suggest that researchers investigate variables for levels of consequential nonindependence. Kenny and colleagues (1998) suggest that any correlation exceeding .45 should be categorized as nonindependent. Correlations were examined between the dependent variables (i.e., total CSI scores, subscale FACT-P scores, and subscale FACT-GP scores) to check for consequential nonindependence. Three correlations were found to be significant and correlate above .45; a correlation between total CSI scores ($r = .67, p < .01$), a correlation between the FACT-P social subscale and the FACT-GP social subscale ($r = .55, p <$

.01), and a correlation between the FACT-P functional subscale and the FACT-GP social subscale ($r = .48, p < .01$). Further, the achieved power for the test for nonindependence was greater than .8, based on the population correlation of the sample. Power for tests of nonindependence are based on the sample size and population correlation. Larger sample sizes allow for smaller population correlations and adequate power (Cohen, 1992), and conversely, larger population correlations allow for smaller samples to achieve adequate power. A sample of 72 couples and population correlations greater than .5 yield adequate power (e.g., .8; Cohen, 1992) for the test of nonindependence.

When working with data indicating consequential nonindependence in SEM, Kenny and colleagues (2006) suggest providing a covarying (i.e., double headed) arrow between the error terms of the variables that correlate above .45 within a dyad. Thus, the structural equation model was changed to add covariance between scores on the CSI, scores on the FACT-P social subscale and FACT-GP social subscale, and scores on the FACT-P functional subscale and the FACT-GP social subscale. The changed structural model is shown below (Figure 10).

Structural Equation Modeling Statistical Assumptions

In order to move forward with the primary analyses, statistical assumptions should be met before analyzing data using SEM. Multiple sources (e.g., Byrne, 2010; Kline, 2010) suggest a variety of statistical assumptions to check, most of which fall in line with assumptions of multiple regression, a precursor to SEM (Tabachnick & Fidell, 2013). Statistical assumptions examined in this study included (a) checking for outliers, (b) normality assumptions, (c) limited multicollinearity, and (d) appropriate linearity.

Both univariate and multivariate outliers were searched for in the dataset. First, univariate outliers of dependent variables were detected by converting total (CSI) and subscale (FACT-P, FACT-GP, and SIS) scores to z-scores. Scores were then listed as ascending and examined. A general guideline for detecting outliers is 3.29 standard deviations above the mean (Tabachnick & Fidell, 2013). Four variables were found to be outliers: one score on the survivor CSI, one score on the partner CSI, one score on the SIS, and one score on the FACT-GP physical subscale. Due to these univariate outliers, transformations were attempted on each variable. Based on the shape of the distribution for each variable, which were negatively, Tabachnick and Fidell (2013) suggested a reflection and square root. However, after examination of the transformed variables, univariate outliers still existed and the transformation did not improve the normality of the distribution. Thus, the four transformed variables were deleted, leaving the original numbers. Univariate outliers for the independent variables (i.e., subscales of the SIS) were detected. Based on the distribution of scores, which each had positive skew, square root transformations were performed. The square root transformations yielded distributions free of outliers and reduced skewness and kurtosis in the dataset.

Multivariate outliers were examined in the dataset utilizing the Mahalanobis distance, the distance between a point and a centroid. Performing a regression analysis in the dataset and creating a new variable revealing the distribution as a standardized score provided a measure of Mahalanobis distance. Because Mahalanobis distance is measured by χ^2 , a new variable was created with a χ^2 analysis of the Mahalanobis distance variable. No significance values were equal to or less than 0.01. No case demonstrated a significant χ^2 value (which would indicate

multivariate outliers), and it was determined that the data met the assumption for multivariate normality.

Next, tests for normality include examining the distribution of scores in a dataset, usually through skewness and kurtosis indices. In examining the skewness of variables, none had a skewness greater than 1.9, falling under the generally-approved value of less than 3 (Klein, 2010). Kurtosis values are especially important when conducting SEM analyses as they are susceptible to extreme kurtosis, usually defined as a kurtosis value above 9 (Byrne, 2010). In examining the kurtosis of variables, none had a kurtosis greater than 7, falling under the generally-approved value of less than 9.

However, multivariate kurtosis, which is especially important when conducting SEM analyses, was found to exceed normal values. Byrne (2010) suggests examining Mardia's normalized estimate of multivariate kurtosis (1970; 1974) to assess for multivariate normality through Analysis of Moment Structures (Amos; 2012). The cutoff level suggested by Bentler (2005) is for no value to be larger than five. Throughout each confirmatory factor analysis (CFA) conducted before the primary structural analysis (detailed in the next section), the estimate of multivariate kurtosis was larger than five.

In order to control for non-normality, multiple options were examined. First, the estimation method chosen for the SEM analysis, maximum likelihood, tends to perform well with non-normal data (Gold, Bentler, & Kim, 2003; Sharma, Durvasula, & Dillon, 1989; Yuan & Bentler, 2000). Asymptotic distribution-free estimation tends to perform better than maximum likelihood with non-normal data, however it was not chosen as it requires larger sample sizes than were available for the present study ($N > 1,000$). In addition to alternate estimation methods,

alternative χ^2 statistics were considered (Bollen & Stine, 1992; Satorra & Bentler, 2001). Bootstrapping (Byrne, 2010) was explored as it was available in AMOS 21. Bootstrapping of data allows researchers to explore generated subsamples of their data to work with estimated sample sizes that are randomly substituted (Byrne, 2010). Bootstrapping thus should alter estimates, variances, and fit indices for data. As displayed in Table 5, bootstrapping did not alter fit indices in any substantial way from the original CFA analyses with factor loadings created by the authors of the SIS. Of note, however is the change in the χ^2 significance due to Bollen-Stine bootstrap (Bollen & Stine, 1992). However, because the study uses numerous fit indices, the Bollen-Stine bootstrap will not suffice for measuring model fit. Thus, maximum likelihood was used as the estimation method in order to accommodate for multivariate non-normality. Other methods to control for nonnormality were explored in measuring the factor loadings of the chosen assessments, explained in detail in the next section.

Table 5 Stigma Measurement Model Fit Indices Without Bootstrapping and With Bootstrapping

| Bootstrapping | χ^2 | <i>Df</i> | <i>P</i> | CFI | TLI | RMSEA | SRMR |
|-----------------------|----------|-----------|----------|-----|-----|-------|------|
| Without Bootstrapping | 540.44 | 246 | .000 | .79 | .76 | .13 | .11 |
| With Bootstrapping | 540.44 | 246 | .637 | .79 | .76 | .13 | .11 |

Multicollinearity was also examined in the dataset to ensure that the variables do not correlate too highly with one another and become redundant. Both tolerance and VIF values are measures of multicollinearity, with tolerance of greater than .10 and VIF of less than 9 being acceptable values (Tabachnick & Fidell, 2013). Multiple regression analyses were conducted

with total and subscale scores of the assessments for this study. All tolerance values in regression analyses revealed that tolerance was greater than .5 and that VIF values were less than 3.1, offering the conclusion that the sample had limited multicollinearity. However, correlations of independent variables are also measured to examine multicollinearity, with correlations $< .7$ being held as standards for studies looking to reduce multicollinearity. The independent variables were subjected to a correlation analysis, with the highest correlation being $r = .72$. While this value may be troublesome in some analyses, because the independent variables are subscales purported to measure different aspects of one concept (i.e., stigma) and the tolerance and VIF values were acceptable, multicollinearity was deemed to be acceptable for analysis. Finally, linearity was checked by examining residual P-P plots from regression analyses. Based on the regression analyses, all of the data was at least moderately linear. With the statistical assumptions addressed, the primary analyses attempted to answer the primary research hypothesis and exploratory research questions.

Research Hypothesis and Exploratory Research Questions

The purpose of this study was to examine PCa stigma and how it influences both QoL and relationship satisfaction for both survivors and their partners. Further, the study also examined the influence of race on these relationships and the extent to which demographic variables predict stigma. The research hypothesis and exploratory questions were analyzed using SEM (Kline, 2011) and ANOVA (Stevens, 2007). Structural equation modeling and ANOVA analyses were followed for best practice in research, including the five steps of SEM (Crockett, 2012): (a) model specification, (b) model identification, (c) model estimation, (d) model testing,

and (e) model modification. Model specification and identification steps of SEM occurred prior to data analysis. These steps include building hypothesized structural and measurement models to test the primary research hypothesis, as well as to ensure that the hypothesis can be tested by ensuring that the models are appropriately identified (e.g., non-recursive paths, appropriate number of indicator variables per latent variable, and inclusion of marker variables) (Crockett, 2012; Kline, 2011).

The next steps of SEM required examination of data. Numerous fit indices were used for SEM analysis, including (a) χ^2 , (b) comparative fit index (CFI), (c) Tucker-Lewis index (TLI), (d) root mean square error of approximation (RMSEA), and (e) standardized root mean square residual (SRMR). The fit indices chosen represent both incremental fit indices (e.g., CFI and TLI) and absolute fit indices (e.g., RMSEA and SRMR) (Kenny, 2014). Larger values for incremental fit indices indicate a good model fit, whereas smaller values for absolute fit indices indicate good model fit. Kenny (2014) describes incremental fit indices as how close a model is to the best possible model, whereas absolute fit indices measure how bad a model is. Comparative fit indices (not to be confused with the CFI) were not used as the investigator did not statistically compare models. Other fit indices (e.g., normed fit index) were considered for use in the study, but the chosen fit indices were chosen to enhance parsimony and limit redundancy in fit statistics (Kenny, 2014).

Table 6 Fit Indices

| Fit Index | Summary | Cutoff Recommendations |
|-------------------------|---|---|
| Chi-Square (χ^2) | The extent to which the overall model predicts the observed covariance. | The ration of χ^2 should be ≤ 2 or 3, and p value should be nonsignificant to indicate a model with good fit. |

| | | |
|---|---|---|
| Comparative Fit Index (CFI) | Compares the covariance matrix to the χ^2 of the hypothesized model to the χ^2 of the null model. The null model is calculated by assuming latent variables and indicators are uncorrelated. | $\geq .90$ for an acceptable fit; $\geq .95$ for good fit |
| Tucker-Lewis Index (TLI) | Compares the χ^2 of the hypothesized model to the χ^2 of the null model. Describes the extent to which the specified model performs better than a baseline model. | $\geq .90$ for an acceptable fit; $\geq .95$ for good fit |
| Root Mean Square Error of Approximation (RMSEA) | Compares the fit of the independent model (a model which asserts no relationships between variables) to the fit of the estimated model. Measures the amount of variance within the hypothesized model. Measures “badness” of model. | $\leq .08$ is acceptable; $\leq .06$ for good fit |
| Standardized Root Mean Square Residual (SRMR) | Standardized difference between the observed model correlation and predicted model correlation | $\leq .08$ for good fit |

The primary research hypothesis and exploratory questions, partially illustrated along with the new hypothesized path model (Figure 10) are as follows:

Research Hypothesis

The research hypothesis for the study is: Stigma (as measured by the Social Impact Scale; Fife & Wright, 2000) has a negative influence on QoL (as measured by the Functional Assessment of Cancer Therapy - Prostate; Esper et al., 1997 and the Functional Assessment of Cancer Therapy – General Population; Cella et al., 1993) and relationship satisfaction (as

measured by the Couples Satisfaction Index; Funk & Rogge, 2007) of PCa survivors and their partners.

Exploratory Research Questions

1. Are there statistically significant relationships between stigma (as measured by the SIS; Fife & Wright, 2000), QoL (as measured by the FACT-P; Esper et al., 1997 and the FACT-GP; Cella et al., 1993), relationship satisfaction (as measured by the CSI; Funk & Rogge, 2007) and race for PCa survivors and their partners?

2. Are there statistically significant differences in stigma (as measured by the SIS; Fife & Wright, 2000) based on demographic variables (e.g., age and income) for PCa survivors?

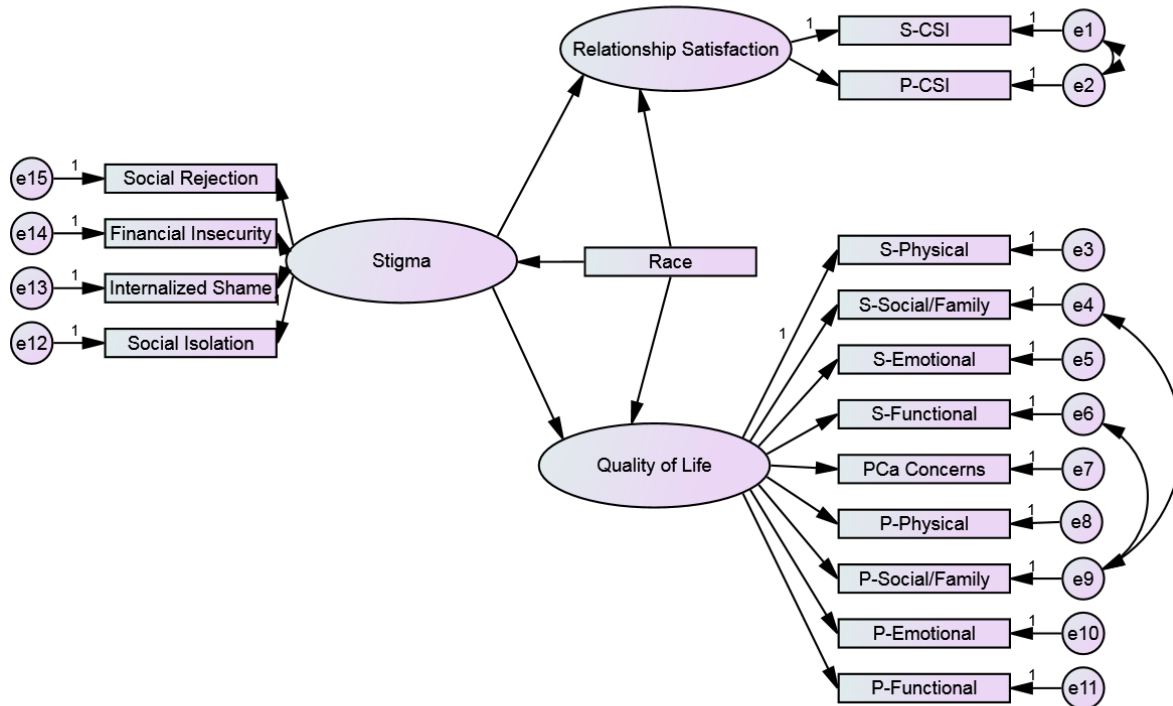


Figure 10 Hypothesized Path Model with Dyadic Adjustments

Confirmatory Factor Analyses

Before beginning primary analysis of the research hypothesis and exploratory questions, CFAs were conducted to ensure that the measurement models (i.e., CFAs of the individual assessments) closely represented the obtained sample. The hypothesized measurement models (Figures 11, 13, 15, 17, and 19) followed the predetermined factor structure of the authors of the chosen assessments. The predetermined factor structure for assessments ranged from one (CSI) to five factors (FACT-P). The measurement models were drawn as hypothesized in the AMOS program and the same fit indices used for the primary analyses (e.g., CFI, RMSEA, SRMR, and χ^2).

It should be noted that the fit indices used in this study have been developed with general cutoff scores endorsed by numerous researchers (e.g., Kline, 2010; Schumacker & Lomax, 2011). For the purposes of the present study, the following fit index cutoff scores were used: (a) nonsignificant χ^2 values that maintain a low ratio with degrees of freedom achieved (e.g., at least 3:1 or 2:1), (b) CFI values above .95, with many researchers (e.g., Bentler, 1990) endorsing values as low as .90 and above, (c) TLI values close to .90 or .95, with a value of 1 indicating perfect model fit (c) RMSEA values below .05, with values above .1 serving as a cutoff for poor fitting models (Kenny, Kaniskan, & McCoach, 2014), and (d) SRMR values of .08 or lower (Hu & Bentler, 1999). Table 6 details the fit indices used in the study along with their purpose and recommended cutoff.

As the CFAs were completed with their hypothesized factor structure, it became apparent that regardless of modifications added to the hypothesized factor structures, none of the assessments fit the sample data. In order to proceed with analysis in these cases, some

researchers (e.g., Mullen, 2014) have suggested exploratory factor analyses (EFAs) in order for the measurement models to truly fit the sample data. By employing EFAs, new factor structures are generated in order to understand how the assessments fit the data. Then, CFAs are conducted to inform the new measurement models to test the hypothesis for the study. Thus, both EFAs and CFAs were completed in order to finalize measurement models. The following sections entails both the EFA and CFA process for each assessment.

Social Impact Scale

The SIS (Fife & Wright, 2000) was originally hypothesized to have a four-factor structure with the 24 items measuring four forms of stigma (e.g., social rejection, financial insecurity, internalized shame, and social isolation). The four forms of stigma measured by the SIS analyzed two sets of questions related to stigma: social stigma and self-stigma. Validity studies have also found that the SIS could be used to measure stigma unidimensionally (Pan et al., 2007). The hypothesized factor structure for the SIS is pictured below (Figure 11). An examination of the factor structure shows that nine items are hypothesized to load on the social rejection factor, three items on the financial insecurity factor, five items on the internalized shame factor, and seven items on the social isolation factor. Table 7 details the fit indices obtained for the original SIS measurement model. The measurement model did not indicate a good model fit, therefore an EFA was used.

The EFA process, which was repeated for all of the assessments, included inputting each item of the SIS into the factor reduction analysis in SPSS. The factor reduction analysis provides factor loadings for a set of variables than can then be used, with modification, as an assessment

(Mvududu & Sink, 2013). Before running the analysis, the investigator chose specific extraction and rotation methods for the EFAs. Principal axis factoring was used as an extraction method, as it is robust to non-normal data (Costello & Osborne, 2005), which was obtained in the current study. A promax rotation was used in addition to the extraction method, which allows for a clarification of factor loadings. A promax rotation was used because it is an oblique rotation method which assumes that the variables are correlated. Because this EFA was being done on an extant measure a promax rotation was used, as a hypothesized factor structure is based on previous findings that the items are correlated. Further, correlation analyses used the items on the SIS, and they were found to have correlations of varying sizes with one another. Finally, the amount of factors extracted from the data was based on eigenvalues, or amount of variance explained by a factor, above one (O'Rourke & Hatcher, 2013). It is common practice to conduct initial factor analyses using an eigenvalue of one or higher as a starting point (Costello & Osborne, 2005).

In screening the factor reduction analysis, items were eliminated from analysis if their communalities level was $< .5$, indicating that the item did not load on any factor given the number of extracted factors (Costello & Osborne, 2005). Then, the structure matrix was read to ensure that more than two items loaded onto the last factor. If the last factor had less than two items that loaded onto it ($> .3$ without items co-loading, or loading onto more than one factor), then the number of factors was reduced by one. Once the number of factors had been reduced so that each factor had more than two items that loaded onto each factor, the factor correlation matrix was read to ensure that factors did not correlate highly ($> .7$). The scree plot was also

examined to indicate the number of factors a set of items should contain in the measurement model.

The initial analysis produced a five factor model. The initial Kaiser-Meyer-Olkin measure of sampling adequacy was .868, meaning that the sample was large enough for factor analysis (values under .5 indicate that the sample size is too small for factor analysis; Field, 2013). Further, Bartlett's test of sphericity was significant, meaning that the items are correlated and suitable for factor analysis (Field, 2013). The initial five-factor model was eventually reduced to a two factor model following the steps detailed above, with 15 items being removed (SIS1-SIS3, SIS8-SIS17, SIS23, SIS24). Items were then reloaded into the CFA individually to include more items without substantially affecting the model fit (i.e., making the measurement model not fit per the predetermined cutoff scores). One item (SIS23) was added to the measurement model from reloading items into the CFA. In addition, one modification index was completed through covarying two error terms (errors 19 and 21). After the data-driven process of searching with the EFA and CFA to find a model that fit, the investigator and dissertation chair examined the factor loadings and determined the theoretical importance of including some items, as well as determining the significance of the items loaded onto the new factors. The new SIS measurement model delineated the two factors into social stigma and self-stigma, with four items loading onto the social stigma factor and six items loading onto the self-stigma factor. These factors were theoretically in-line with the scale as originally hypothesized (Fife & Wright, 2000). The structure matrix (Figure 13) and the scree plot (Figure 14) used in the EFA analysis support the decision to make the SIS a two-factor model. The final SIS measurement model displays the items retained and their factor loadings (Figure 15), with Table 7 detailing fit indices. In addition

to achieving model fit, reliability analyses were conducted with the new factor loadings of the SIS. Both the social stigma factor and the self-stigma factor had excellent internal consistency ($\alpha = .95$ and $\alpha = .94$). After the EFA and CFA was completed for the SIS (Fife & Wright, 2000), the same process was followed for the FACT-P (Esper et al., 1997).

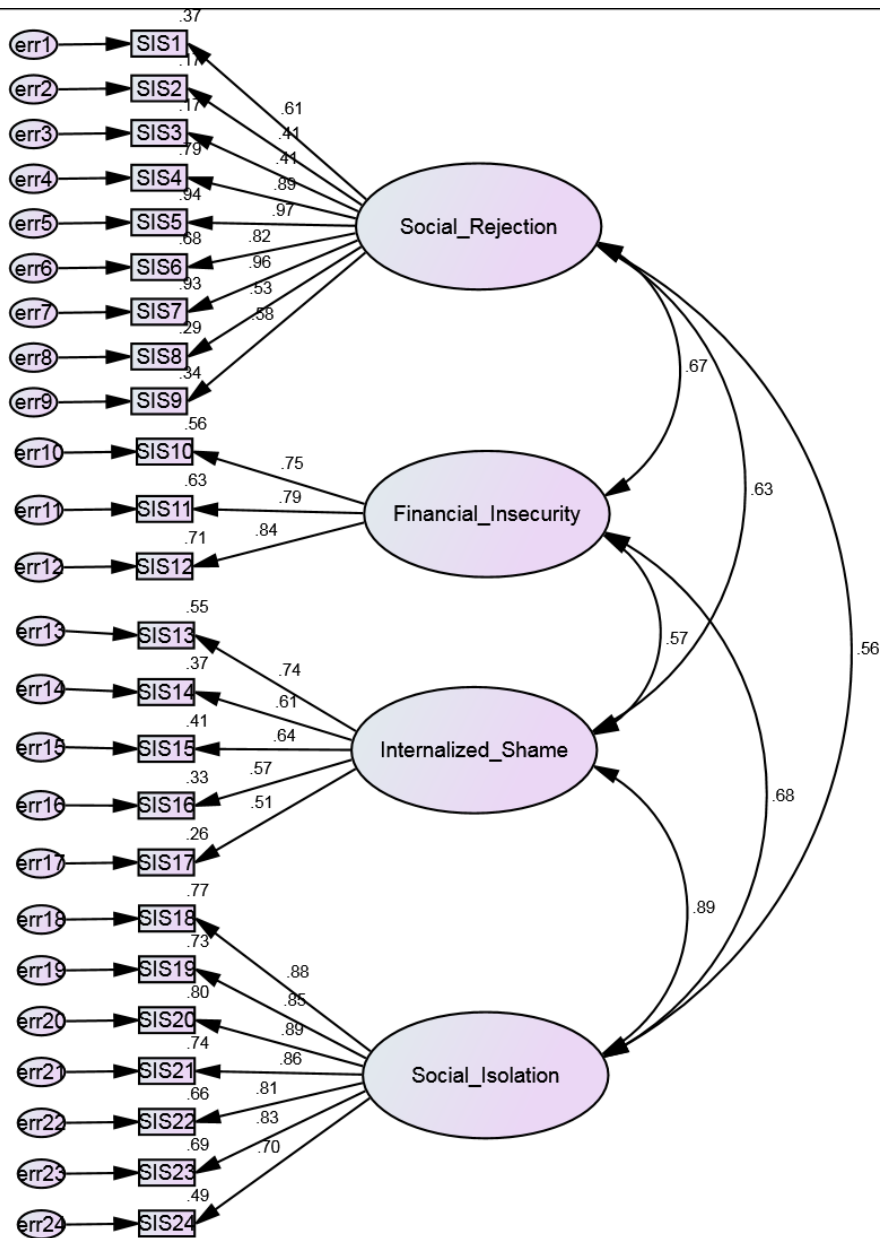


Figure 11 Hypothesized SIS Measurement Model

| Structure Matrix | | |
|------------------|--------|------|
| | Factor | |
| | 1 | 2 |
| SIS7 | .916 | .483 |
| SIS5 | .897 | .480 |
| SIS4 | .897 | .403 |
| SIS6 | .783 | .420 |
| SIS11 | .713 | .456 |
| SIS13 | .663 | .625 |
| SIS12 | .644 | .562 |
| SIS10 | .633 | .564 |
| SIS9 | .630 | .534 |
| SIS1 | .625 | |
| SIS8 | .591 | .442 |
| SIS3 | .504 | .441 |
| SIS20 | .467 | .926 |
| SIS18 | .549 | .857 |
| SIS21 | .625 | .843 |
| SIS19 | .560 | .827 |
| SIS23 | .612 | .815 |
| SIS22 | .538 | .802 |
| SIS24 | .563 | .689 |
| SIS15 | | .593 |
| SIS14 | | .566 |
| SIS16 | | .550 |
| SIS17 | | .549 |
| SIS2 | .533 | .543 |

Extraction Method: Principal
Axis Factoring.

Rotation Method: Promax
with Kaiser Normalization.

Figure 12 Structure Matrix for Social Impact Scale Exploratory Factor analysis

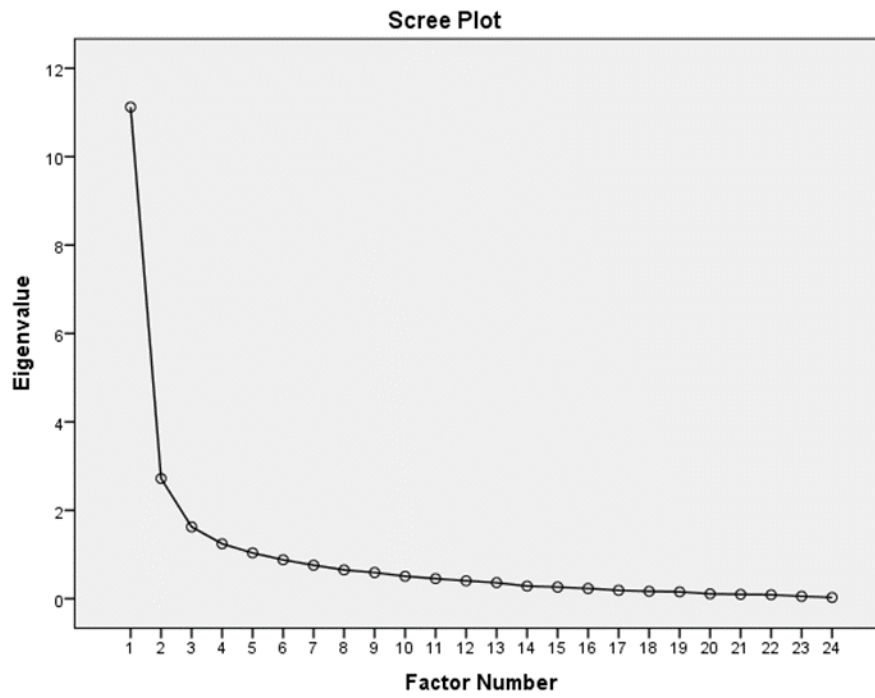


Figure 13 Scree Plot for Social Impact Scale Exploratory Factor Analysis

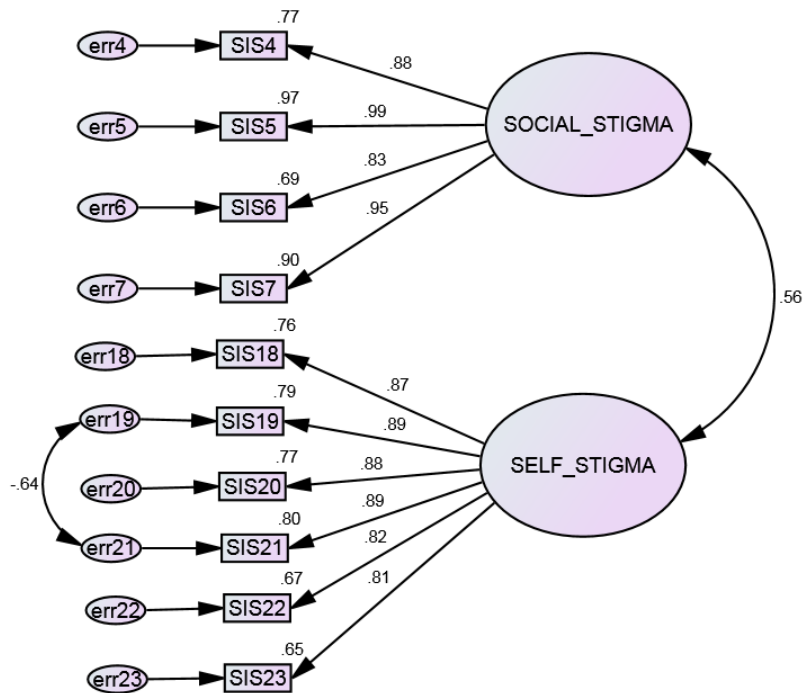


Figure 14 Revised SIS Measurement Model

Table 7 Model Fit Indices of the SIS

| | χ^2 | Df | P | CFI | TLI | RMSEA | SRMR |
|---------|----------|-----|------|-----|-----|-------|------|
| Model 1 | 540.44 | 246 | .000 | .79 | .76 | .13 | .11 |
| Model 2 | 48.55 | 33 | .04 | .98 | .97 | .08 | .04 |

Functional Analysis of Cancer Therapy – Prostate.

The FACT-P (Esper et al., 1997) was the next assessment to measure for model fit through CFA. As displayed in Figure 15, the hypothesized FACT-P model consisted of five factors: (a) physical well-being, (b), social/family well-being, (c) emotional well-being, (d) functional well-being, and (e), additional concerns (prostate-specific). The physical well-being factor consisted of seven items, as did the social/family well-being factor. The emotional well-being factor consisted of six items and the functional well-being factor consisted of seven items. Finally, the additional concerns factor consisted of 12 items.

The initial model fit for the hypothesized factor loading for the FACT-P, similar to the hypothesized SIS model, did not achieve an acceptable fit. Table 8 displays the achieved fit for the hypothesized FACT-P model. In looking for solutions, modifications indices did not yield acceptable changes in model fit. Thus, an EFA was conducted, following the same steps procedures as detailed in the previous SIS EFA. The initial factor reduction yielded a nine factor model. The Kaiser-Meyer-Olkin measure of sampling adequacy was .77, meaning that the sample size was adequate for factor analysis, and the Bartlett test of sphericity was significant, meaning that the items were correlated and factor analysis was possible.

The model was reduced incrementally, yielding a three factor model. Upon further investigation of the third factor, it was not grounded theoretically. Specifically, items 17 and 18, both from the emotional well-being factor in the hypothesized FACT-P model, loaded onto what appeared to be a physical well-being factor. Inspecting factor loadings showed the investigator and the dissertation chair that both items were a distinct factor. Thus, items 17 and 18 were added as a new, fourth factor. As evidenced by the revised factor structure, items 17 and 18 were

assigned as emotional QoL, which shared a large variance ($R^2 = .96$) with the physical QoL factor from which they were reassigned. While it is not in best practice to only have two indicator variables for a factor in CFA (Kline, 2010), some researchers (e.g., Anderson & Gerbing, 1988; O'Rourke & Hatcher, 2013) have found it permissible. Further, the AMOS program will limit analyses wherein the items cannot sufficiently load on a factor (sometimes creating negative variances, or Heywood cases; Dillon, Kumar, & Mulani, 1987). When the four-factor CFA was run, it ran completely. Thus, the four-factor FACT-P measurement model was used. The structure matrix (Figure 16) and the scree plot (Figure 17) used in the EFA analysis support the decision to make the FACT-P a four-factor model. The four factors that were identified were physical QoL, social/family QoL, emotional QoL, and urinary bother. The physical QoL factor consisted of items from the hypothesized physical well-being subscale and questions related to physical issues from the hypothesized additional concerns subscale (e.g., "I have aches and pains that bother me"). The social/family QoL factor consisted of items from the hypothesized social/family well-being subscale. The emotional QoL factor consisted of items from the hypothesized emotional well-being subscale. The urinary bother factor consisted of items from the hypothesized additional concerns subscale relating to urinary concerns (e.g., "I urinate more frequently than usual"). Urinary bother was not an expected factor, but it is an important issue in PCa symptomatology and treatment.

Similar to the SIS, individual items were added back to the FACT-P measurement model. The new FACT-P measurement model consisted of 15 items. Three items were added from the individual items reloading procedure, yielding a measurement model with 18 items. However, after reliability analyses, the added three items were found to significantly reduce reliability,

yielding an alpha level as low as .09. Thus, the items in the reliability analysis were examined for possible deletion, based on alpha level if the item was deleted. When two of the added three items were deleted, the FACT-P received acceptable reliability levels for all of its factors, with the physical QoL factor yielding an alpha of .84, the social QoL factor yielding an alpha of .84, the emotional QoL factor yielding an alpha of .76, and the urinary bother yielding an alpha of .85. The final FACT-P measurement model consisted of 16 items. The modified FACT-P is displayed in Figure 18, with fit indices detailed in Table 8. An examination of the partners' FACT-GP (Cella et al., 1993) measurement model followed

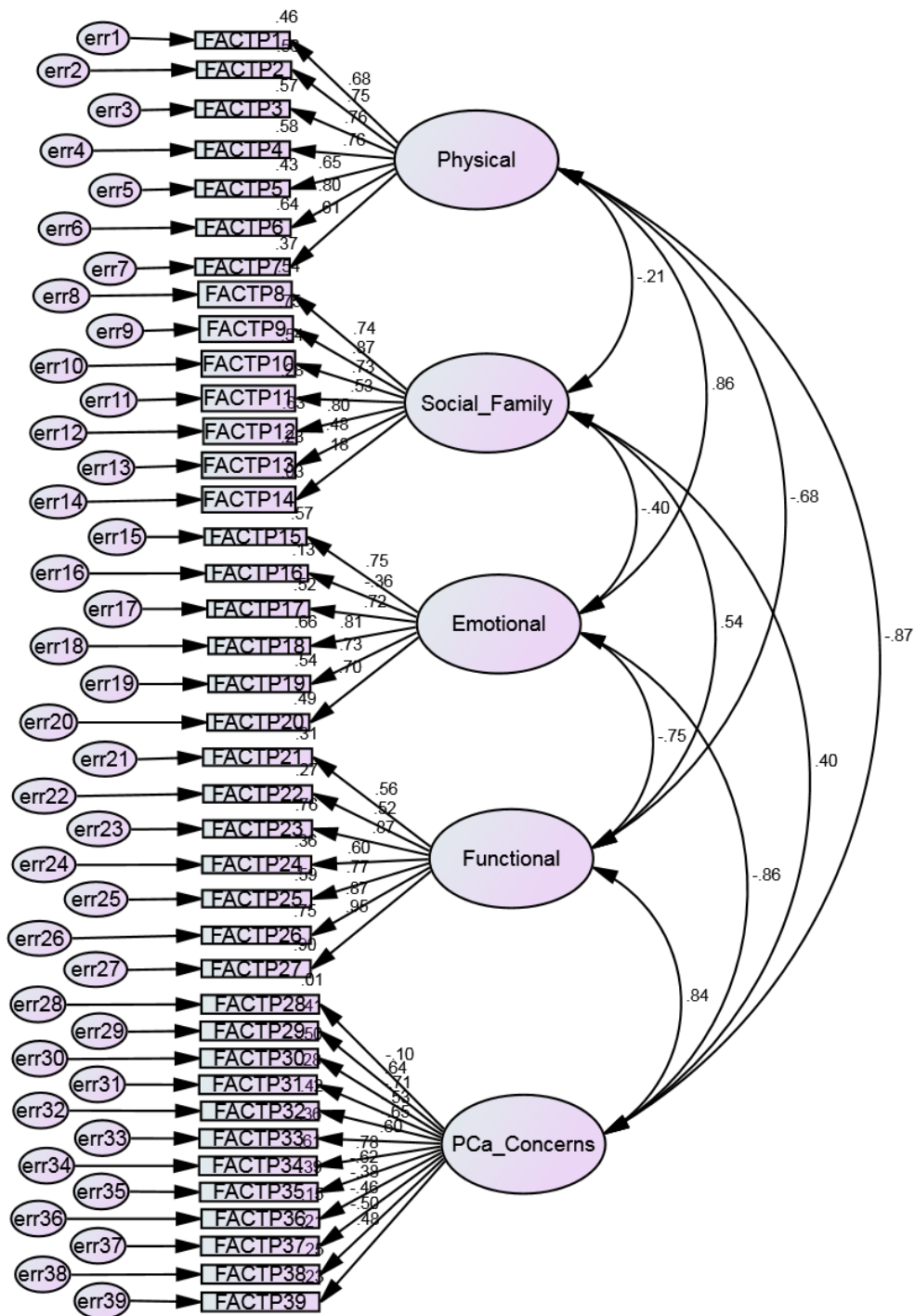


Figure 15 Hypothesized FACT-P measurement model

Structure Matrix

| | Factor | | | |
|---------|--------|-------|-------|-------|
| | 1 | 2 | 3 | 4 |
| FACTP17 | .832 | | | .422 |
| FACTP6 | .794 | -.329 | .342 | .456 |
| FACTP2 | .781 | | | .452 |
| FACTP34 | -.744 | .628 | -.534 | -.485 |
| FACTP15 | .721 | -.607 | .448 | .386 |
| FACTP18 | .720 | -.377 | .388 | .538 |
| FACTP21 | -.709 | | -.441 | -.446 |
| FACTP29 | -.707 | .323 | -.509 | |
| FACTP23 | -.703 | .695 | -.653 | -.379 |
| FACTP3 | .702 | | .417 | .535 |
| FACTP35 | .670 | | .536 | |
| FACTP4 | .654 | | .431 | .645 |
| FACTP1 | .648 | | .578 | .430 |
| FACTP5 | .596 | -.360 | .541 | .434 |
| FACTP7 | .587 | | | .327 |
| FACTP22 | -.536 | .366 | | |
| FACTP28 | | | | |
| FACTP12 | | .802 | -.340 | |
| FACTP9 | | .759 | | |
| FACTP10 | | .706 | | -.390 |
| FACTP8 | | .677 | | |
| FACTP25 | -.529 | .612 | -.595 | -.491 |
| FACTP24 | -.582 | .599 | -.352 | |
| FACTP11 | | .498 | | |
| FACTP13 | | .486 | | |
| FACTP16 | -.368 | .370 | | |
| FACTP38 | | | .830 | |
| FACTP37 | | | .776 | |
| FACTP27 | -.691 | .732 | -.762 | -.396 |
| FACTP26 | -.646 | .602 | -.695 | -.400 |
| FACTP36 | | | .643 | |
| FACTP33 | -.485 | .446 | -.518 | -.327 |
| FACTP39 | -.397 | | -.409 | -.361 |
| FACTP14 | | | -.352 | |
| FACTP30 | .573 | -.344 | .407 | .908 |
| FACTP31 | .385 | | | .831 |
| FACTP32 | .529 | | .447 | .684 |
| FACTP20 | .523 | -.482 | .507 | .640 |
| FACTP19 | .539 | -.449 | .378 | .544 |

Extraction Method: Principal Axis Factoring.
Rotation Method: Promax with Kaiser Normalization.

Figure 16 Structure Matrix for FACT-P Exploratory Factor Analysis

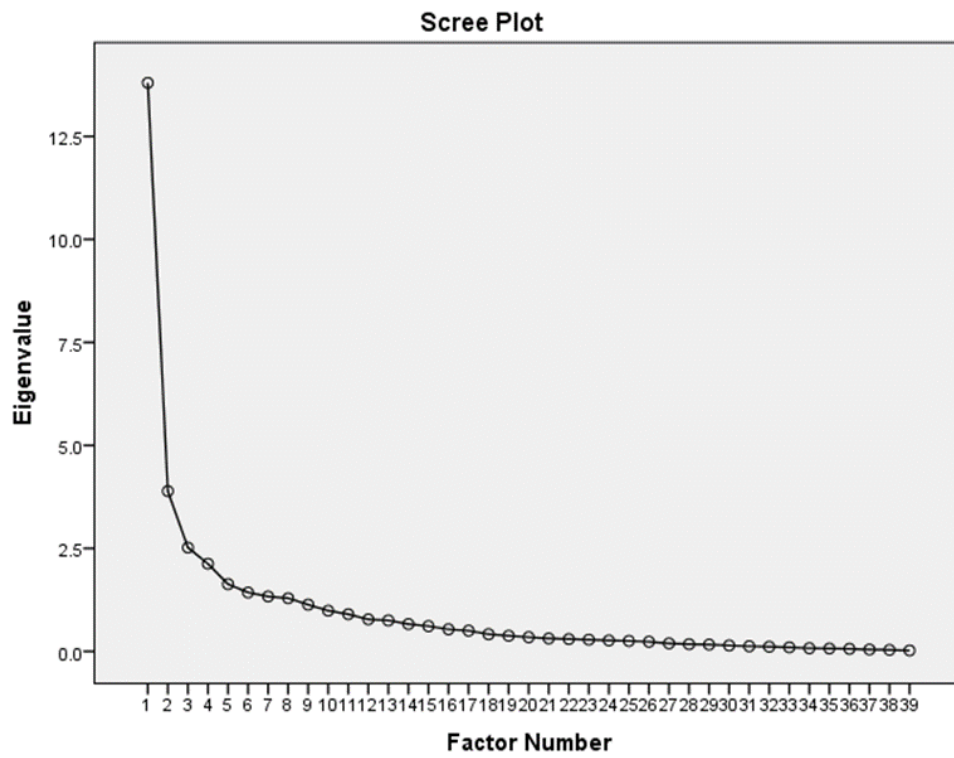


Figure 17 Scree Plot for FACT-P Exploratory Factor Analysis

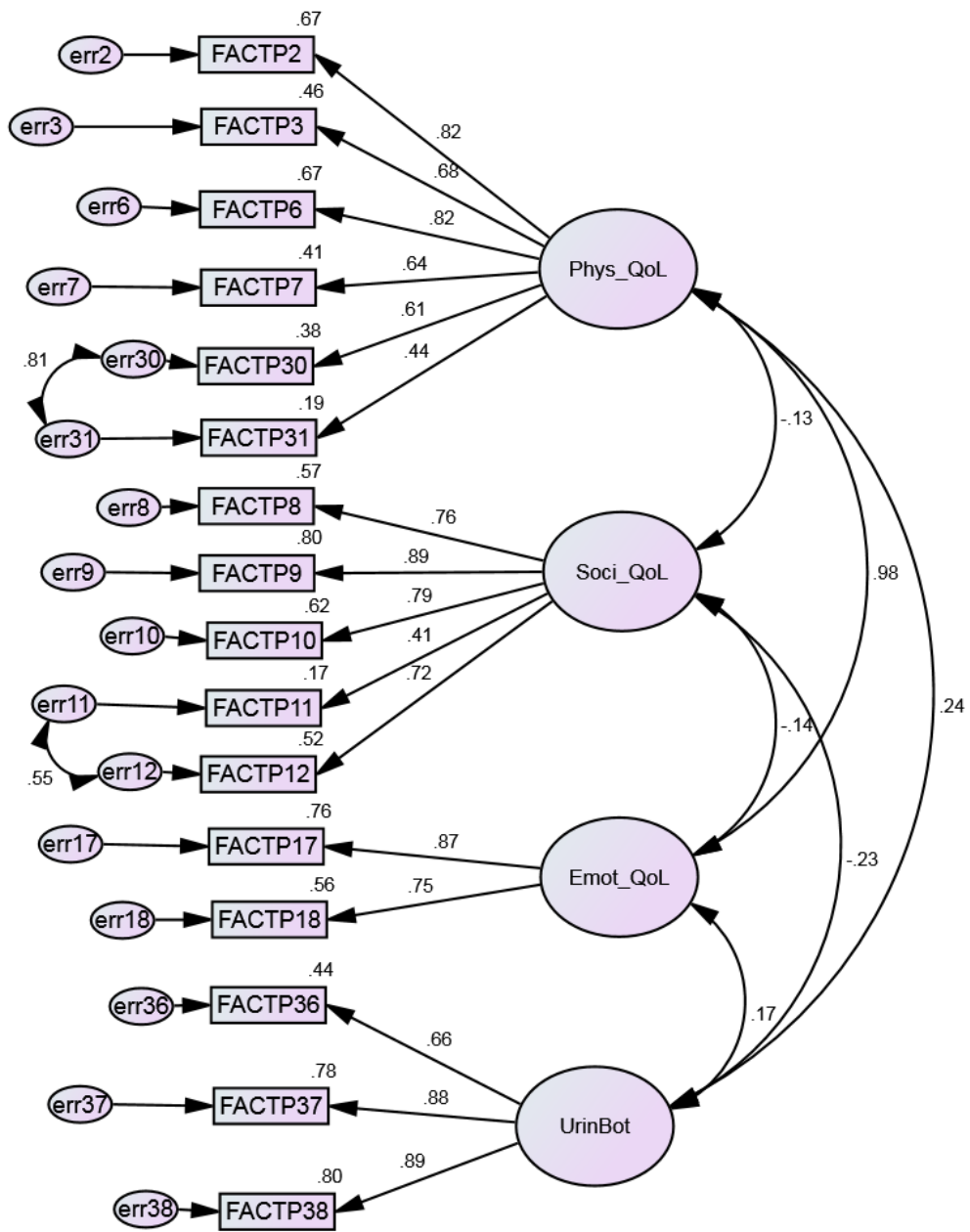


Figure 18 Modified FACT-P Measurement Model

Table 8 Model Fit Indices of the FACT-P

| | χ^2 | <i>Df</i> | <i>P</i> | CFI | TLI | RMSEA | SRMR |
|---------|----------|-----------|----------|------|-----|-------|------|
| Model 1 | 1450.3 | 692 | .000 | .617 | .59 | .124 | .11 |
| Model 2 | 111.95 | 96 | .13 | .97 | .97 | .05 | .8 |

Functional Assessment of Cancer Therapy – General Population

The FACT-GP (Cella et al., 1993) was the third assessment to be examined as a measurement model for the main analysis of the study. The hypothesized FACT-GP model (Figure 19) has four factors: (a) physical well-being, (b) social/family well-being, (c) emotional well-being, and (d) functional well-being. Similar to the FACT-P (Esper et al., 1997), the FACT-GP was designed to measure QoL as a multidimensional concept. The physical and functional well-being factors consisted of six items, the social/family well-being factor of five items, and the emotional well-being factor of four items. Based on the initial CFA, the fit indices did not indicate that the model was a good fit for the data (Table 9). Modification indices did not yield an acceptable fitting model. Thus, as with the SIS and the FACT-P, an EFA was conducted on the FACT-GP.

Following the same steps laid out in the SIS EFA, the FACT-GP was examined for a different factor structure than originally hypothesized. The FACT-GP was found to be suitable for factor reduction with a Kaiser-Meyer-Olkin measure of sampling adequacy of .778 and a significant Bartlett test of sphericity. The EFA yielded a five-factor model. The model was then incrementally reduced to a two-factor model with 11 items retained from the original 24 items. Upon examination of the factor loadings, two items were found to not load on their expected

factor, but had a higher ($> .8$) error covariance. Thus, the model was split into a three-factor model, with the two items placed on their own factor. However, this solution again yielded a poor model fit. Thus, the items were deleted. Items were then individually reloaded into the CFA to increase the number of items in the measurement model. However, each added item reduced the fit indices to unacceptable ranges. The structure matrix (Figure 20) and the scree plot (Figure 21) used in the EFA analysis support the decision to make the FACT-GP a two-factor model.

Upon examining the new factors, the revised FACT-GP measurement model was found to measure physical QoL on one factor and emotional QoL on the other factor (Figure 22). Five items loaded onto the physical QoL factor and four items were loaded on the emotional QoL measure. Fit indices (Table 9) indicated that the new model was a good fit for the data.

Reliability analyses were also run for both factors, with the physical QoL factor achieving good internal consistency ($\alpha = .85$) and the emotional QoL factor achieving good internal consistency ($\alpha = .8$).

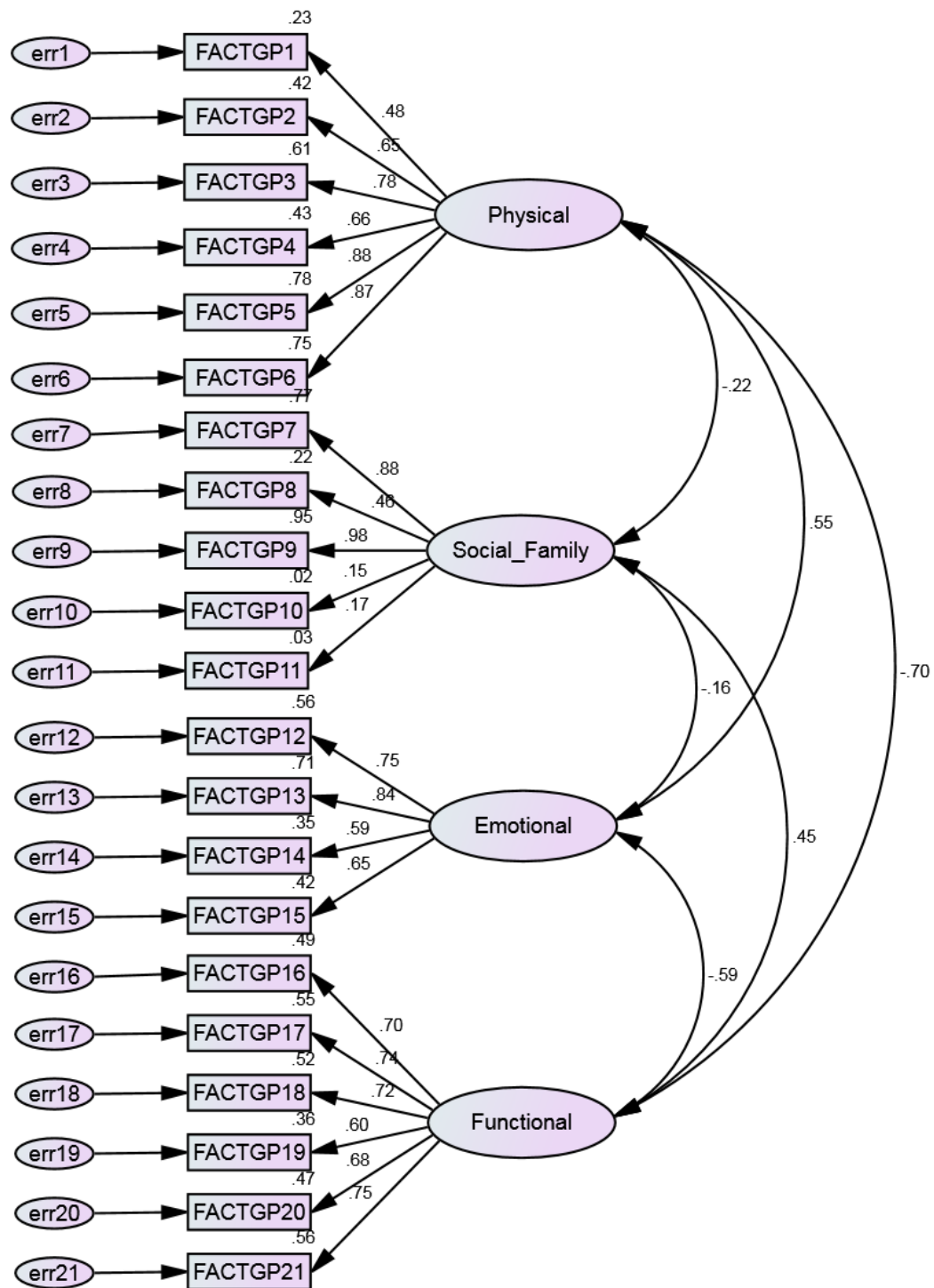


Figure 19 Hypothesized FACT-GP Measurement Model

| Structure Matrix | | | |
|------------------|--------|-------|-------|
| | Factor | | |
| | 1 | 2 | 3 |
| FACTGP5 | .839 | .429 | |
| FACTGP6 | .817 | .426 | |
| FACTGP3 | .779 | .522 | -.350 |
| FACTGP4 | .723 | .380 | -.429 |
| FACTGP2 | .677 | | |
| FACTGP19 | -.638 | -.333 | .443 |
| FACTGP16 | -.597 | -.377 | .529 |
| FACTGP1 | .490 | .489 | |
| FACTGP12 | | .763 | -.375 |
| FACTGP13 | .512 | .735 | |
| FACTGP21 | -.598 | -.703 | .566 |
| FACTGP15 | | .683 | |
| FACTGP14 | | .641 | |
| FACTGP10 | | -.392 | .337 |
| FACTGP7 | | | .780 |
| FACTGP9 | | | .764 |
| FACTGP17 | -.530 | -.390 | .607 |
| FACTGP20 | -.545 | -.389 | .607 |
| FACTGP18 | -.462 | -.505 | .593 |
| FACTGP8 | | -.359 | .505 |
| FACTGP11 | | | |

Extraction Method: Principal Axis Factoring.
Rotation Method: Promax with Kaiser
Normalization.

Figure 20 Structure Matrix for FACT-GP Exploratory Factor Analysis

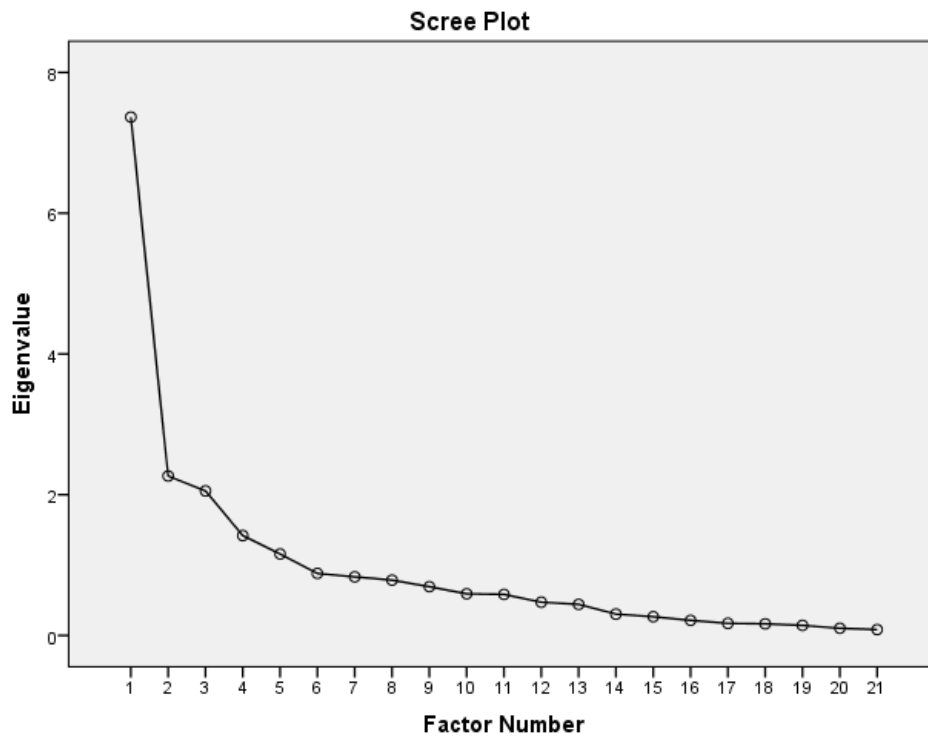


Figure 21 Scree Plot for FACT-GP Exploratory Factor Analysis

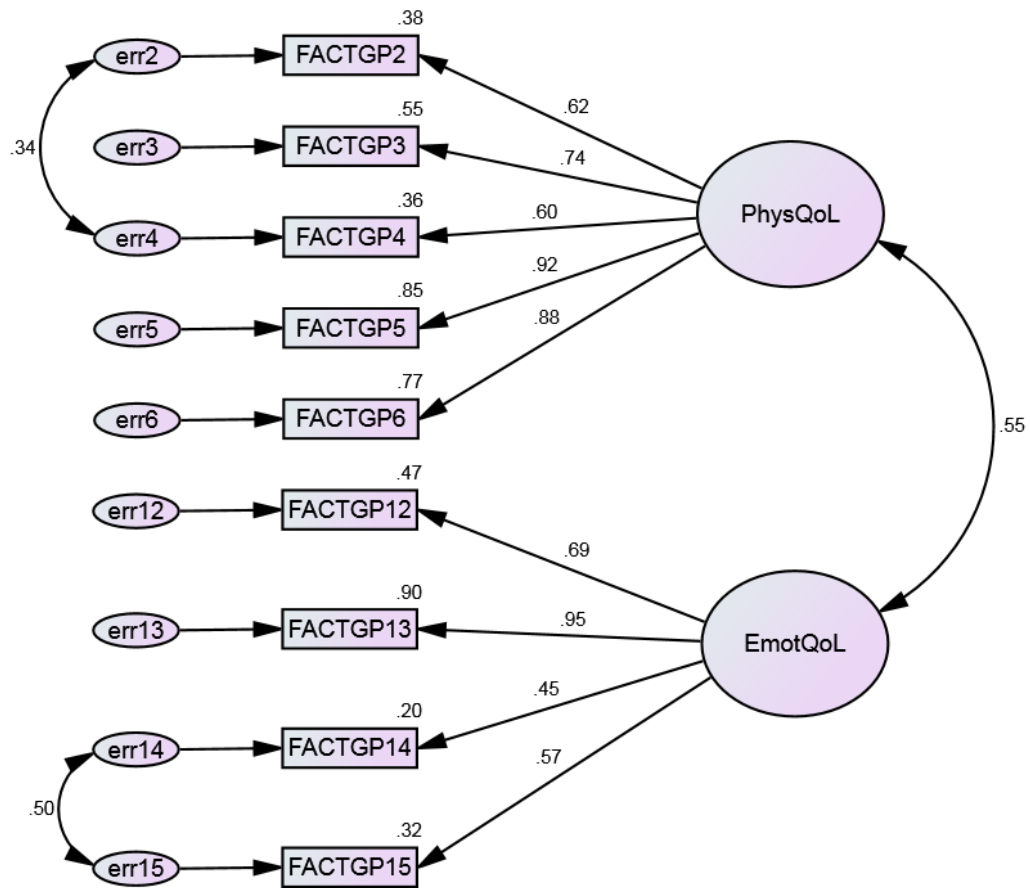


Figure 22 Revised FACT-GP Measurement Model

Table 9 Model Fit Indices of the FACT-GP

| | χ^2 | <i>df</i> | <i>p</i> | CFI | TLI | RMSEA | SRMR |
|---------|----------|-----------|----------|-----|-----|-------|------|
| Model 1 | 352.93 | 183 | .000 | .78 | .75 | .11 | .11 |
| Model 2 | 33.24 | 24 | .099 | .97 | .95 | .07 | .06 |

Couples Satisfaction Index for Survivors

The CSI was the fourth assessment to be subjected to a CFA to confirm model fit. The hypothesized CSI measurement model consists of 16 items, all measuring one factor of relationship satisfaction. Although measurement models using dyadic data should be measured in CFAs together (Kenny et al., 2006), the CSI measurement models were analyzed separately in order to account for a possible Heywood case (Dillon et al., 1987), based on the hypothesized models both being one-factor models, found in the structural model, to be detailed in the section pertaining to the structural model analysis. For the sake of thoroughness, however, the measurement models were run both separately and together and yielded the same results. Thus, the investigator felt confident in moving on with analyses separately. The initial, hypothesized model of the PCa survivors' CSI (Figure 23) was found to have poor model fit (Table 10). In order to allow for a measurement model to fit the obtained data well, an EFA was conducted.

The initial EFA for PCa survivors' CSI yielded a Kaiser-Meyer-Olkin measure of sampling adequacy of .915 and a non-significant Bartlett's test of sphericity, meaning that the EFA was suitable for analysis. The factor reduction yielded a two-factor model, with both factors being highly correlated (>.7). Thus, the model was constricted to yield one factor, and three items deleted due to low communality values. The structure matrix (Figure 24) and the scree plot

(Figure 25) used in the EFA analysis support the decision to make the PCa survivors' CSI a one-factor model. Compared to the previous measurement models inspected, the PCa survivors' measurement model (Figure 26) required more modification indices to allow for a proper model fit (Table 10). This occurrence could have been due to redundancy due to high correlations and also indicated by the exceptional internal consistency of the one factor ($\alpha = .974$; Briggs & Cheek, 1986). Researchers (e.g., Little, Cunningham, Shahar, & Widaman, 2002) have suggested that item parceling is an appropriate measure to reduce the number of indicator variables. Item parceling would entail aggregating scores on two or more items to reduce the number of indicator variables. However, due to the amount of modification done to the PCa survivors' CSI, and the overall negative stance toward item parceling in research methodology (Little et al., 2002), modification indices were chosen in order to retain the largest amount of items possible. Further, items were individually reloaded to the measurement model, with one item being added to the model, yielding a one-factor solution with 14 items. Despite the process involved in finding an acceptable model fit for PCa survivors' CSI, the RMSEA value was deemed to be on the border of a poor fit. A closer examination into the fit indices provided in the AMOS output revealed that the RMSEA is analyzed with a 90% confidence interval. The confidence interval is of particular importance to this study, as the low sample size can be seen as a cause for inflated RMSEA values (Kenny et al., 2014). The lower 90% confidence interval value for PCa survivors' CSI was .06, which is indicative of a good fit. Thus, the revised PCa survivors' CSI measurement model was found to be acceptable. The modified PCa survivors' CSI is displayed in Figure 26, with fit indices detailed in Table 10. The one factor for the revised PCa survivors'

CSI was identified still as a measurement of relationship satisfaction. Internal consistency for the PCa survivors' CSI ($\alpha = .972$) was acceptable.

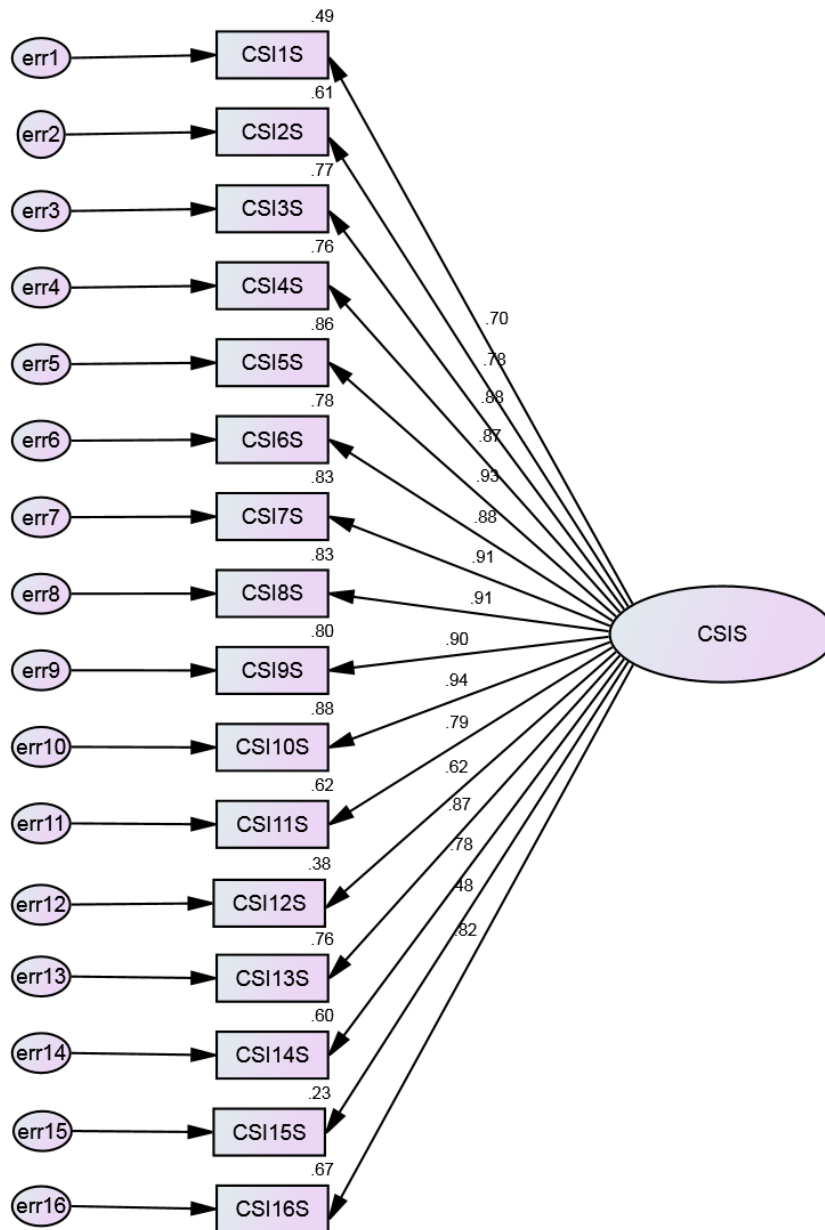


Figure 23 Hypothesized PCa Survivor CSI Measurement Model

Structure Matrix

| | Factor | |
|--------|--------|------|
| | 1 | 2 |
| CSI10S | .940 | .643 |
| CSI5S | .920 | .685 |
| CSI7S | .908 | .629 |
| CSI8S | .904 | .592 |
| CSI9S | .896 | .590 |
| CSI3S | .882 | .609 |
| CSI13S | .881 | .761 |
| CSI6S | .871 | .667 |
| CSI4S | .870 | .608 |
| CSI16S | .827 | .694 |
| CSI2S | .789 | .533 |
| CSI14S | .781 | .695 |
| CSI11S | .772 | .768 |
| CSI1S | .721 | .508 |
| CSI12S | .591 | .827 |
| CSI15S | .448 | .751 |

Extraction Method: Principal
Axis Factoring.
Rotation Method: Promax with
Kaiser Normalization.

Figure 24 Structure Matrix for CSI – Survivor Exploratory Factor Analysis

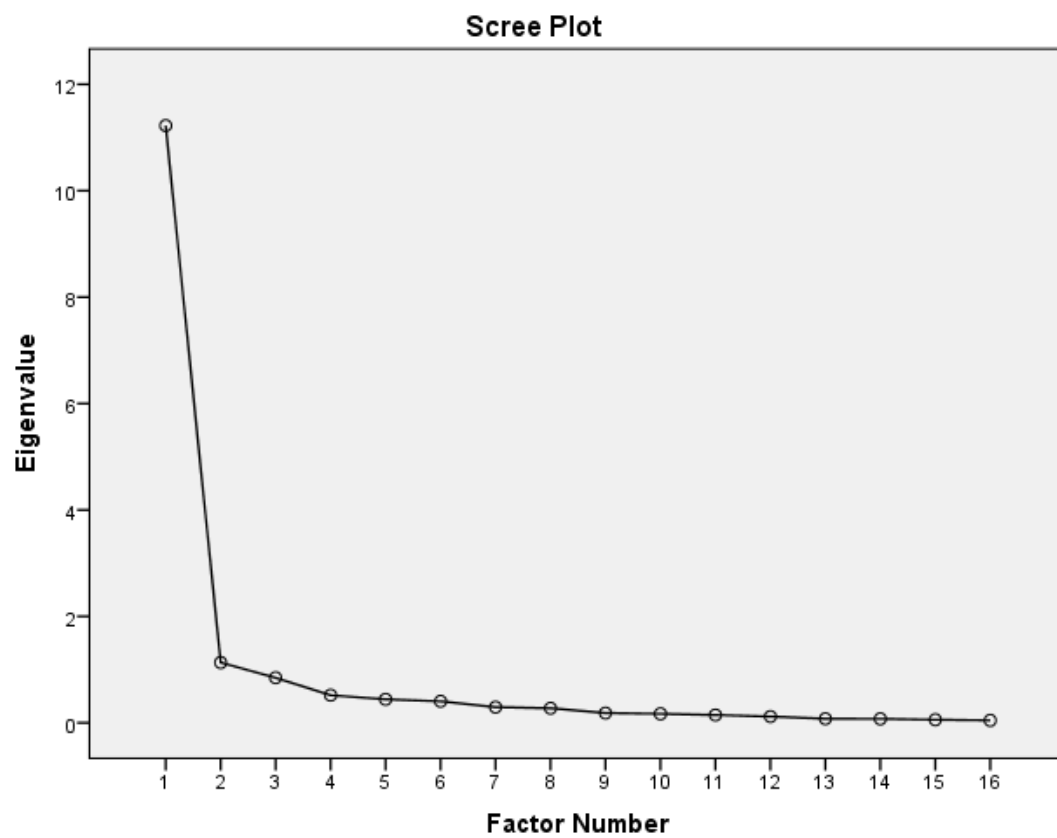


Figure 25 Scree Plot for CSI – Survivor Exploratory Factor Analysis

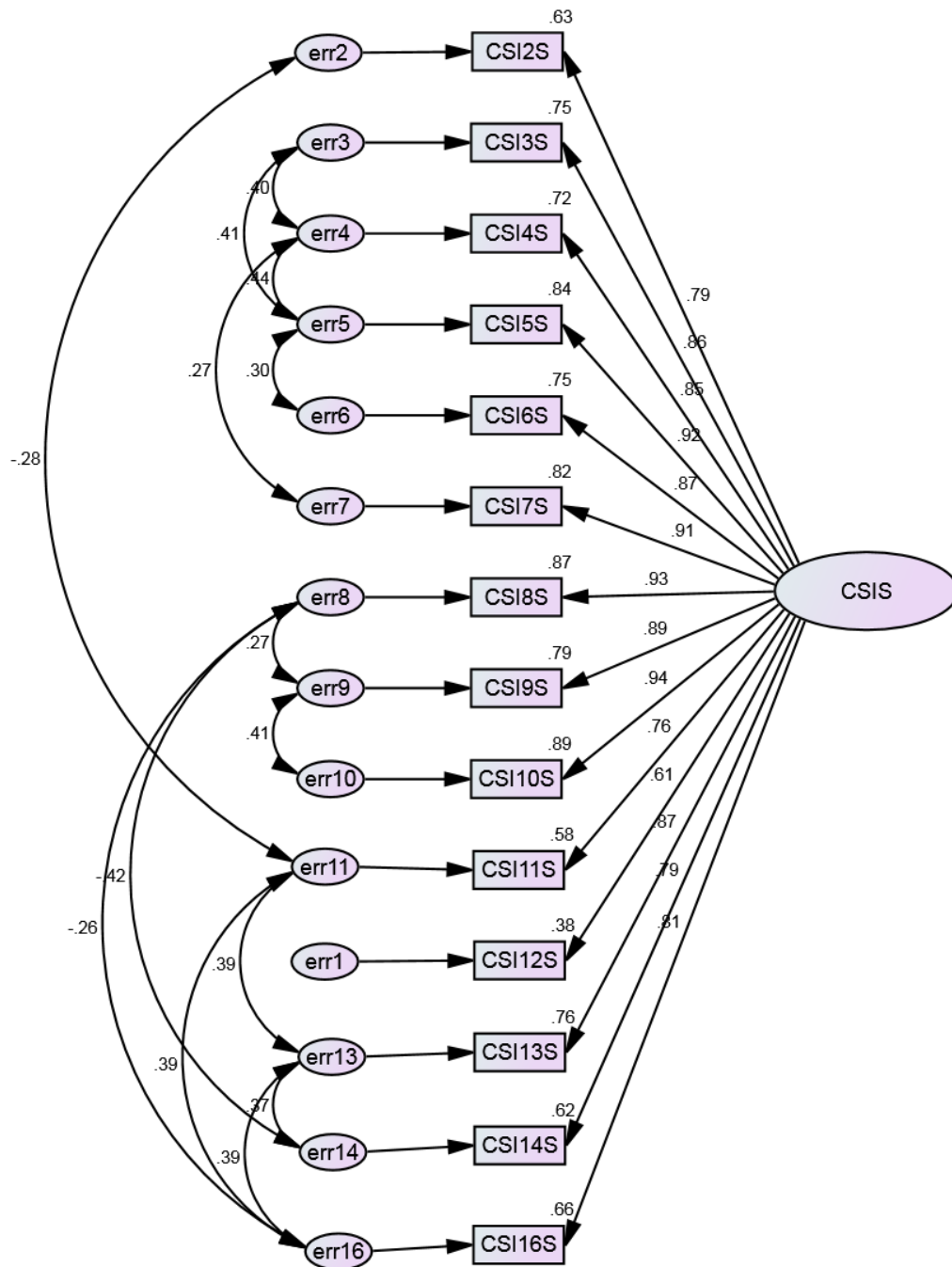


Figure 26 Revised PCa Survivor CSI Measurement Model

Table 10 Model Fit Indices of the PCa Survivor CSI

| | χ^2 | <i>df</i> | <i>p</i> | CFI | TLI | RMSEA | SRMR |
|---------|----------|-----------|----------|-----|-----|-------|------|
| Model 1 | 329.67 | 104 | .000 | .84 | .81 | .17 | .06 |
| Model 2 | 103.17 | 63 | .001 | .97 | .95 | .09 | .04 |

Couples Satisfaction Index for partners

Similar to the process for PCa survivors' CSI, the partners' CSI measurement model was examined. The process followed for the PCa survivors' CSI was followed almost identically for partners' CSI. The initial, hypothesized model of the partners' CSI (Figure 27) was run with the data from the study and was found to have poor model fit (Table 11). In order to allow for a measurement model to fit the obtained data well, an EFA was conducted to ensure the factor structure of the PCa survivors' CSI.

The initial EFA that was conducted for partners' CSI yielded a Kaiser-Meyer-Olkin measure of sampling adequacy of .933 and a non-significant Bartlett's test of sphericity, meaning that the EFA was suitable for analysis. The factor reduction yielded a two factor model, with both factors being highly correlated ($> .7$). Thus, the model was constricted to yield one factor and three items were deleted due to low communality values. The structure matrix (Figure 28) and the scree plot (Figure 29) used in the EFA analysis support the decision to make the partners' CSI a one-factor model. The partners' CSI required less modification indices to obtain a model with adequate fit. Items were individually reloaded to the measurement model, with two items being added to the model, yielding a one-factor solution with 15 items. The modified partner CSI is displayed in Figure 30, with fit indices detailed in Table 11. The one factor for the

revised PCa survivors' CSI was identified still as a measurement of relationship satisfaction, with an exceptional internal consistency ($\alpha = .968$).

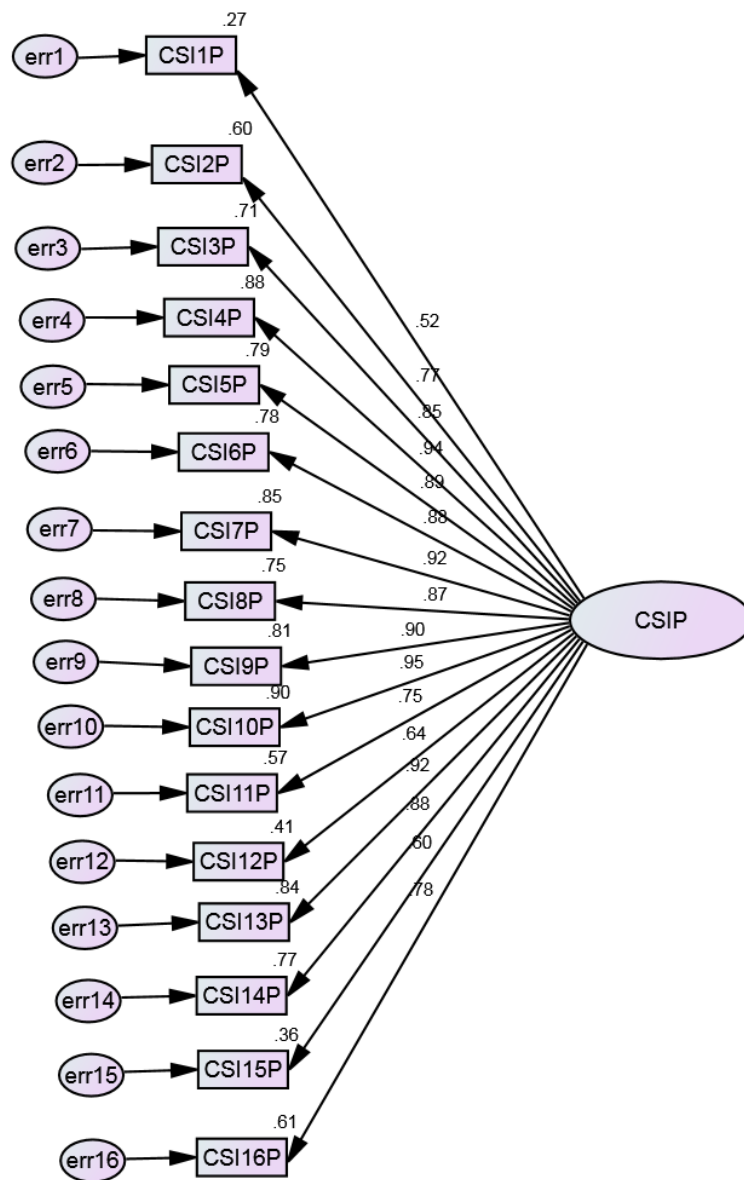


Figure 27 Hypothesized Partner CSI Measurement Model

Structure Matrix

| | Factor | |
|--------|--------|------|
| | 1 | 2 |
| CSI4P | .945 | .661 |
| CSI10P | .942 | .724 |
| CSI7P | .920 | .706 |
| CSI5P | .911 | .542 |
| CSI13P | .909 | .803 |
| CSI6P | .887 | .645 |
| CSI9P | .882 | .748 |
| CSI14P | .873 | .717 |
| CSI3P | .865 | .521 |
| CSI8P | .856 | .686 |
| CSI16P | .773 | .636 |
| CSI2P | .771 | .612 |
| CSI11P | .727 | .650 |
| CSI1P | .521 | .406 |
| CSI12P | .593 | .847 |
| CSI15P | .549 | .828 |

Extraction Method: Principal
Axis Factoring.

Rotation Method: Promax with
Kaiser Normalization.

Figure 28 Structure Matrix for CSI – Partner Exploratory Factor Analysis

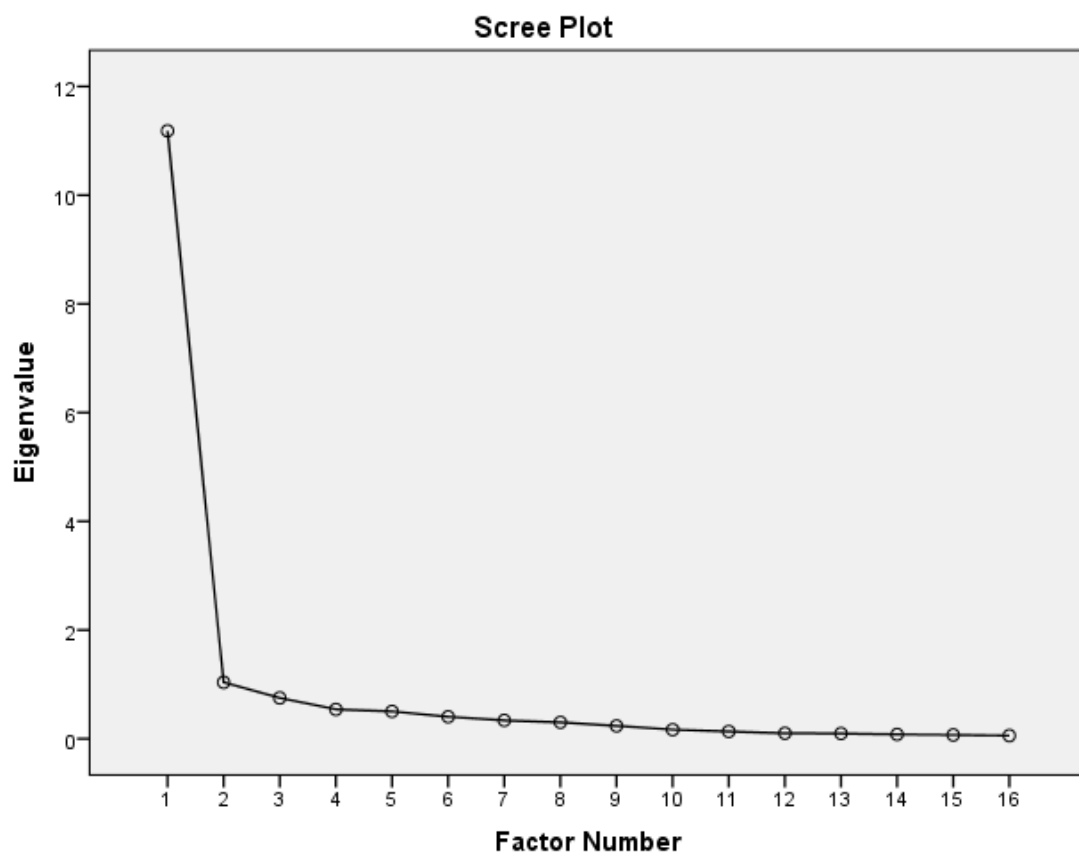


Figure 29 Scree Plot for CSI – Partner Exploratory Factor Analysis

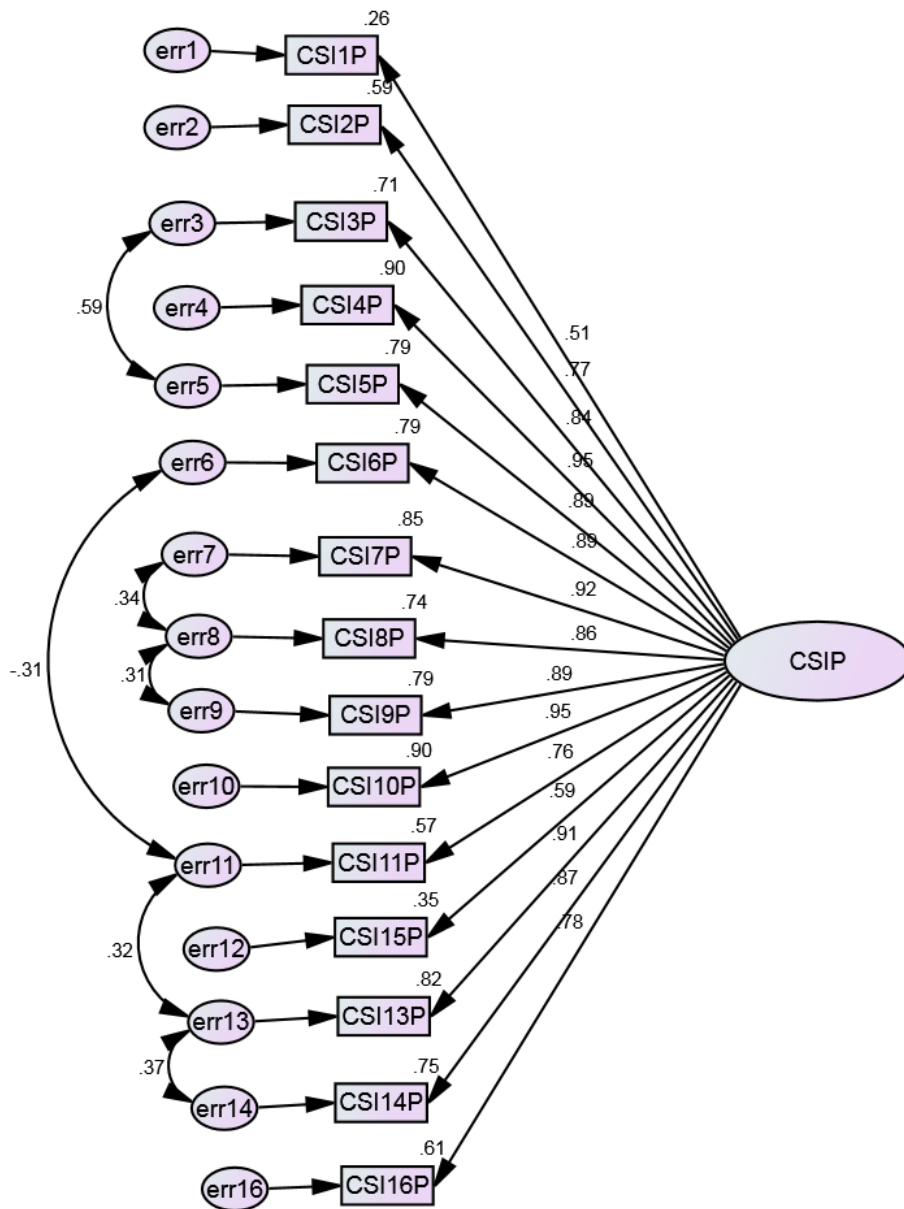


Figure 30 Revised Partner CSI Measurement Model

Table 11 Model Fit Indices of the Partner CSI

| | χ^2 | <i>df</i> | <i>p</i> | CFI | TLI | RMSEA | SRMR |
|---------|----------|-----------|----------|-----|-----|-------|------|
| Model 1 | 231.94 | 104 | .000 | .9 | .89 | .13 | .05 |
| Model 2 | 108.5 | 84 | .037 | .98 | .97 | .06 | .03 |

Final measurement model

The final measurement model combined each of the measurement models in a final CFA. Due to using the common fate model with dyadic data, the couple-based measurement models were combined. As with each of the other measurement models, Maximum Likelihood estimation was used in the analysis and various fit indices were used to evaluate the model. The initial final measurement model (Figure 31) did not indicate good fit (Table 11). Of greater importance than the unfit model, however, was the negative variance, as displayed by the standardized estimate greater than one on the PCa survivors' relationship satisfaction path. Because of the negative variance, the χ^2 statistics and degrees of freedom were not able to be estimated. Upon further study, a standardized loading larger than one and a negative error variance is indicative of a Heywood case (Dillon et al., 1987).

A solution to the Heywood case was found in searching other models of dyadic data (e.g., actor-partner interdependence model), as the two observed relationship satisfaction variables could not include another observed variable, as the latent variable is a dyadic variable. In order to allow the model to properly identify and account for the shared experience of PCa survivors and their partners, the model was treated as a hybrid common fate model (Ledermann & Kenny, 2012). A hybrid common fate model, as detailed in Chapter Three, models the influence of an

internal or external event on a dyad. In pure common fate models, the internal or external event is a dyadic latent variable regressing on another dyadic latent variable. In a hybrid common fate model, an individual latent variable (e.g., stigma) can act as an external event that predicts an influence on the dyad, or rather, that the dyad experiences a common fate from the external event. In order to properly identify such a model, Ledermann and Kenny (2012) suggest that the factor loadings of the common fate variables be fixed to one and that the squared standardized factor loading becomes the amount of variance in an observed variable that is explained by the latent variable.

Further respecification of the model was necessary due to the new measurement models and consequential nonindependence for dyadic data (Kenny et al., 2006). The correlation analyses detailed earlier in Chapter Four were based off of the hypothesized factor loadings for the assessments. As the new factor loadings were specified in the measurement models, a new correlation analysis was necessary to detect consequential nonindependence. A correlation analysis between the factors indicating QoL and relationship satisfaction was conducted; only relationship satisfaction ($r = .68, p < .05$) violated consequential nonindependence (Kenny et al., 1998). However, because the relationship satisfaction variable has fixed factor loadings and is being treated as a common fate variable, the error covariance between the two items was not necessary for the model. After accounting for the common fate model, the final measurement model was able to run, but the model did not yield an acceptable fit to the data.

Modification indices were examined to adjust model fit after the initial SEM analysis. The modification indices output in AMOS indicated that freeing the error variance between e8 and e10 would provide a better model fit. Although it is not always in best practice to covary

error terms between two latent variables (Kline, 2011), there was theoretical justification as emotional QoL and relationship satisfaction have been found to correlate highly in previous studies (e.g., Song et al., 2011; Zhou et al., 2011). Due to the dyadic nature of the data, the error variances between e5 and e9 were also freed to account for the common fate model (Ledermann & Kenny, 2012). Co-varying emotional QoL and relationship satisfaction error variances improved the model fit, but it had not reached an acceptable range. The modification indices indicated that freeing the error variance between e7 and e8 would result in a better fitting model. Similar to the previous modification, the error variance between e3 and e5 was also freed to account for the common fate model. The resulting analysis (Figure 32) yielded a good fit (Table 11).

After finalizing each of the measurement models, a new structural model was created (Figure 33) utilizing the new factors obtained in the EFA and CFA analyses. New assessment subtotals and total scores were created for the new factors, with scoring procedures for reverse scoring (Cella et al., 1993; Esper et al., 1997). The following section details the model testing and model modification steps of SEM for the study (Crockett, 2012), with the new structural model measured and re-specified.

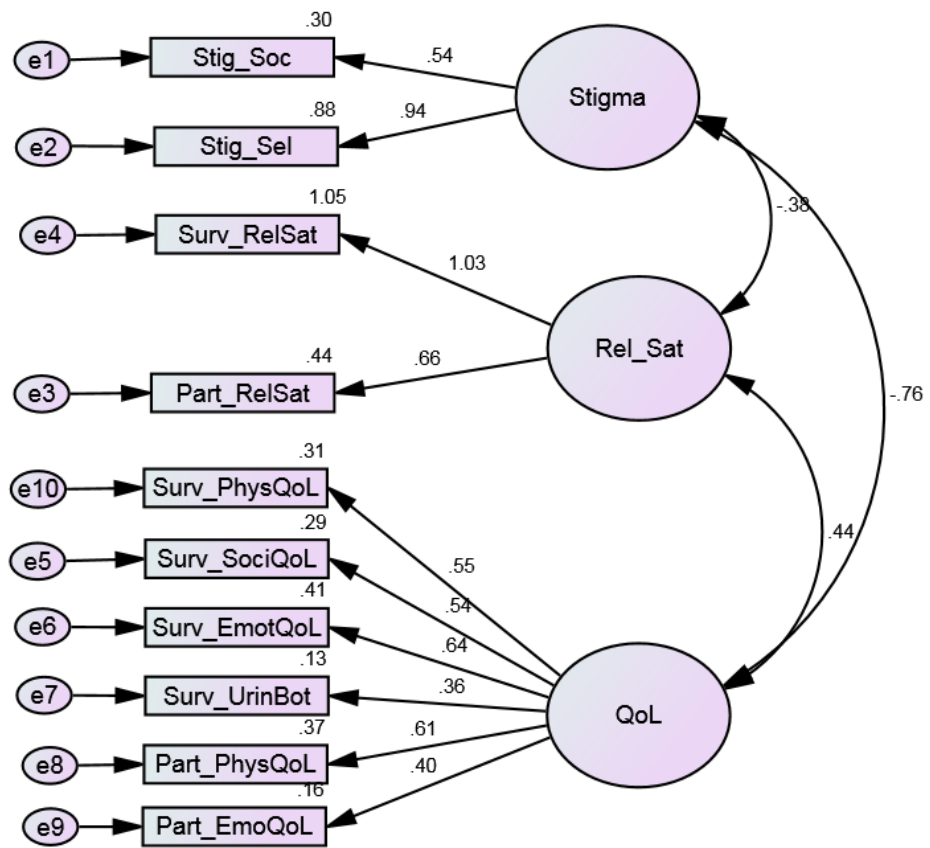


Figure 31 Initial Final Measurement Model

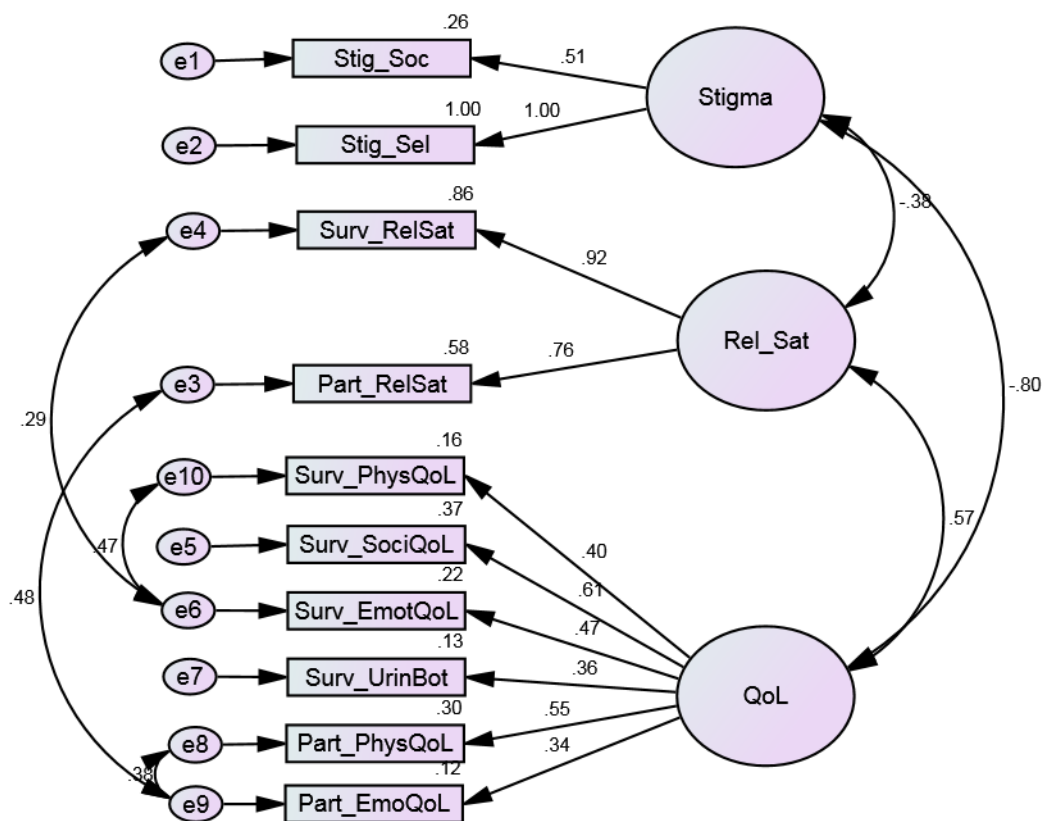


Figure 32 Revised Final Measurement Model

Table 12 Model Fit Indices for Final Measurement Model

| | χ^2 | <i>df</i> | <i>p</i> | CFI | TLI | RMSEA | SRMR |
|---------|----------|-----------|----------|------|-----|-------|------|
| Model 1 | N/A | N/A | N/A | .813 | .74 | .122 | .09 |
| Model 2 | 31.87 | 29 | .32 | .98 | .97 | .037 | .07 |

Structural Equation Model

The hypothesized structural model for the study (Figure 10) that tests the research hypothesis and answers the first exploratory research question. In light of the measurement model re-specifications, the structural model had to be adapted to fit the new measurement models. The new model (Figure 33) shows three latent variables: (a) stigma, as measured by social stigma and self-stigma; (b) QoL, as measured by PCa survivors' physical QoL, social QoL, emotional QoL, urinary bother, and partners' physical QoL and emotional QoL; and (c) relationship satisfaction, as measured by PCa survivors' and partners' relationship satisfaction. The model also includes an observed variable, race, to answer exploratory research question number one. The stigma latent variable acts as an exogenous (independent) variable, predicting both QoL and relationship satisfaction. Stigma is also an endogenous (dependent) variable, with race predicting stigma. The QoL and relationship satisfaction latent variables are both endogenous variables, being predicted by stigma and race. The final step in testing the SEM requires the race variable to be dummy coded.

Dummy coding

The process of modeling a nominal variable is not widely discussed in SEM textbooks (e.g., Byrne, 2010; Kline, 2011; Schumacker & Lomax, 2012) and the topic is also not common

in scholarly literature. Noted statistical experts (e.g., Linda and Bengt Muthén) offered suggestions for modeling a nominal variable in SEM, and these were employed in the study. The race variable, as defined by PCa survivors' race was dummy coded to allow for a regression analysis in the SEM (Muthén, 2009). However, in doing so, it came to the attention of the investigator that due to the limited diversity of the sample (e.g., 14 non-White couples) that the race variable would be modeled as a single dummy coded variable, with the value of 1 assigned to White couples and the value of 0 assigned to non-White couples (e.g., American Indian/Alaska Native, Asian, and Black couples). The lack of diversity in the sample still allows for exploratory research question number one to be answered, but in a more restricted way than originally conceptualized.

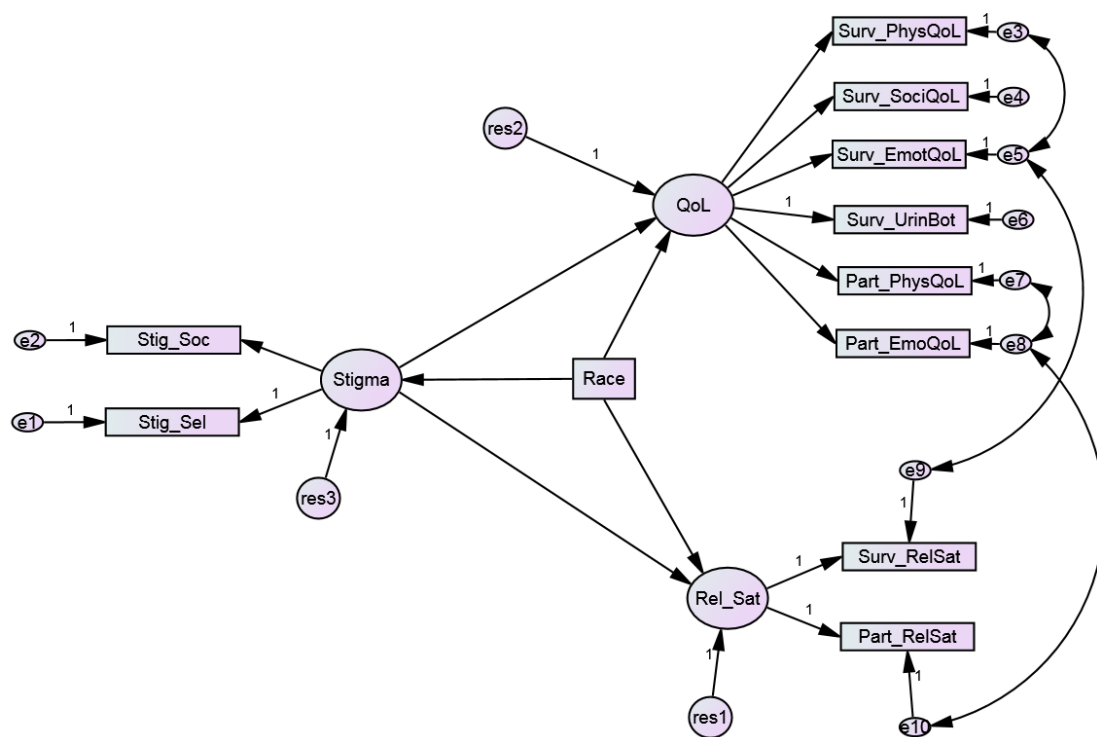


Figure 33 Structural Model

Initial analyses

The new SEM for the study, following measurement model respecification, addressing consequential nonindependence, and offering dummy coding is presented in Figure 34. The initial solution was run and found to have an acceptable model fit (Table 13). Other available modification indices did not provide significant statistical or theoretical meaning, so the re-specified SEM offers the most parsimonious and best fitting model to the data. Almost all the factor loadings for each of the observed variables in the structural model (Figure 34) meet criteria for appropriate measurement. However, two variables (e.g., survivors' urinary bother and partners' emotional QoL) fall below the .4 cutoff value (Stevens, 1992). The survivors' urinary bother factor loading was .39, which is below the cutoff. The PCa survivors' urinary bother factor was retained due to the theoretical significance of urinary bother and incontinence being an issue for PCa survivors from the effects of the disease and treatment (Kopp et al., 2013). The partners' emotional QoL factor loading was .33, which is below the cutoff. The partners' emotional QoL factor was retained due to QoL being a multidimensional construct (The WHOQOL Group, 1998), and to measure the influence stigma has on partners' emotional QoL, which researchers found is affected by the disease and its treatment more than PCa survivors' emotional QoL (Northouse et al., 2007). Further, Comrey and Lee (1992) suggest a factor loading cutoff value as low as .32, which each of the observed variables meet.

The estimates for the SEM are detailed in Figure 34. As displayed, there is a significant influence of stigma on both QoL, with stigma explaining 86% of variance in QoL ($\beta = -.92$, $R^2 = .86$, $p < .05$), and relationship satisfaction, with stigma explaining 19% of variance in relationship satisfaction ($\beta = -.44$, $R^2 = .19$, $p < .05$). These results, along with the model fit,

indicate that the primary research hypothesis (i.e., stigma has a negative influence on QoL and relationship satisfaction of PCa survivors and their partners) is confirmed. Further, with the exception of the race variable (detailed later in exploratory research question number one), each regression path in the model is significant at the .05 level. Race could be removed from the model to improve model fit, but it was retained for theoretical purposes. The covariances in the model are all significant at the .05 level except for covariance between e9 and e5. Variances in the model were all significant at the .05 level with the exception of res2, e1, and e9. However, due to the common fate model being employed, the covariance had theoretical basis.

Follow-up analyses

In addition to the structural model that confirms the research hypothesis, researchers using SEM are encouraged to explore equivalent models for alternatives to the original model (Kline, 2011). Alternative models inspected a model with the race variable removed and directional relationships between QoL and relationship satisfaction. Although the structural model used to confirm the main research hypothesis is both a good fit and is parsimonious, the following analyses provide other views of the data.

Figure 35 displays a model in which the race variable is removed. As shown in Table 13, the model displays a reduced, yet acceptable fit. The estimates for the model with the race variable removed show little difference, with stigma's explained variance reducing from 3% to 0%, QoL's explained variance reducing from 86% to 84%, and relationship satisfaction's explained variance remaining unchanged. Therefore, the alternative model without the race

variable is more parsimonious, but does not provide any substantially different information from the structural model.

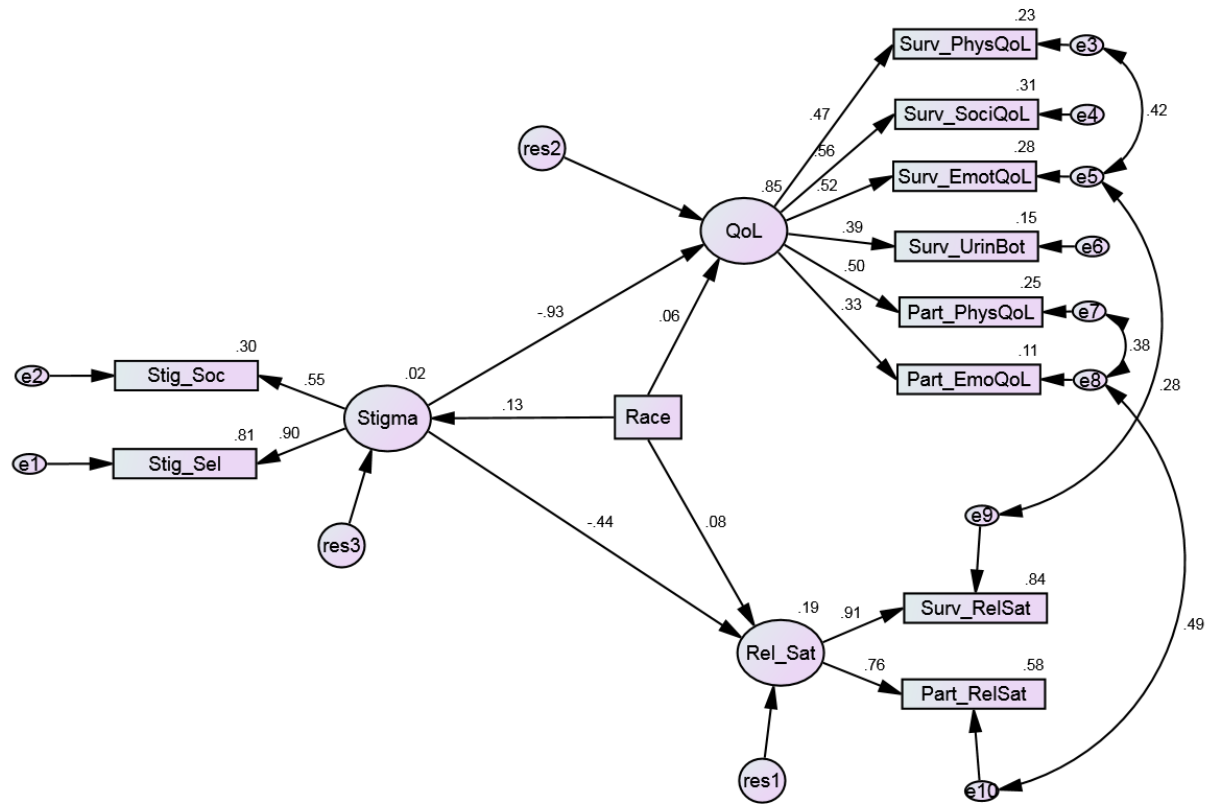


Figure 34 Structural Model with Estimates

Table 13 Model Fit Indices for Structural Models

| | χ^2 | <i>df</i> | <i>p</i> | CFI | TLI | RMSEA | SRMR |
|-----------------------------------|----------|-----------|----------|------|-----|-------|------|
| Model 1 | 41.15 | 37 | .3 | .977 | .96 | .04 | .07 |
| Model 2 (without race) | 35.03 | 30 | .241 | .973 | .96 | .05 | .08 |
| AltModel 1 (QoL→ RelSat) | 31.87 | 29 | .326 | .985 | .97 | .037 | .08 |
| AltModel 3 (RelSat→ QoL) | 31.87 | 29 | .326 | .985 | .97 | .037 | .08 |

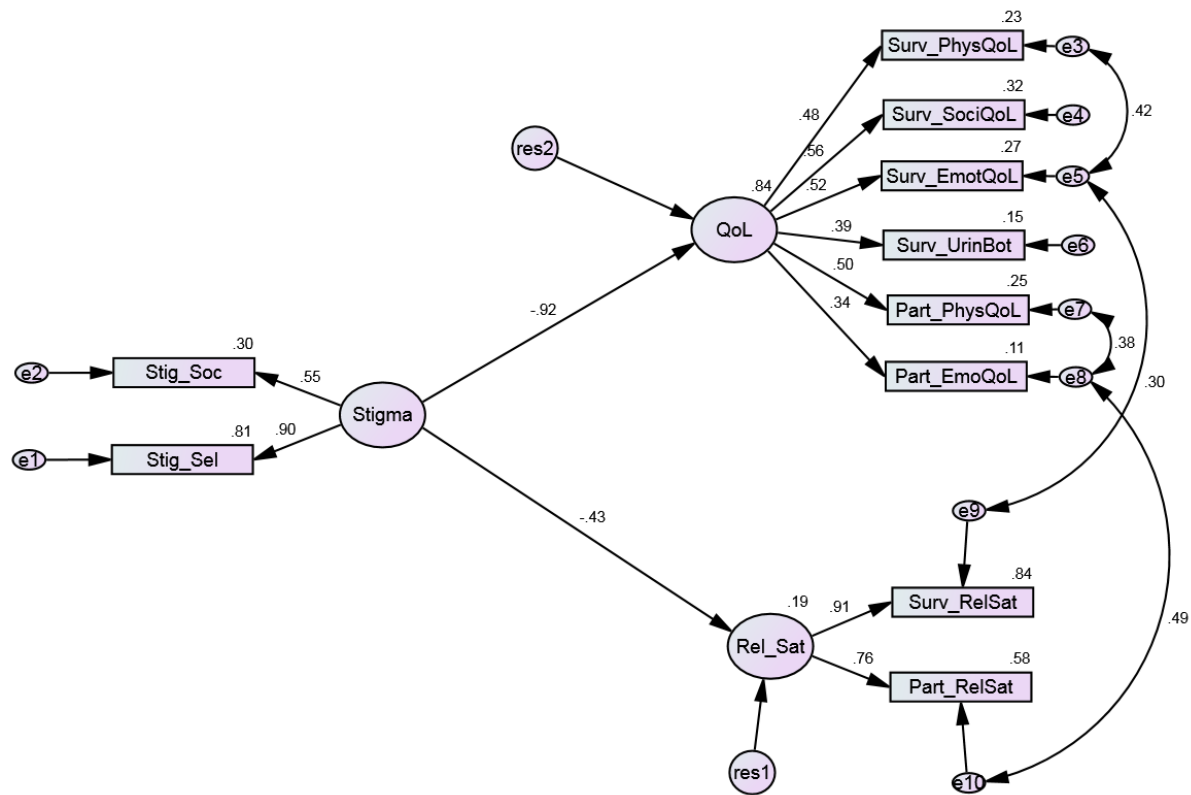


Figure 35 Structural Model with Race Variable Removed

Figure 36 displays a model in which QoL influences relationship satisfaction while the variable of race is removed. The residual term for the stigma variable was also removed, as removing the race variable made the stigma variable an exogenous variable, rather than exogenous and endogenous. The model proved to be a good fit (Table 13), and fit even better than the final structural model. The estimates for this model, however, are very different from the final structural model. The first is that stigma now has a positive, non-statistically significant relationship with relationship satisfaction ($p > .05$). Also, the positive relationship between QoL and relationship satisfaction, although strong ($R^2 = .56$), is not statistically significant ($p > .05$).

However, the relationship between stigma and QoL reduced in size ($R^2 = .64$) and remained significant ($p < .05$).

A final alternative model, with relationship satisfaction influencing QoL was also analyzed (Figure 37), yielding identical fit indices to the previous model (Table 13). Similar to the previous model, the relationship between QoL and relationship satisfaction was not significant ($p > .05$). However, the relationship between stigma and relationship satisfaction remained significant. Also, the positive relationship between stigma and relationship satisfaction from the previous model became negative in this alternative model ($r = .22, p < .05$).

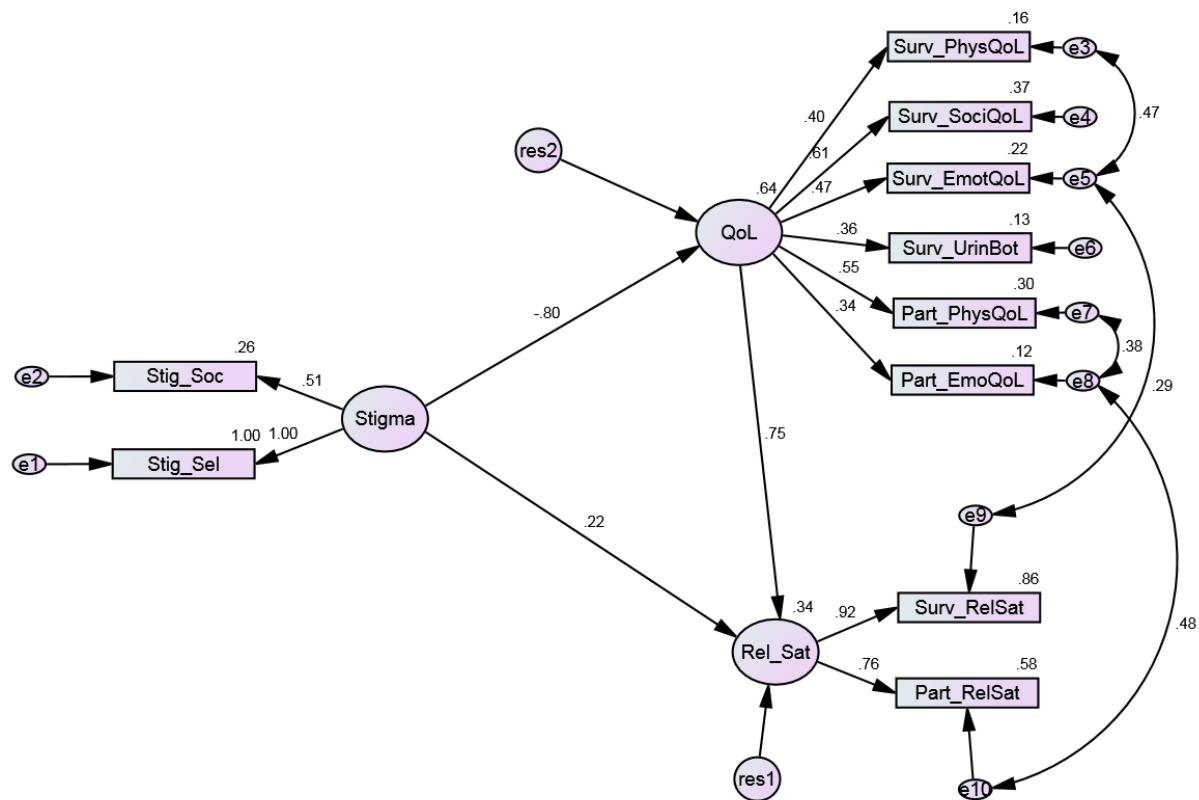


Figure 36 Structural Model with QoL Influencing Relationship Satisfaction

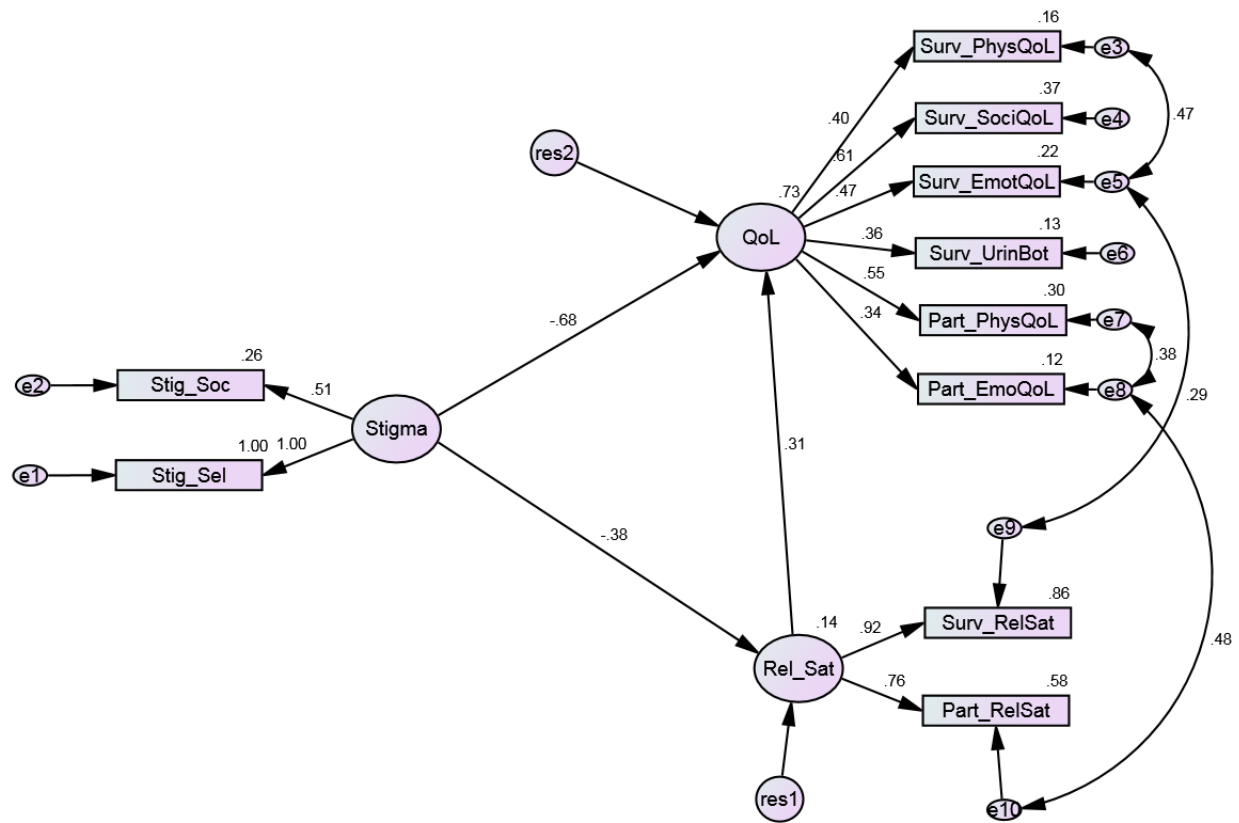


Figure 37 Structural Model with Relationship Satisfaction Influencing QoL

Exploratory Research Questions

1. Are there statistically significant relationships between stigma (as measured by the SIS; Fife & Wright, 2000), QoL (as measured by the FACT-P; Esper et al., 1997 and the FACT-GP; Cella et al., 1993), relationship satisfaction (as measured by the CSI; Funk & Rogge, 2007) and race for PCa survivors and their partners?

Included in the SEM which answered the primary research hypothesis, the nominal variable of race is also modeled. Including race into the SEM allowed the investigator to examine exploratory research question number one. Because race is a nominal variable, there

was not any hypothesized measurement error, and thus, no error variance was included in the model. Race was found to not have a statistically significant relationship between stigma ($\beta = .132, R^2 = .01, p > .05$), QoL ($\beta = .05, R^2 = .003, p > .05$), or relationship satisfaction ($\beta = .08, R^2 = .006, p > .05$). It should also be noted that race, based on the lack of diversity in the sample, is based on either a majority race (e.g., White) or minority race (e.g., American Indian/Alaska native, Asian, or Black). Although there could be differences between the observed groups, they could not be measured in the analysis.

To investigate exploratory research question one further, a point-biserial correlation (Lomax & Hahs-Vaughn, 2012) was conducted to assess correlations between dummy coded races and the subscale (stigma and QoL measures) or total (relationship satisfaction measures) scores. None of the relationships were deemed significant ($p > .05$). However, two correlations were found to border on significance (i.e., $p < .06$). The first correlation was between those identified as Asian and PCa survivors' urinary bother ($r = -.23, p = .056$), indicating that not being Asian was related to increased PCa survivors' urinary bother. The second correlation was between those identified as White and partners' emotional QoL ($r = -.22, p = .057$), indicating that not being White was related to increased partners' emotional QoL.

2. Are there statistically significant differences in stigma (as measured by the SIS; Fife & Wright, 2000) based on demographic variables (e.g., age and income) for PCa survivors?

To answer exploratory research question number two, a MANOVA was used to measure mean differences in stigma based on demographic variables (Tabachnick & Fidell, 2013). A MANOVA allows researchers to assess mean differences with multiple independent and dependent variables. The demographic variables chosen each had at least two levels to assess for

mean difference. Following the demographic variables listed in parentheses is the number of levels for that variable. Demographic variables used to assess for mean differences were PCa survivors' age (8), race (7), educational level (8), income (7), time since diagnosis (7), stage of cancer (6), whether the survivor had been treated or not (2), type of treatment (11), whether treatment had been completed or not (2), and other chronic illnesses diagnoses (2). In addition to PCa survivors' demographic variables, their partners' age (8), race (7), educational level (8), and experiences of chronic illness (2) were used to test for mean differences in stigma. The independent variables used were the subtotal social stigma and self-stigma, taken from the revised measurement model of the SIS (Fife & Wright, 2000). Pillai's Trace (Tabachnick & Fidell, 2013) was used to detect levels of significance and effect size.

The MANOVA yielded no statistically significant differences ($p > .05$) in mean social stigma and self-stigma scores. A MANOVA was also conducted with the subscale totals from the original SIS measurement model, which also yielded non-significant findings. In addition to the MANOVA analyses, an analysis of variance (ANOVA) was used with the summed SIS score as a dependent variable (Stevens, 2007), as previous researchers have found that the SIS can be used to measure stigma unidimensionally (Pan et al., 2007). Demographic variables yielded no statistically significant results in mean differences of stigma. Of note throughout each multivariate test was an inadequate observed power ($< .5$), leading to increased chance of Type II error. Thus, from the current analysis, there are no statistically significant differences between stigma based on demographic variables for PCa survivors.

Chapter Summary

In Chapter Four, the data of the present study were analyzed. Sampling and data collection was reviewed before moving onto data analysis. The participant characteristics were analyzed to develop a better understanding of who participated in the study. Data cleaning procedures were detailed, along with examining statistical assumptions to ensure that the research hypothesis and exploratory research questions could be answered. Data analysis of the research hypothesis included EFAs and CFAs to develop measurement models to fit the data collected in the current study. Data analysis also included analyzing the structural model to confirm the research hypothesis. Follow-up analyses explored other models to better understand how the model could be adapted to better fit the data. Finally, data were analyzed to answer the exploratory research questions. Chapter Five of the dissertation concludes by reviewing the study, discussing limitations, providing implications for cancer survivors, counselors, counselor educators, and examining areas of future research based on the results of the study.

CHAPTER FIVE: DISCUSSION

The purpose of Chapter Five is to review the results of the present study. Chapter Five also places the results of the study in contrast to and comparison to the studies reviewed in Chapter Two. Chapter Five details the (a) results of the main research hypothesis; (b) results of the exploratory research questions; (c) limitations of the study; (d) strengths of the study; (e) areas of future research; and (f) implications for counseling and mental health fields.

Summary of the Study

The purpose of this study was to assess the influence of prostate cancer (PCa) stigma on survivors and their partners. Specifically, this study aimed to investigate the directional relationships between stigma, quality of life (QoL), and relationship satisfaction. Previous researchers (e.g., Else-Quest et al., 2009; Fergus et al., 2002) have indicated that PCa survivors are affected by stigma, but no empirical research to date has focused on the influence stigma has on PCa survivors or their partners.

The primary research hypothesis for the study aimed to test that stigma (as measured by the SIS; Fife & Wright, 2000) will have a negative influence on QoL (as measured by the FACT-P; Esper et al., 1997 and the FACT-GP; Cella et al., 1993) and relationship satisfaction (as measured by the CSI; Funk & Rogge, 2007) of PCa survivors and their partners. In short, as stigma increases, QoL and relationship satisfaction decrease. The main research hypothesis was grounded in previous research indicating that PCa survivors have lower QoL than the general population (Zenger et al., 2010). Further, the effects of the disease and its treatment causes a decrease in QoL (Torvinen et al., 2013; Vanagas et al., 2013). The main research hypothesis was

also grounded in previous research indicating that the effects of the disease and its treatment can cause survivors to experience sexual dysfunction, incontinence, and a sense of not being able to accomplish tasks that were previously simple (Kopp et al., 2013; Pedersen et al., 2012; Rivers et al., 2012). Partners are also affected by disease, and in many cases, are more emotionally distraught than survivors (Northouse et al., 2007). Finally, public perception or lack of knowledge about PCa and its treatment can effect survivors and partners (Vrinten et al., 2014; Walsh & Worthington, 2012).

In addition to the main research hypothesis, two exploratory questions were considered based on noted health disparities (NCI, 2011) that have been found for PCa survivors. The second exploratory research question focused on what else can contribute to experienced stigma, as many of the demographic items (e.g., income and treatment) have been found to have an influence on QoL and relationship satisfaction (DiIorio et al., 2011; Harden et al., 2008; Northouse et al., 2007; Zenger et al., 2010). Specifically, research questions were focused on the relationship of race and other demographic variables to stigma, QoL, and relationship satisfaction.

The study was approved by the University of Central Florida's IRB on November 12th, 2014. Data collection lasted until January 31, 2015. Participants were invited to take part in the study from three primary sources: a cancer center in northeast Florida, PCa support groups in Florida, and online PCa support groups. Participants consisted of individuals who were diagnosed with PCa and their romantic and/or intimate partners. In the face-to-face samples, 158 couples were approached to complete the study, with 65 couples returning assessment packets, yielding a 41% response rate. Seven couples from online PCa support groups completed

assessment packets online. Due to the changing numbers of those in online PCa support groups, a response rate could not be calculated. The final sample for the study was 72 couples.

The assessment packets used for the study consisted of six different instruments: (a) an investigator-generated PCa survivor demographic form, (b) an investigator-created partner demographic form, (c) the SIS (Fife & Wright, 2000), (d) the FACT-P (Esper et al., 1997), (e) the FACT-GP (Cella et al., 1993), and (f) the CSI (Funk & Rogge, 2007). Statistical analyses consisted of SEM (including regression and CFA; Byrne, 2009; Kline, 2011), MANOVAs, and an ANOVA (Tabachnick & Fidell, 2013). Structural equation modeling addressed the main research hypothesis and exploratory question number one. The MANOVAs and ANOVA were used to answer exploratory question number two. In interpreting the results of the analysis, an alpha level of .05 was used to detect statistical significance. Further, effect sizes of .1, .3, and .5 indicated a small, medium, and large effect size, respectively (Cohen, 1988). The following section offers information on participant demographics, descriptive data analysis reviewed from Chapter Four, and a detailed examination of the results of the primary research hypothesis and the exploratory research questions.

Summary of Results

A total of 72 couples participated in the study. The ages of PCa survivors (47.2%) and partners (43.1%) were mostly between the ages of 66 and 75, falling in line with trends for those diagnosed with the disease (NCI, 2011). Participants primarily identified as Caucasian (79.2%), similar to the majority of PCa research (Parahoo et al., 2013). Although the sample had limited diversity, participants from non-majority races were more represented compared to the majority

of published PCa research not specifically targeting one racial or ethnic group (Penedo et al., 2013).

Participant characteristics for PCa-specific questions provided more detail about cancer treatment and state of survivorship. The majority of PCa survivors were between one and three years post-diagnosis (41.7%). The stage of cancer question yielded some challenges, as 44.4% of PCa survivors did not know their stage of cancer. This outcome is expected in some ways, as the majority of discussion around PCa severity refers to PSA levels or Gleason scores (Walsh & Worthington, 2012). Sixty-eight PCa survivors in the sample had been treated for the disease, with the majority receiving multiple types of treatment (40.3%), mostly external radiation in conjunction with hormone therapy. Of those who answered the question, 51.4% of participants had completed treatment. Finally, for both PCa survivors and partners, many participants experienced multiple chronic illnesses (e.g., diabetes, heart disease, or other cancer).

Descriptive data analysis yielded numerous interesting results. Results indicated that the majority of PCa survivors felt some amount of stigma, as found in previous literature (Else-Quest et al., 2009), but the value was on the lower end of the scale for all participants (Social Rejection: $M = 11.02$, $Mdn = 9$, $Mode = 9$; Financial Insecurity: $M = 4.01$, $Mdn = 3$, $Mode = 3$; Internalized Shame: $M = 7.48$, $Mdn = 7$, $Mode = 5$; Social Isolation: $M = 10.28$, $Mdn = 7$, $Mode = 7$). Further, the mean values obtained on the SIS were all lower than the cancer norming groups in Fife and Wright's (2000) original study. Although the SIS was normed on two separate samples (e.g., individuals with HIV and individuals with cancer), no normed values have been detailed in the current literature to determine what value indicates a high or low level of stigma. During administration of the SIS, it became apparent to the investigator that a large portion of

PCa survivors were not working or were retired, yielding some items on the SIS (e.g., “My employers/co-workers have discriminated against me”) not applicable to a large portion of survivors. As found in the present study and others (NCI, 2011), the majority of PCa survivors are of retirement age. Further, the treatment schedule for external radiation calls for PCa survivors to attend treatment daily, limiting the possibility of scheduling for survivors who work daily.

Results indicated that participants tended to have high levels of quality of life as measured by the FACT-P (Esper et al., 1997) and the FACT-GP (Cella et al., 1993). Mean scores on the FACT-GP subscales were pro-rated (Brucker et al., 2005) in order to compare scores between PCa survivors’ QoL (i.e., FACT-P scores) and partners’ QoL (i.e., FACT-GP scores). Pro-rating scores on the FACT-GP illustrate that the QoL for PCa survivors and their partners were similar: FACT-P physical well-being: $M = 22.77$, FACT-GP physical well-being: $M = 23.8$; FACT-P social/family well-being: $M = 21.62$, FACT-GP social/family well-being: $M = 21.6$; FACT-P emotional well-being: $M = 19.09$, FACT-GP $M = 19.74$; FACT-P functional well-being: $M = 21.59$, FACT-GP functional well-being: $M = 21.26$. Brucker and colleagues (2005) provided normative data based on populations with and without cancer. Brucker and colleagues provided T-score conversion charts to aid in interpretation of the FACT-G (Cella et al., 1993), from which the FACT-P and FACT-GP are based, indicating that T-scores of 50 are the center of a normal distribution, with standard deviations of 10.

Prostate cancer survivors and their partners had above average QoL as compared to the normative data of individuals with cancer, except in the social/family well-being subscale, wherein the mean value of couples was just below (T-score = 49) the average cutoff (50).

However, compared to the non-cancer group, PCa survivors' physical well-being (49); PCa survivors' emotional well-being (48.5); and partners' emotional well-being (49) were below average. The FACT-P additional concerns subscale yielded scores that indicated that most PCa survivors in the sample experienced symptoms related to the disease and its treatment. It should be noted, however, that some PCa survivors told the investigator that the physical symptoms they experienced (found on the physical well-being subscale or additional concerns subscale) were due to other concerns (e.g., arthritis) and consequences of aging, rather than just the disease.

Participants in the current investigation scored high on the CSI (Funk & Rogge, 2007), indicating higher than average relationship satisfaction. Funk and Rogge (2007) report that the cut-off score for a distressed relationship satisfaction is 51.5 on the 16-item version of the CSI. Mean values for PCa survivors ($M = 66.66$, $SD = 14.38$) and partners ($M = 64.76$, $SD = 15.17$) were above the cut-off value for distress. PCa survivors scored higher overall than partners and had lower variation in scores. Interestingly, during the administration of assessment packets, numerous couples stated that they did not want to complete the CSI, noting that they did not want to take a survey that would start an argument between themselves and their partners. The concerns surrounding PCa survivors who did not choose to participate could account for the generally high scores in the sample.

In sum, participants in the current investigation consisted of PCa survivors who were not highly stigmatized, reported good QoL, and were satisfied with their relationships. Also, partners in the sample similarly reported good QoL and were satisfied with their relationships. These trends are common in mental health and psychosocial research, as individuals who tend to participate in research tend to be more mentally well, leading to selection bias (explained further

in the limitations section; Gall et al., 2007). The trends found in the sample may have also contributed to the multivariate kurtosis (explained in Chapter Four) found in the sample. Following the descriptive data analysis, CFAs were conducted on each of the instruments to ensure that the instruments' constructs fit the data. The final measurement model is detailed below.

Instrumentation and Measurement Models

The four data collection instruments used in the study were subjected to CFAs, with the CSI (Funk & Rogge, 2007) being measured for PCa survivors, as well as partners. Confirmatory factor analyses were conducted to ensure that the instruments used in the study reflected their hypothesized subscales and properly measured sample data. Each of the CFAs yielded poor model fit, regardless of methods used to improve fit (e.g., bootstrapping and modification indices), and therefore, it was suggested that EFAs be conducted to identify factors from the collected data.

The EFAs followed similar processes for each instrument (Costello & Osborne, 2005). Principal axis factoring was the extraction method chosen as it allows for items to be correlated and Promax rotation was used as the EFAs were conducted on previously developed instruments. The EFA analyses were geared toward already developed scales with subscales that had hypothesized correlations. Initially, EFAs were conducted to extract factors with eigenvalues of 1 or higher (O'Rourke & Hatcher, 2013), and factors were reduced if the last factor contained less than two items that loaded on that factor. Further, items with low communalities ($< .25$) were deleted, as they were not likely to load on any factor. Cross-loading items were deleted if

the difference between the cross-loading was less than 0.2 (Costello & Osborne, 2005). After each instrument's EFA, the factor structure was loaded into AMOS (2012) to conduct a CFA.

Individual items were reloaded to the CFA, which had been previously deleted in the EFA analysis, to retain the maximum number of items. Modification indices were then followed to increase model fit of CFAs. After measurement models reached minimum allowable fit (Schumacker & Lomax, 2012), items were again reviewed for theoretical basis, and were re-included in the analysis if they were theoretically necessary. Further, other factors were created if theoretically necessary. For example, items from the FACT-P emotional well-being subscale loaded onto the new PCa survivor physical QoL factor. Although there is rationale that emotional and physical QoL relate to one another (Cohen & Herbert, 1996), the items were discussed with the dissertation chair and it was decided to separate the physical and emotional items onto different factors. This decision allowed for the analysis to determine to what extent stigma influenced physical QoL and emotional QoL separately for PCa survivors.

Although none of the measurement models yielded good fit with their hypothesized factor structure, the poor model fit was not surprising, as the SIS had not been used with a PCa-specific sample. Further, a larger sample could have provided a better fitting model (Kline, 2010). In regards to the SIS, the items measured a generalized form of social and self-stigma related to medical illness, as it was designed to do (Fife & Wright, 2000). Fife and Wright originally designed the instrument to measure four types of stigma: two related to social stigma and two related to self-stigma. In the current study, the SIS was found to measure stigma less intricately than hypothesized by Fife and Wright, which is partially supported by Pan and colleagues (2007). Pan and colleagues found that the SIS yielded generally unidimensional

results, which is also less intricate than how Fife and Wright (2000) found the instrument to load. Further, the first question on the SIS is a work related item (e.g., “My employer/co-workers have discriminated against me”) which could have caused a testing effect (Onwuegbuzie & McLean, 2003) to assume that the remainder of questions related to work. The problem with this beginning is that many of the participants were above the general age of retirement in the United States, and thus could not honestly answer the first item or other job-related items (e.g., “My job security has been affected by my illness”). Thus, although there were theoretical and data-based issues with the SIS, it was able to effectively measure two types of stigma found in previous literature and aided in interpreting the results of the present study (e.g., Link & Phelan, 2001; Vogel et al., 2013).

Both the FACT-P (Esper et al., 1997) and the FACT-GP (Cella et al., 1993) had poor fitting models, based on the hypothesized factor structure. Previous researchers (e.g., Hahn, Rao, Cella, & Choi, 2008; Janda et al., 2009) have found that the four factor structure from which the FACT-P and the FACT-GP are based is a valid structure. Other researchers (e.g., Smith, Wright, Selby, & Velikova, 2007; Sánchez, Ballesteros, & Arnold, 2011) advise that the four-factor structure be used with caution.

The five factor structure of the FACT-P was put forth with caution due to the low reliability of the fifth additional factor ($\alpha = .123$). As found in the analysis, the FACT-P retained three of the four hypothesized factors, with the items on the functional well-being subscale not loading onto any factor. Further, a three-item factor was generated from the additional concerns subscale regarding problems with urinary function, or urinary bother. The urinary bother factor had not been identified in previous literature, to the investigator’s knowledge. Thus, the majority

of constructs that the FACT-P purports to measure were measured in the current study, even though multiple items were removed and the functional well-being factor was eliminated.

Similarly, the FACT-GP measured less of the purported factors than hypothesized. Of the four hypothesized factors, only physical QoL and emotional QoL factors were retained. It is difficult to compare this finding with previous findings, as the FACT-GP is rarely used and was only normalized in the past 10 years (Brucker et al., 2005; Janda et al., 2009). Thus, the translation of a QoL measure intended for cancer survivors to a population without a cancer diagnosis could be a limitation for the FACT-GP. Further, the influence of PCa survivors, through their own QoL (Zhou et al., 2011) or during assessment (Onwuegbuzie & McLean, 2003), could have influenced the responses on the FACT-GP and yielded a factor structure different from the hypothesized structure (Cella et al., 1993). Although the FACT-GP factor structure used in the current study did not reflect the hypothesized factor structure, the items used in the study fell in line with the hypothesized physical QoL and emotional QoL items and factors.

Similar to the SIS (Fife & Wright, 2000), the CSI (Funk & Rogge, 2007) had not been previously used with a sample of PCa survivors and their partners. Utilizing a new instrument with a new population could have yielded the misfit found in the analysis of the present study. The hypothesized factor structure yielded a one factor structure, whereas the EFA analysis yielded a two factor structure for both PCa survivors and their partners. The investigator and the dissertation chair examined the second factor, and it was decided that the second factor did not differ from the rest of the items on the first factor. Thus, the EFA was constrained to one factor, and the items from the second factor were deleted. Following recommendations indicated by the

modification indices, the one-factor model yielded a good fit, which is in line with studies on the CSI (Funk & Rogge, 2007; Graham et al., 2011 CHECK). As indicated by the sheer amount of modification indices and the very high internal consistency, the CSI for both PCa survivors and their partners was most likely redundant. The redundancy was not out of line with previous research, as Funk and Rogge originally presented the CSI as 32-, 16-, and 4-item versions. The 16-item version was used in the present study to reduce test fatigue that may have been brought on by the 32-item version and to also ensure that the variable was being measured, which would have been difficult if half of the 4-item version did not fit the data (e.g., resulting in a Heywood case). However, in retrospect, the 4-item version could have been used with the current population as the CSI appeared to be valid. Therefore, although there was redundancy in the assessments, they still measured relationship satisfaction for PCa survivors and their partners.

The SIS (Fife & Wright, 2000), the FACT-P (Esper et al., 1997), the FACT-GP (Cella et al., 1993), and both CSIs (Funk & Rogge, 2007) were combined in one measurement model, which yielded poor model fit and also provided a Heywood case (Dillon et al., 1987). However, upon reviewing literature on the common fate model (Ledermann & Kenny, 2012), the factor loadings for the relationship satisfaction latent variable were set to one to account for dyadic data. Setting factor loadings to one for the relationship satisfaction is necessary because it is a dyadic latent variable measured by single factor indicators. A couple is inherently two individuals, and measuring two individuals' relationship satisfaction with an assessment containing only a single factor would more than likely result in a Heywood case. Fixing the factor loadings for the relationship satisfaction latent variable allows the full measurement model to be identified, rather than underidentified.

With the Heywood case addressed, the full measurement model was again tested and found to have poor model fit. Modification indices were followed to improve model fit. Dissimilar to the previous measurement models, the output in AMOS (Arbuckle, 2012) indicated that freeing the variance between partners' emotional QoL and their relationship satisfaction would improve the model fit more than any other modification. Although it is not in best practice to free variances between two factors, the decision was both data and theory driven. The modification would provide the greatest change in χ^2 and it made theoretical sense that partners' emotional QoL should be correlated with their relationship satisfaction. In order to provide a similar common fate between both partners, the variance was freed between PCa survivors' emotional QoL and their relationship satisfaction. Further modification indices were followed for both members of dyads, with PCa survivors' physical and emotional QoL variance being freed, which was then applied to partners as well. The resulting full measurement model (Figure 38) yielded a good fit, with χ^2 being nonsignificant ($df = 29$, χ^2 ratio = 31.87, $p > .05$) and CFI = .98, RMSEA = .037, and SRMR = .07

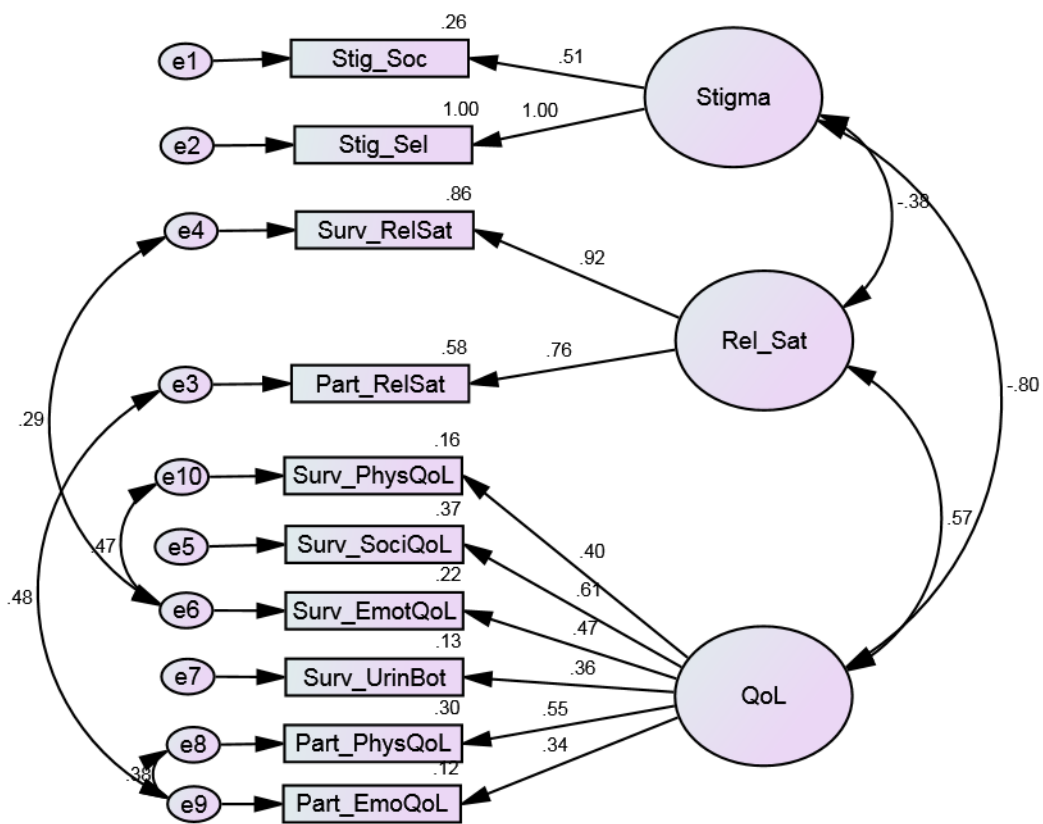


Figure 38 Full Measurement Model

Primary Research Question Results

Research Hypothesis

The research hypothesis for the study was: Stigma (as measured by the Social Impact Scale; Fife & Wright, 2000) has a negative influence on QoL (as measured by the Functional Assessment of Cancer Therapy - Prostate; Esper et al., 1997 and the Functional Assessment of Cancer Therapy – General Population; Cella et al., 1993) and relationship satisfaction (as measured by the Couples Satisfaction Index; Funk & Rogge, 2007) for PCa survivors and their partners.

In order to test the research hypothesis, a structural model was developed, which consisted of latent variables (e.g., stigma, QoL, and relationship satisfaction) combined with the full measurement model (Figure 38). The tested model (Figure 39) yielded a good model fit with χ^2 being nonsignificant ($df = 37$, χ^2 ratio = 41.15, $p > .05$) and CFI = .977, TLI = .96, RMSEA = .04, and SRMR = .07. Stigma, along with race, accounted for 85% of the variance for QoL and 19% of variance for relationship satisfaction. With the removal of the variable race, stigma accounted for 84% of variance in QoL and 19% of variance in relationship satisfaction. Relationships between stigma and QoL ($r = -.93$, $\beta = -.92$, $p < .05$) and stigma and relationship satisfaction ($r = -.44$, $\beta = -.44$, $p < .05$) were negative, suggesting that higher levels of PCa stigma predicted lower levels of QoL and relationship satisfaction for both survivors and their partners. Therefore, more experiences of stigma predict worse QoL and worse relationship satisfaction in couples dealing with PCa. The research hypothesis was therefore accepted.

CFI = .973, TLI = .96, RMSEA = .05, and SRMR = .08. The model without the race variable was more parsimonious than the structural model (e.g., less paths and observed variables) and should be kept as the final structural model. However, the structural model with the race variable was kept as the final model as it aided in answering exploratory research question number one.

Another follow-up analysis was conducted without the race variable, and with a directional path with QoL influencing relationship satisfaction yielded substantially different results. First, the model yielded a good fit with χ^2 being nonsignificant ($df = 29$, χ^2 ratio = 31.87, $p > .05$) and CFI = .985, TLI = .97, RMSEA = .037, and SRMR = .08. Second, QoL had a significant ($p < .05$), positive relationship ($r = .75$) with relationship satisfaction. Third, the relationship between stigma and relationship satisfaction became nonsignificant ($p > .05$) and positive ($r = .22$). These results provide a unique view on the data that had not originally been hypothesized. That is, that QoL provides a possible mediation effect in the relationship between stigma and relationship satisfaction.

The final follow-up analysis was conducted without the race variable, and with a directional path with relationship satisfaction influencing QoL yielded further interesting results. First, the model yielded a good fit with identical fit indices to the previous model. Second, relationship satisfaction had a significant ($p < .05$), positive relationship ($r = .31$) with QoL. Third, the relationship between stigma and relationship satisfaction had re-established a significant ($p < .05$) and negative ($r = -.38$) relationship.

Summary of Results of the Hypothesis

The results of the data analysis revealed several findings. Stigma has a strong negative influence on the QoL of PCa survivors and their partners. Further, stigma has a moderate negative influence on the relationship satisfaction of PCa survivors and their partners. The structural model analyzed yielded a good fit to the data. The final structural model was not the most parsimonious model possible; however, the race variable was included in order to answer exploratory research question number one. Alternative models examining the relationships between stigma, QoL, and relationship satisfaction yielded interesting results. When a path is drawn in the structural model from QoL to relationship satisfaction, the relationship between stigma and relationship satisfaction becomes a nonsignificant, positive relationship. These results require further analyses in later studies; however, the results may point to a possible mediated relationship, with QoL mediating the relationship between stigma and relationship satisfaction. Another alternative model, with a path drawn from relationship satisfaction to QoL, yielded results that were in line with the final structural model to test to research hypothesis. That is, stigma had a moderate, negative influence on both QoL and relationship satisfaction. Also, relationship satisfaction had a moderate, positive influence on QoL, similar to findings in previous research (e.g., Zhou et al., 2011).

Data Analysis in Relation to Current Literature

The results of the study were consistent with previous studies focused on issues related to stigma for PCa survivors (e.g., incontinence or erectile dysfunction; Burns & Mahalik, 2008; Campbell et al., 2012; Else-Quest et al., 2009; Fergus et al., 2002; Jenkins et al., 2004; Maliski et

al., 2008; Rivers et al., 2011; Rivers et al., 2012; Taylor-Ford et al., 2013). The current investigation is the first empirical study to examine the influence of stigma on QoL and relationship satisfaction for couples. However, researchers have examined the effects of PCa on quality of life for survivors and their partners.

Prostate Cancer Stigma and Quality of Life

The present study adds to the current literature on QoL for PCa survivors. Similar to the findings of the present study, researchers have found that many events can influence the QoL of PCa survivors (e.g., Chipperfield et al., 2013; Diefenbach et al., 2008; Nelson et al., 2009; Vanagas et al., 2013). The current study suggests that stigma is another psychosocial variable that is able to predict lower QoL for PCa survivors and their partners. Nonetheless, the descriptive data analysis of the SIS scores indicate that the stigmatization felt by PCa survivors is lower than a norm group of cancer survivors (Fife & Wright, 2000). Therefore, even small experiences of stigma can have a great influence on the QoL of PCa survivors and their partners. This finding is particularly true for self-stigma, a greater indicator of stigma than social stigma in the final model. In addition, the QoL of PCa survivors was found to be lower than a PCa norm group and a non-cancer norm group in social/family well-being and emotional well-being, with partners' emotional well-being lower than a non-cancer norm group. Lower QoL as compared to a non-cancer norm group is in line with previous studies examining the QoL of PCa survivors as compared to general populations (e.g., Torvinen et al., 2013; Zenger et al., 2010). Previous researchers have found that other psychosocial variables can predict lower QoL and related variables for PCa survivors.

Taylor-Ford and colleagues found that PCa survivors' ($N = 47$) body image changed over time, from start of treatment to two-year follow up. Change in body image affected PCa survivors receiving a hormone treatment (e.g., ADT) in particular ($B = -0.62, p < .05$). Changes in body image over time could be the result of increasing stigma, both social and self-stigma. With hormone therapy, changes in the body occur (e.g., breast enlargement, penile shortening, and testicular shrinkage) that could relate to developing a new stigmatized identity (Maliski et al., 2008) due to PCa, which has a negative relationship with QoL ($R^2 = .11$; Taylor-Ford et al., 2013). In the work of Taylor-Ford and colleagues, changes in body image predicted changes in QoL. Similarly, in the present study, stigma had a negative relationship with QoL, meaning that stigma predicted changes in QoL. It is possible that measuring stigma may encompass the feelings related to body image change over time in a less detailed fashion. The current study further supports Taylor-Ford and colleagues' study related to the psychosocial influence of PCa and treatment on survivors' QoL.

Burns and Mahalik (2008) conducted a study on sexual functioning, masculinity, and social, role, and mental health QoL for PCa survivors ($N = 234$). They found that PCa survivors with traditional masculine norms and poor sexual functioning had worse social ($R^2 = .017$), role ($R^2 = .021$), and mental health functioning ($R^2 = .018$) than individuals with less traditional masculine norms. Similarly, PCa survivors with less traditional masculine norms and good sexual functioning had better social, role, and mental health functioning compared to those with less traditional masculine norms. In essence, the study found that sexual functioning moderates the relationships between masculine norms and social, emotional, and role functioning. Although personality variables such as adherence to masculine norms were not collected in the current

study, the majority of participants were older than 55, therefore, participants may be more likely to adhere to traditional masculine norms, which could predict occurrence of stigma (Hooker, Wilcox, Burroughs, Rheaume, & Courtenay, 2012; Rice, Fallon, & Bambling, 2011; Vogel, Heimerdinger-Edwards, Hammer, & Hubbard, 2011).

Jenkins and colleagues (2004) examined the role of sexuality and its relationship to QoL in Black PCa survivors treated for localized disease ($N = 1230$). The researchers indicated there was a significant correlation between Black PCa survivors' importance of erection score and self-perception of being powerful and aggressive on a measure of sexual self-schema ($R^2 = .17$), which led the authors to conclude there was a connection between Black survivors' self-concept and ability to maintain erections for sexual activity. Although the researchers found that the results were greater for Black PCa survivors than White survivors, both groups were affected. Because PCa and its treatment may cause sexual issues (Walsh & Worthington, 2012), PCa can be a particularly debilitating disease for Black survivors' sexual identity. Further, stigma has often been linked to sexuality, whether it concerns topics such as risky sexual behavior (Chan, Rungpueng, & Reidpath, 2009) or inability to have sex (Bergvall & Himelein, 2014; Fergus et al., 2002). Based on this information in light of the current study, PCa can be seen to possibly cause stigma due to issues related to sexuality and the importance that survivors place on different aspects of their sexuality, which could influence QoL and relationship satisfaction. Therefore, in review of the works of Taylor-Ford and colleagues (2013); Burns and Mahalik (2008); and Jenkins and colleagues (2004), many factors can influence QoL for PCa survivors, including stigma – as results from the current study indicated.

Prostate Cancer Stigma and Relationship Satisfaction

The present study also assessed the influence of stigma on relationship satisfaction for PCa survivors and their partners. Previous studies measuring psychosocial issues and their influence on relationship satisfaction for PCa survivors and their partners examined data from purely individual levels or examined intradyadic influence within a couple. The current study used a common-fate model to approach the data to understand how couples are influenced by an individual level internal event (Ledermann & Kenny, 2012). The descriptive data analysis indicated that the sample had an above average relationship satisfaction, as reported by both PCa survivors and their partners, as compared to a norming group (Funk & Rogge, 2007). Further, the majority of couples did not meet criteria to be categorized as “distressed.” The results of the study indicate that stigma has a moderate influence on relationship satisfaction, but on average, not enough to cause relational distress. A wider variety of couples dealing with PCa could provide a better image as to how these findings apply to the majority of couples dealing with PCa. The results of the SEM analysis fall in line with the findings of previous studies.

Researchers indicate (e.g., Harden et al., 2013 Northouse et al., 2007; Song et al., 2012), QoL and relationship satisfaction of couples influence one another, with the influence of PCa survivors being stronger than their partners (Zhou et al., 2011). Zhou and colleagues investigated marital satisfaction, mental, and physical health for advanced disease-stage PCa survivors and their partners ($N = 29$). The researchers found that PCa survivors’ mental and physical health predicted their marital satisfaction ($\beta = .79, .64$) and their partners’ marital satisfaction ($\beta = .33, .28$), but that partners’ mental and physical health predicted only their own marital satisfaction ($\beta = .43, .67$). Zhou and colleagues found that the marital satisfaction of PCa couples can be

predicted by survivors' mental and physical health, indicating the importance that both partners place on the survivors' health to increase marital satisfaction. Similar to the current study, stigma predicted not only the QoL and relationship satisfaction of PCa survivors, but also their partners. The shared experience (as measured by the test for nonindependence) of couples in the study indicate that stigma, even if only experienced by PCa survivors, influences partners. Further, the shared QoL and relationship satisfaction variables were examined for influence in the follow-up analyses for the research hypothesis. In two alternate models, QoL positively influenced relationship satisfaction, similar to the findings of Zhou and colleagues (2011).

Northouse and colleagues (2007) studied PCa survivors and their partners ($N = 263$) to understand how disease stage affects couples. Overall QoL was lower in advanced stages of PCa for survivors and their partners, compared to newly diagnosed survivors and their partners. This applied to every QoL subscale except the social subscale. Prostate cancer survivors and their partners differed on physical and emotional subscales of QoL, with survivors experiencing more physical troubles and their partners experiencing more emotional troubles. Newly-diagnosed PCa survivors and their partners rated more positive appraisal of illness, positive appraisal of caregiving, less uncertainty, and less hopelessness compared to the other two stages of disease studied. Self-efficacy was higher in newly-diagnosed PCa survivors and their partners, but partners had less self-efficacy than survivors regardless of disease stage. The current study examined the influence of stigma on QoL and relationship satisfaction for PCa and their survivors and provided a new dimension to interpret the findings of Northouse and colleagues (2007). Surprisingly, the PCa survivors' physical QoL had a lower factor loading (.47) than partners' physical QoL (.5). Also, PCa survivors' emotional QoL had a higher factor loading

(.52) than partners' emotional QoL (.33). Although this provides contrary results to Northouse and colleagues' study, this finding could possibly be explained by stigma being a psychosocial issue, rather than disease stage, which is a physical issue. Thus, stigma influences PCa survivors' emotional QoL more than partners' emotional QoL. Similar and contrary to these studies (e.g., Northouse et al., 2007; Zhou et al., 2011), the experiences of PCa stigma can influence the QoL of both survivors and their partners either through the external influence of stigma on the couple, disagreements or lack of communication about experienced stigma.

Existence of Prostate Cancer Stigma

The present study provides further evidence of the existence of PCa stigma. To the investigator's knowledge, only two previous studies have examined PCa stigma to any extent (Else-Quest et al., 2009; Fergus et al., 2002). The current study found similar results to previous studies that examined PCa stigma, albeit with more detail in how it influences QoL and relationship satisfaction for survivors and their partners. The present study, along with previous studies, further validates the existence of PCa stigma.

Fergus and colleagues (2002) discussed PCa survivors ($N = 18$) experiencing "an invisible stigma" (p. 311). Participants in the study described an overall theme of the act of preserving one's manhood when being diagnosed or treated for PCa. The invisible stigma felt by participants related to hiding the fact that they could no longer sexually perform, with a fear to admit that to any friends or future sexual partners. Also, participants discussed how a lack of libido was linked to feelings of sadness and depression and that physical interventions did not restore what was lost from PCa and treatment. However, participants noted that incontinence was

a worse experience than erectile dysfunction, providing a possible rational for the urinary QoL factor to measure PCa survivors' QoL. Based on the current study, the findings of Fergus and colleagues appear to be in line with a quantitative investigation. In regards to stigma, self-stigma had a greater factor loading (.9) than social stigma (.55), indicating that self-stigma was a more prominent predictor of stigma. The findings of Fergus and colleagues provide a qualitative component to this finding, as an invisible, or discreditable stigma would indicate an internal fear of others discovering an aspect of a person (e.g., erectile dysfunction) that causes internalized feelings of shame and depression. Further, the urinary bother factor in measuring QoL in the present study is theoretically grounded in the findings of Fergus and colleagues (2002).

Else-Quest and colleagues (2009) measured stigma as experienced by PCa survivors and found that the amount of stigma ($M = 2.21$) was not significantly different ($p > .05$) than stigma as experienced by lung cancer ($M = 2.48$) and breast cancer ($M = 2.03$) survivors. Further, stigma was correlated with self-blame ($r = .3, p < .05$), self-esteem ($r = -.26, p < .05$), anxiety ($r = .27, p < .05$), anger ($r = .34, p < .05$), depressed affect ($r = .31, p < .05$), and internal attribution of disease ($r = .29, p < .05$). However, stigma was measured with one item designed by the researchers, making the results of the study tenuous. Thus, the current study focused on examining stigma, as measured by the SIS (Fife & Wright, 2000), and how it influences the lives of couples facing PCa. In this study, PCa survivors did experience stigma, which influenced their QoL and relationship satisfaction, as well as their partners' QoL and relationship satisfaction. The stigma that PCa survivors experienced was more in line with self-stigma (Vogel et al., 2013) than social stigma (Link & Phelan, 2001). Other types of stigma (e.g., anticipatory stigma and label avoidance) were not measured, however, it can be inferred that those aligning with self-

stigma would be experienced by PCa survivors and influence their and their partners' QoL and relationship satisfaction.

Exploratory Research Question One

Are there statistically significant relationships between stigma (as measured by the SIS; Fife & Wright, 2000), QoL (as measured by the FACT-P; Esper et al., 1997 and the FACT-GP; Cella et al., 1993), relationship satisfaction (as measured by the CSI; Funk & Rogge, 2007), and race for PCa survivors and their partners?

Exploratory research question one was analyzed in the structural model used to answer the research hypothesis. A dummy coded race variable was included in the model to account for relationships between stigma, QoL, relationship satisfaction, and race. The dummy coded race variable was coded such that White couples ($n = 57$) and couples of non-majority races (Black, American Indian/Alaska Native, and Asian; $n = 15$) were compared for analysis. The analysis revealed no significant relationships between race and stigma ($\beta = .132$, $R^2 = .01$, $p > .05$); race and QoL ($\beta = .05$, $R^2 = .003$, $p > .05$); or race and relationship satisfaction ($\beta = .08$, $R^2 = .006$, $p > .05$). To further explore differences based on race, a point-biserial correlation (Lomax & Hahs-Vaughn, 2012) assessed correlations between dummy coded races and observed variables. None of the relationships were deemed significant ($p > .05$). With an increased sample size, the correlations' magnitude and significance may have been informative. But, the current study cannot draw any conclusions on racial health disparities.

Data Analysis in Relation to Current Literature

Framed within previous literature, the influence of race for PCa survivors continues to yield mixed results. For example, Penedo and colleagues (2006) found that Black and Hispanic PCa survivors experienced lower QoL compared with White survivors, with race accounting for 11% of total variance. However, Nelson, Balk, and Roth (2010) examined archival data and found that Black PCa survivors experienced greater emotional well-being, lower clinical levels of depression, and equal levels of distress and anxiety as compared to White survivors. Thus, although the results of the present study indicate that race is not a significant predictor of stigma, QoL, or relationship satisfaction, the limited sample size could be a contributor to this finding.

Exploratory Research Question Two

Are there statistically significant differences in stigma (as measured by the SIS; Fife & Wright, 2000) based on demographic variables (e.g., age and income) for PCa survivors? Exploratory research question two was analyzed with a MANOVA (Tabachnick & Fidell, 2013) to better understand couples who may be more affected by stigma, based on demographic variables. Demographic variables that contained less than two cases (e.g., PCa survivors aged 86-95) were removed in order for the analysis to appropriately detect mean differences. The MANOVA yielded no statistically significant mean differences ($p > .05$) in social stigma and self-stigma scores. A MANOVA was also conducted with the subscale totals from the original SIS measurement model, and also yielded non-significant findings. In addition to the MANOVA analyses, an analysis of variance (ANOVA) was used with the summed SIS score as a dependent

variable (Stevens, 2007). Further, demographic variables yielded no statistically significant results in mean differences of stigma.

Data Analysis in Relation to Current Literature

The results of exploratory research question two are not easily comparable to previous research. Previous studies have not investigated differences in experienced stigma for PCa survivors. However, demographic variables do influence QoL (e.g., Diefenbach et al., 2008; Torvinen et al., 2013). The results of the MANOVA and subsequent analyses should be taken with caution, as many of the grouped variables were uneven in their distribution (e.g., number of PCa survivors treated for the disease). The results indicate the experience of stigma affected PCa survivors equally despite demographic variables.

In sum, the current investigation both support and challenge findings from previous research focused on QoL and relationship satisfaction for couples dealing with PCa (e.g., Else-Quest et al., 2009; Fergus et al., 2002; Taylor-Ford, 2013; Zhou et al., 2011). The study highlights that stigma negatively and equally influences QoL and relationship satisfaction for PCa survivors and their partners. Within that, race is not a significant predictor of stigma, QoL, or relationship satisfaction in the sample.

Limitations of the Study

Limitations are inherent in every study (Gall et al., 2007). The present study contains limitations including (a) research design limitations, (b) sampling limitations, and (c) instrumentation limitations that should be considered when interpreting results.

Research Design Limitations

This study's research design, a quantitative correlational research design, allows researchers to establish relationships between variables. However, the research design does not allow researchers to establish causality. That is to say, that although relationships between stigma, QoL, and relationship satisfaction for couples facing PCa were indicated, we do not know if stigma causes QoL or relationship satisfaction to decrease. Some researchers and theorists have argued that the use of SEM implies causation (Pearl, 2000), due to the fact that it accounts for many methodological variables (e.g., error measurement and CFA) for which other correlational analyses (e.g., multiple regression and path analysis) do not account. However, due to the preceding limitations, claims of causality are not included in the present study.

Another research design limitation that threatened internal validity was possible characteristic correlations (Frankel et al., 2012). Characteristic correlations occur when correlations between variables are explained by variables not being measured (e.g., personality variables). Characteristic correlation controls were attempted by gathering information on demographic variables. However, not every characteristic of a person or couple can be assessed, and thus, characteristic correlations remain a limitation of the present study.

Sampling Limitations

In the current study, sample size was a limitation. Due to the data collection method, the minimum sample described in Chapter Three ($N = 300$) could not be reached. Therefore, the sample size was smaller than what is suggested for SEM (e.g., $N > 200$; Kline, 2011). The smaller sample size could have led to the poor model fit encountered with measurement models,

inflated effect sizes, and inability to detect group differences (Schumacker & Lomax, 2012; Slavin & Smith, 2009; Tabachnick & Fidell, 2013). However, multiple studies (e.g., Sideridis, Simos, Papanicolaou, & Fletcher, 2014; Wolf, Harrington, Clark, & Miller, 2013) have found that SEM can produce meaningful results with smaller sample sizes. Further, other researchers (Zhou et al., 2011) have conducted similar studies with smaller sample sizes than the present study and have contributed to the field of couples PCa research.

The sample size was also limited due to the use of dyadic data. A larger sample size could have been obtained if the present study had only examined the experiences of PCa survivors, as gathering data from both PCa survivors and their partners allowed for more chances for assessments to not be completed and not returned. Many potential participants were not accompanied to appointments by their partners, which made it necessary for PCa survivors to take home assessment packets, rather than filling them out at their appointment. Also, multiple PCa survivors approached to participate in the study were single. Thus, collecting dyadic data lead to a smaller sample size, but was necessary based on the research questions in the present study. In a review of dyadic PCa studies, sample sizes ranged from 29 couples (Zhou et al., 2011) to 164 couples (Merz et al., 2011), leaving the present study of 72 couples within the range for published studies in high-impact journals.

Another limitation of the sample is a lack of diversity. Exploratory research question one inquired about race predicting stigma, QoL, and relationship satisfaction. Only 15 couples in a sample of 72 couples were from non-majority racial backgrounds. Thus, interpretations on questions related to race are tenuous. However, the proportion of participants from non-majority

backgrounds (20.8%) is higher than some studies examining racial differences in prostate cancer, such as Jenkins and colleagues (10.6%; 2004) and Taksler and colleagues (9.8%; 2012).

Selection bias (Gall et al., 2007) is another limitation to the study. There may be inherent differences between individuals who choose to participate in research and those who do not. Selection bias could explain the lack of variance in scores on the SIS, the FACT-P, the FACT-GP, and the CSI, leading to the multivariate kurtosis found in the data. Therefore, it is assumed that selection bias may be a contributor to the nonnormality of data collected in the present study. Additionally, selection bias was apparent in the study during the data collection process, as the investigator spoke to at least one member of each couple. Potential participants who did not complete the assessments varied in their reasoning, with most being disinterested or feeling as though they did not want to disclose information that was asked for in the instruments. In addition, numerous PCa survivors did not want to engage in discussions with their partners about their relationship. One PCa survivor was considering divorcing his partner and stated that bringing home the assessment packet could start an argument that he would rather not have at that time. Other potential participants were in a new relationship and felt it was too soon to have their partner evaluate their relationship.

The final sampling limitation occurred in the use of an online sample. Compared to the face-to-face sample, the online sample had significantly different experiences of self-stigma. The online sample was included in the study, as it was a small subsample. However, it may be important in future research to look specifically at differences in levels of stigma between face-to-face sample and online samples to understand how to reach individuals experiencing increased stigma. Therefore, the results of this study should be interpreted with an understanding that there

are differences in experiences of stigma between participants in the face-to-face sample and the online sample.

Instrument Limitations

All measures in counseling research have some amount of measurement error, regardless of psychometric properties. The CSI (Funk & Rogge, 2007) was expected to be the largest instrumentation limitation, as the instrument is relatively new and has not been as widely used as related assessments (e.g., the Dyadic Adjustment Scale; Spanier, 1976). However, each of the instruments used in the study had to be adjusted. Confirmatory factor analyses help assess for measurement error. During the measurement model testing phase of analysis, the investigator found that each of the measurement models had to be adjusted by using EFA (Costello & Osborne, 2005; O'Rourke & Hatcher, 2013). Therefore, the items used to measure stigma, QoL, and relationship satisfaction differed from how they were hypothesized (Cella et al., 1993; Esper et al., 1997; Fife & Wright, 2000; Funk & Rogge, 2007). Thus, the measures used in the research hypothesis and exploratory research questions do not fully reflect the previously constructed measures. Parceling of items was considered prior to conducting EFAs, however, the process of parceling is not held in high regard in SEM analysis (Little et al., 2002). However, due to the amount of items that were removed due to EFAs, parceling may be beneficial in future studies to retain items and ensure acceptable factor loadings and model fit.

Other instrument limitations included testing effects and evaluation anxiety (Onwuegbuzie & McLean, 2003). Testing effects are a threat to internal validity in the study, as the answers on one scale may have changed the ways individuals answered items on another

scale (e.g., the SIS could trigger feelings of social isolation and influence participants' ratings of QoL and relationship satisfaction). Further, evaluation anxiety may have been present for some participants, as they could have felt a need to respond or perform at a certain level, causing errors in self-report. Given the results and limitation of the present study, several recommendations for future research are provided in the next section.

Recommendations for Future Research

Future research should consider the limitations that were presented in the current study. An increased response rate may increase generalizability of the results (strengthening external validity). Further, PCa research has consistently lacked racial diversity within the sample (Parahoo et al., 2013); therefore research focused on increasing inclusion or targeting specific ethnic and racial groups is encouraged. Potential ways to recruit a more diverse sample may include joining with doctors and nurses who work regularly with PCa survivors and their partners to provide potential participants with assessments, as they may be seen as more trustworthy than an outside researcher (Wilson et al., 2013).

Expanding future research to include data on both psychosocial and biological factors is encouraged. For example, predicting instances of stigma based on biological factors (e.g., PSA and Gleason score) could be helpful in preventative interventions to bypass the influence of PCa stigma. The rationale for this line of research is grounded in research that QoL is often found to be worse for survivors with advanced disease (e.g., Torvinen et al., 2013; Vanagas et al., 2013), of which PSA and Gleason scores can be indicative. Other PCa-specific data can pertain to radiation or chemotherapy dosages in treatment of the disease. In the current study, treatment

options and stage of cancer did not predict differences in experienced stigma; however, more accurate measurement of PCa-specific data could produce different results. Future research could examine the course of treatment in conjunction with variables in this study. For example, latent-growth curve modeling (Preacher, Wichman, MacCallum, & Briggs, 2008) could be employed with cohorts of PCa survivors and their partners from first consultation of treatment options, through treatment, and through multi-year follow-up. This type of research could be helpful in understanding how preventative factors (e.g., relationship satisfaction or dyadic coping) can be helpful throughout treatment or how stigma can become internalized (Vogel et al., 2013) over the course of treatment. These trends can then be used to design interventions to prevent the development of stigma.

Additional recommendations for future research include qualitative investigations addressing PCa stigma to illuminate why and how stigma influences QoL and relationship satisfaction for survivors and their partners. Dyadic interviews (Morgan, Ataie, Carder, & Hoffman, 2013) could allow partners to interact with one another when asked questions related to PCa stigma and how it affects them. The themes developed in qualitative data analysis could lead to future studies and interventions to help eliminate instances of PCa stigma and increase the QoL and relationship satisfaction of survivors and their partners.

Future research could also examine the possible mediation of the relationship between stigma and relationship satisfaction. If QoL is a mediator variable explaining the influence of stigma on relationship satisfaction, future interventions based on this finding could help eliminate the influence of stigma on relationship satisfaction. Specifically, research into increasing QoL for couples could help to eliminate a contributor (e.g., stigma) to lower

relationship satisfaction. Furthermore, several researchers have examined the influence of PCa couples' QoL and relationship satisfaction, but none have examined how stigma may moderate those relationships. By examining two groups (e.g., couples experiencing low levels of stigma and couples experiencing high levels of stigma), researchers can examine how the relationships between PCa survivors' and their partners' QoL and relationship satisfaction is attenuated by the presence of low or high levels of stigma. The results of this research can lead to identifying couples at risk for increased stigmatization. Also, although the study was not able to include a large enough subsample of same-sex couples, future research could examine the experiences of same-sex couples dealing with PCa and how the disease affects them, specifically looking at issues related to stigma (Blank, 2005). Because same-sex couples could experience PCa differently due to the possibility of both partners being diagnosed with the disease, it is important to understand for PCa most effects in the widest variety of ways.

Although PCa is considered to be a "couple's disease" (Couper, 2007), the experiences of the immediate or extended family could also be examined. In the investigator's experience at the cancer center, siblings or children of survivors sometimes accompanied them to appointments. The influence of PCa stigma on a family through family stigma (Park & Park, 2014) may affect their QoL or familial relationship satisfaction as well. For example, one PCa survivor receiving treatment at the cancer center suffered from dementia and was accompanied by his extended family. The possible caregiver strain (Phillips, Gallagher, Hunt, Der, & Carroll, 2009) experienced by the extended family member (e.g., the survivors' growing incompetence to provide his own care) could lead to relational strains.

Finally, instrument development is an area of future research based on the results of the study. The SIS (Fife & Wright, 2000) was used to measure stigma as it is a general medical illness stigma scale, similar to the *Stigma Scale for Chronic Illnesses* (Rao et al., 2009) or the *Chronic Illness Anticipated Stigma Scale* (Earnshaw, Quinn, Kalichman, & Park, 2013). Similar to the development of lung cancer stigma scales (Cataldo et al., 2011), a PCa stigma scale could be created to measure specific details that could cause stigma for PCa survivors, as well as assessing for newer types of stigma, such as family stigma (Park & Park, 2014) or anticipated stigma (Newheiser & Barreto, 2014; Quinn et al., 2014).

Implications

The current study contributes to the counseling literature: (a) one of the first empirical examinations of PCa stigma, (b) insight into the relationship between PCa stigma, QoL, and relationship satisfaction for survivors and their partners, and (c) information on demographic variables that influence these relationships. The study empirically establishes relationships between stigma and QoL for couples facing PCa and relationships between stigma and relationship satisfaction for couples facing PCa that were missing from the counseling, medical, and mental health research. Below are implications for PCa survivors and their partners; counseling; counselor educators; and researchers.

Prostate Cancer Survivors and Their Partners

The initial implications of the present study apply to PCa survivors and their partners. The results of the present study indicate that PCa survivors experience stigma and that those experiences of stigma negatively influence the QoL and relationship satisfaction for survivors

and their partners. The study provides new questions as well, such as what makes PCa stigmatizing other than the theoretical rational posited in Chapter Two; how partners contribute to stigmatization; and what can help reduce the influence of stigma on QoL and relationship satisfaction.

The sample of PCa survivors and their partners had mostly average or above average QoL (Brucker et al., 2005) and non-distressing relationship satisfaction (Funk & Rogge, 2007). Thus, it can stand to reason that participants in the current investigation were relatively well in terms of QoL and relationships with their intimate partners. Yet, stigma still had negative influences on QoL and relationship satisfaction, with effect sizes ranging from medium (relationship satisfaction $R^2 = .19$) to large (QoL $R^2 = .85$) (Cohen, 1992). Although small sample sizes can inflate effect sizes (Slavin & Smith, 2009), the threat of stigma should still be considered by PCa survivors and their partners. Data analysis revealed that for a sample of PCa survivors and their partners who are relatively well, stigma had a detrimental influence, making it a concern for couples. PCa survivors and their partners should treat possible stigmatization as a threat to their QoL and relationship satisfaction.

Although assessments on communication styles were not administered, the investigator's first hand experiences speaking with couples to administer assessments highlighted the need for skills training and interventions focused on communication. Opening communication on multiple fronts could lead to either a reduction in PCa stigma or a reduction in its influence on QoL and relationship satisfaction. First, communication within the couple should be paramount in reducing stigma. Multiple researchers (e.g., Badr & Carmack Taylor, 2009; Boehmer & Clark, 2001; Manne et al., 2010; Song et al., 2012) point to open communication being beneficial to

PCa survivors and their partners. Beneficial topics include: reaction to diagnosis, discussion of treatment options, reactions to treatment options, discussion of side effects, emotional issues, physical issues, sexuality, fear of recurrence after remission, and possible reactions to recurrence. Further, communication with medical professionals should be developed. If communication is not open during patient visits, miscommunication or incorrect communication can lead to possible further stigmatization. For example, if a PCa survivor asks when their disruptive frequent urination would end, a doctor may say that it will end over the next few months. If the frequent urination does not end in the next three months, it may impact the PCa survivor's ability to engage in daily activities for fear of frequent urination, leading to possible social isolation and internalized stigma and shame. Previous researchers (DiIorio et al., 2011; Kerr, Engel, Schlesinger-Raab, Sauer, & Hölzel, 2003; Ong, Visser, Lammes, & de Haes, 2000) have found that communication with and trust of medical staff is an indicator of health-related QoL. Opening up conversation between medical professionals, PCa survivors, and partners could increase the knowledge of those affected by the disease, which could lead to better normalization of symptoms and side effects of treatment.

In sum, results from the current investigation highlight the need for PCa survivors and their partners to increase open communication. Stigma originates as a social phenomenon (Link et al., 1989), and PCa survivors and their partners can help limit social stigma by increasing open communication within a couple or within a medical system. Otherwise, social stigma can lead to internalized stigma (Vogel et al., 2013), which would increase negative influences on QoL and relationship satisfaction. As seen in the current study, self-stigma was a greater predictor of stigma for PCa survivors, which led to negative influences for QoL and relationship satisfaction

for survivors and their partners. Open communication can also be enhanced through interventions from mental health professionals.

Counseling Implications

The current study, in conjunction with others (e.g., Else-Quest et al., 2009; Fergus et al., 2002), establishes that PCa stigma not only exists, but has a negative influence on the lives of PCa survivors. Due to the continued improvements of PCa treatment, survivors will continue to live longer, leaving QoL a concern for survivors and those who care for them. Findings in the current study indicate that a reduction in stigma could be related to increases in QoL and relationship satisfaction. Utilizing different modes of counseling could be helpful in reducing stigma to aid in providing better QoL and relationship satisfaction for PCa survivors and their partners. Based on this study, self-stigma should be a central focus in stigma reduction, as it was a better indicator of stigma experienced by PCa survivors than social stigma. The current study provides counseling implications related to (a) individual support; (b) group support; and (c) couples and family support.

Individual Support

Individual counseling can be a helpful resource for PCa survivors. Individual counseling can aim to decrease feelings related to stigma, which can then lead to possible increased QoL and relationship satisfaction. Screening PCa survivors who come into counseling can be done through an assessment, such as the SIS (Fife & Wright, 2000), or through an intake session with questions related to feelings of shame, doubt, or social rejection since diagnosis or treatment of PCa. Upon screening for possible stigma, clinical mental health counselors can then assess

further if felt stigma is related to social stigma (Link & Phelan, 2001), self-stigma (Vogel et al., 2013), label avoidance (Jones & Corrigan, 2014), anticipatory stigma (Newheiser & Barreto, 2014; Quinn et al., 2014), family stigma (Park & Park, 2014), or a mixture. The current study indicates, self-stigma was experienced at increased levels by PCa survivors and may lead to a greater negative influence on QoL and relationship satisfaction for survivors and their partners. Thus, feelings of clients could relate to loneliness, social isolation, inequality with others, general competency, and self-worth. These qualities relate directly to the items that loaded on the self-stigma factor of the revised SIS (Fife & Wright, 2000). The questions that lead to understanding stigma can be difficult for clinical mental health counselors to ask, and for clients to answer, as they relate to sexual dysfunction, incontinence, and even the reconceptualization of an identity developed over many years (Maliski et al., 2008).

Feelings related to stigma can be addressed through developing a strong therapeutic relationship that fosters acceptance (Livingston, Milne, Fang, & Amari, 2012; Masuda, Hill, Morgan, & Cohen, 2012) and allows PCa survivors to express feelings of shame, anxiety, depression, and anger. The expression of feelings related to stigma can then allow clinical mental health counselors to work with clients in a variety of theoretical orientations (e.g., cognitive-behavioral therapy, existential therapy, person-centered counseling, or narrative therapy), with an aim to reduce feelings related to stigma and increase QoL and relationship satisfaction for PCa survivors. In addition, psychoeducation has been found to be an effective approach to reducing self-stigma (Mittal, Sullivan, Chekuri, Allee, & Corrigan, 2012) for those with mental health-based stigma. Further, coping skills training to address issues relating to self-esteem and help-seeking behaviors can also be effective in reducing self-stigma. However, it may be difficult to

accomplish these goals as many individuals with similar characteristics to PCa survivors (e.g., male older adults) often do not seek counseling (Mackenzie, Scott, Mather, & Sareen, 2009). Therefore, developing a relationship with healthcare providers and becoming visible in the PCa community could lead to trustworthiness and an ability to help PCa survivors in need of individual counseling (Jimenez, Bartels, Cardenas, & Alegría, 2013).

Group Support

Group interventions, including the development of PCa support groups, can help reduce the influence of stigma on QoL for PCa survivors. Previous literature indicates group interventions can effectively reduce self-stigma, the more influential type of stigma found in the current study (Luckstead et al., 2011; Luoma, Kohlenberg, Hayes, Bunting, & Rye, 2008).

Groups also provides a sense of hope (Yalom & Lesczc, 2005) to PCa survivors and their partners. Group counseling interventions can include psychoeducation about the terminology surrounding PCa (e.g., PSA, Gleason score, and image-guided radiation therapy); normalization of a diagnosis of cancer and treatment; development of helpful coping skills; and self-care between treatments (Mittal et al., 2012). An atmosphere wherein humor, trust, and honesty are supported could help minimize PCa stigma (Arrington, 2010; Oliffe, Ogrodniczuk, Bottorff, Hislop, & Halpin, 2009). Additionally, helping PCa survivors who are willing to lead support groups to establish groups (e.g., finding or providing space for groups, teaching minor group counseling skills, or co-leading groups) can be beneficial to PCa survivors in their geographic area (Voerman et al., 2007). Groups led by PCa survivors can provide credibility to the group in addressing the needs of PCa survivors, leading more survivors to join groups and benefit from

group experiences (Thaxton, Emshoff, & Guessous, 2005). Group-based interventions have also been found to aid in reducing social stigma (found to be a predictor of lower QoL and relationship satisfaction in the current study), specifically those that utilize positive stories of people in similar situations as group members (e.g., long-term PCa survivors) (Livingston, Milne, Fang, & Amari, 2012).

Couples and Family Support

The intradependence of PCa couples related to QoL and relationship satisfaction is established in research (e.g., Merz et al., 2011; Northouse et al., 2007). Prostate cancer stigma is a negative influence on QoL and relationship satisfaction, and as such, survivors and their partners should be treated together to help alleviate the influence of stigma. Increasing communication within couples (Manne et al., 2010) could help to reduce feelings of stigma, as PCa would often be a discreditable stigma, or unseen stigma, as opposed to a discrediting, or visible stigma (Fergus et al., 2002; Goffman, 1963). Understanding the influence of PCa survivors and their partners on a dyad level could help to assess how much of an influence one partner has on another, ranging from minimal influence to codependence (Zhou et al., 2011). In the case of a codependent situation, couples could engage in interventions grounded in establishing equality in a relationship (Silverstein & Goodrich, 2003). In addition, relationships may include a caregiving aspect. Self-care for partners could relieve stress and improve communication within a couple, and as such, utilizing techniques (e.g., mindfulness techniques) could help decrease possible stigmatizing attitudes and increase relationship satisfaction (Wood, Gonzalez, & Barden, in press).

Finally, although the present study did not address other family members, it may be beneficial to address family stigma (Park & Park, 2014). Because stigma originates as a social phenomenon, addressing stigma from a systemic point of view may allow counselors to understand how stigma can originate and be perpetuated in a family system. Social stigma has been found to become internalized (Vogel et al., 2013), leading to self-stigma. As self-stigma was a greater indicator of lower QoL and relationship satisfaction, preventative social support could help minimize the internalization of stigma, thus aiding in greater QoL and relationship satisfaction. Understanding how social stigma affects a family system and how to minimize the internalization of stigma could benefit family counseling. Approaching stigma from a systemic orientation may help in finding how stigma can originate and be perpetuated in a family system, and/or how a family can act as a buffer to limit experienced stigma, limiting the negative influence on QoL and relationship satisfaction for PCa survivors and their partners.

Counselor Education Implications

There are multiple and diverse implications for counselor education based on the findings of the present study. Implications are grounded not only in the findings of the present study, but in the findings of previous studies and national trends. Implications for counselor education include medical-illness education and a focus on trauma-causing events.

Medical-Illness Education

Given estimates that over 233,000 new PCa survivors will be diagnosed in the U.S. in 2014 (NCI, 2011), the chances of a counselor counseling either a survivor or someone who has been affected by the disease is likely. Therefore, counselor educators need to understand the

importance of preparing their students to counsel individuals affected by the disease. Also, the results of the present study illustrate the need for counselor trainee awareness of psychosocial issues such as stigma, QoL, and relationship satisfaction for clients. Although it will not be possible to provide a comprehensive knowledge of how every medical illness affects clients, it may be necessary to implement courses or sections of courses with information on medical illnesses (Livneh & Antonak, 2005; Manis & Bodenhorn, 2006; Sperry, 2009). A course designed to address the mental health care (including sections for marriage and family therapists and school counselors) of working with individuals and families with medical illness could be taken as an elective or provided as a workshop for students entering internship settings based in hospitals or other medical care facilities (Freadling & Foss-Kelly, 2014).

Further, the concept of stigma could be expanded to disease and disability (Corrigan, 2014), rather than only stigma of mental health and psychopathology (e.g., Overton & Medina, 2008). Preparing counselors to understand stigma in all its forms can help counselors initiate helpful conversations with individuals at risk for stigmatization. Internalized stigma in particular, which was found to be influential in the current study, has negative correlations with many psychosocial variables (e.g., hope and self-esteem) and predicts less treatment adherence (Livingston & Boyd, 2010). Because stigma exists for marginalized populations (e.g., homeless individuals or individuals living with HIV), discussion of stigma can be integrated into multicultural or social justice course work already present in many counselor education programs (Hayes et al., 2004). Providing further education of medical illnesses and how they affect clients would allow for greater psychoeducational interventions. By preparing students with knowledge about a variety of illnesses and how they affect clients, counselors would be more adept to

develop psychoeducational curriculum, which is effective in reducing stigma (Mittal et al., 2012).

Trauma-Causing Events

Due to the large number of individuals diagnosed with PCa, most counselors will encounter and work with survivors or someone who is affected by cancer. Previous researchers (e.g., Jayadevappa et al., 2012; Mickeviciene et al., 2012) have demonstrated that PCa can influence overall QoL and other psychosocial issues while the current study demonstrates that stigma has influences on QoL and relationship satisfaction. Thus, it stands to reason that the results of the current study, in conjunction with cancer diagnosis trends and previous research, can be viewed as an indicator that counselors should be prepared to address issues surrounding PCa, including stigma (with an emphasis on self-stigma) as it can be a concern in therapy to increase the QoL and relationship satisfaction of PCa survivors and their partners. As seen in previous studies, a focus on psychoeducation (Mittal et al., 2012) in counseling is a way to reduce self-stigma, which could then be linked to increasing QoL and relationship satisfaction for PCa survivors and their partners. In order for counselors to provide psychoeducation interventions, they need to be versed in the ways in which PCa can affect survivors and their partners.

The Council for Accreditation of Counseling and Related Educational Programs (CACREP) outlines multiple areas in which students should be competent both in knowledge and in clinical skill. Some of the sections in the 2009 standards apply directly to knowledge and clinical care to PCa survivors. Based on the definition of a trauma-causing event, a diagnosis of

PCa can be a trauma-causing event to PCa survivors and their partners, similar to what other researchers have found (Morris & Shakespeare-Finch, 2011). Outside of PCa, there were an estimated 1.6 million new cancer cases in 2014. Addressing trauma-causing events is covered in curriculum for each counseling specialty listed in the 2009 standards, both at the masters and doctoral level. Thus, it stands to reason that preparing counselors to provide care to PCa survivors and their partners (as well as survivors of other cancer sites) is integral to upholding current professional standards. Counselor educators can prepare counselors to provide care to PCa survivors by gearing them toward wellness-based approaches to trauma care, such as interventions to encourage post-traumatic growth for both survivors and their partners (Calhoun & Tedeschi, 2006; Connerty & Knott, 2013; Morris & Shakespeare-Finch, 2011; Svetina & Nastran, 2012). Similarly, wellness and prevention based strategies could limit the internalization of stigma, which was found to be a significant predictor of QoL and relationship satisfaction in the current study. Counselor educators can prepare their students to better the QoL and relationship satisfaction of PCa survivors and their partners by helping clients process trauma-causing events. Counseling interventions could then help to limit self-stigma (Mittal et al., 2012) and increase the QoL and relationship satisfaction of PCa survivors and their partners.

Research Implications

The present study provided a confirmation of findings from previous literature (e.g., Else-Quest et al., 2009; Fergus et al., 2002) and also posed new questions to researchers. Outside of specific recommendations for areas of future research, the present study also yields implications

for researchers. The final implication section details implications for couples-based research and instrument development.

Couples-Based Research

One area of research that needs increased attention is dyadic data. Although dyadic data analysis (Kenny et al., 2006) is gaining traction in couples-based research, some areas deserve more attention. Conceptualizing and designing research studies grounded in dyadic methods and the influence of each partner on one another is critical to furthering understanding of the psychosocial influence of PCa. The mixed use of individual level and couple level data has rarely been explored in current literature (Ledermann & Kenny, 2012; Peugh et al., 2013). In the current study, the investigator examined the influence of an individual-level variable (e.g., stigma) on a couple-level variable (e.g., relationship satisfaction). Understanding nonindependence within a couple and basing analytic decisions on the research questions in light of nonindependence is an important consideration when researching problems that affect couples. For example, in the current study, there would have been greater measurement error if the data were analyzed as independent-level variables, as multiple variables were consequentially nonindependent. By assessing for consequential nonindependence, the analysis yielded more trustworthy results, as the shared experience was accounted for in the analysis. Further, understanding how dyads react or change based on an individual-level variable such as a couple's reaction to childbirth or how a cancer diagnosis can influence the dyadic coping of a couple is encouraged. The couples-based research implications for this study encourage researchers to rest not only on individual level variables or dyad level variables, but to

understand a mix of both to understand how individuals within a dyad influence one another, how external events influence dyads, and how they all work with and against one another to change the ways couples interact.

Instrument Development

As mentioned in the recommendations for future research, the results of the study provide the medical and mental health literature with new knowledge of PCa stigma, and its relationship with QoL and relationship satisfaction for couples facing the disease. The instrument used to measure stigma, the SIS (Fife & Wright, 2000), measured a general medical illness stigma. However, just as medical illnesses differ, reasons for experiencing stigma can differ as well. Therefore, it is necessary to create a new measure to assess PCa stigma. The NCI has provided funding for stigma research in the past, and currently is providing funding to characterize and reduce stigma (i.e., PA-13-246). One of the initiatives of the NCI is to develop “methodological studies aimed at improving detection of cancer-related stigmas” (National Institute of Health, 2013). The current study provides evidence of PCa stigma and how it influences the QoL and relationship satisfaction of couples facing the disease. With the help of methodologists and experts in the fields of oncology, psycho-oncology, and PCa survivors, the development of a new instrument to better measure PCa stigma is possible. Although the results of the study suggest that an instrument to measure PCa stigma specifically may be warranted, that is not to detract from the stigma measured in the current study. The SIS (Fife & Wright, 2000) has been used in numerous studies and exists as a validated measure of stigma for medical illnesses, and the findings of the study utilizing the SIS should still be seen as evidence of stigma and its influence

on PCa survivors and their partners. Thus, an implication of the study should not be to disregard the SIS or similar stigma scales, but to improve upon the ways that PCa stigma is measured.

Chapter Summary

Chapter Five reviewed and compared the results of the current study with extant literature. This study was the first empirical investigation to examine PCa stigma, QoL and relationship satisfaction for both survivors and their partners. Results of the study support the hypothesized theoretical model with measurement modifications. Limitations to the study (e.g., research design, sampling, and instrumentation) limit generalizability; however, results provide new information to the field of PCa research that can be used to develop a future line of studies to improve the QoL and relationship satisfaction of PCa survivors and their partners.

APPENDIX A: IRB APPROVAL LETTER



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: **UCF Institutional Review Board #1**
FWA00000351, IRB00001138

To: **Andrew W. Wood**

Date: **November 12, 2014**

Dear Researcher:

On 11/12/2014, the IRB approved the following activity as human participant research that is exempt from regulation:

| | |
|-----------------|---|
| Type of Review: | Exempt Determination |
| Project Title: | The Influence of Stigma on Quality of Life and Relationship Satisfaction for Prostate Cancer Survivors and Their Partners |
| Investigator: | Andrew W. Wood |
| IRB Number: | SBE-14-10700 |
| Funding Agency: | |
| Grant Title: | |
| Research ID: | N/A |

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the [Investigator Manual](#).

On behalf of Sophia Dziegielewska, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

A handwritten signature in black ink, appearing to read "Patria Davis", with a small dot above the "i".

Signature applied by Patria Davis on 11/12/2014 04:03:18 PM EST

IRB Coordinator

APPENDIX B: EXPLANATION OF RESEARCH



EXPLANATION OF RESEARCH

Title of Project: Quality of Life and Relationship Satisfaction for Prostate Cancer Survivors and Their Partners.

Principal Investigator: Andrew Wood, M.S., NCC

Faculty Supervisor: Sejal M. Barden, Ph.D.

You are being invited to take part in a research study. Whether you take part is up to you. The purpose of the research is to examine thoughts and feelings related to prostate cancer, your well-being, and a romantic or intimate relationship you are involved in (e.g., husband/wife, boyfriend/girlfriend, partner).

As part of this study, you will be asked to fill out a packet with three to four questionnaires, which should take approximately 15-30 minutes. Each questionnaire is geared toward asking you questions about your thoughts and feelings. Please answer with your honest, initial thoughts and don't attempt to overthink your responses – there are no right or wrong answers. Your responses will be kept anonymous throughout the study and will not be linked back to you in any way.

Your participation is completely voluntary and you may stop at any point in filling out the questionnaires if you would like, with no penalty to you.

For every person that participates in the study, \$1.00 will be donated to the Prostate Cancer Foundation, which is then matched by the Safeway Foundation, making each individual who participates in the study contribute a \$2.00 donation to prostate cancer research and awareness.

You must be 18 years of age or older to take part in this research study. This research is in no way affiliated with the organization at which it is taking place, and your responses will not be made available to any physician, nursing staff, group leader, or partner. Further, your involvement or responses in this study will in no way impact the treatment or support you are receiving from this organization.

If you experience any distress or crisis in completing the assessments provided to you, the phone number for a crisis hotline and a website for finding mental health professionals in your area are provided below.

Crisis Hotline (24 hour): 1-800-273-8255

Mental Health Professionals in your area: www.goodtherapy.org

Study contact for questions about the study or to report a problem: If you have questions, concerns, or complaints about the study, please contact Andrew Wood, doctoral candidate,

1 of 2



University of Central Florida IRB
IRB NUMBER: SBE-14-10700
IRB APPROVAL DATE: 11/12/2014

IRB Protocol No.

Date:

Counselor Education Program, College of Education and Human Performance, (386) 546-2493, a.wood@knights.ucf.edu or Dr. Sejal Barden, Faculty Supervisor, Counselor Education Program, College of Education and Human Performance, (407) 823-3063, sejal.barden@ucf.edu

IRB contact about your rights in the study or to report a complaint: Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been reviewed and approved by the IRB. For information about the rights of people who take part in research, please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901.



APPENDIX C: DEBRIEFING FORM



Debriefing Statement

For the study entitled:
"The Influence of Stigma on Quality of Life and Relationship Satisfaction for Prostate Cancer Survivors and Their Partners."

Dear Participant;

During this study, you were asked to fill out a packet with three to four questionnaires. You were told that the purpose of the study was to examine thoughts and feelings related to prostate cancer, your well-being, and a romantic or intimate relationship you are involved in. The actual purpose of the study was assess feelings of stigma and how it may affect the quality of life and relationship satisfaction of you and your partner.

We did not tell you everything about the purpose of the study because information about stigma could have generated thoughts that might have minimized or maximized your actual experiences.

You are reminded that your original consent document included the following information: "Your participation is completely voluntary and you may stop at any point in filling out the questionnaires if you would like, with no penalty to you." If you have any concerns about your participation or the data you provided in light of this disclosure, please discuss this with us. We will be happy to provide any information we can to help answer questions you have about this study.

The responses in this study are de-identified and cannot be linked to you.

Study contact for questions about the study or to report a problem: If you have questions, concerns, or complaints or think the research has hurt you or provided you with any discomfort: Andrew Wood, Doctoral Candidate, Counselor Education Program, College of Education and Human Performance, (386) 546-2493 or by email at a.wood@knights.ucf.edu, Dr. Sejal Barden, Faculty Supervisor, Department of Counselor Education at (407) 823-3063 or by email at sejal.barden@ucf.edu.

IRB contact about your rights in the study or to report a complaint: Research at the University of Central Florida involving human participants is carried out under the oversight of the Institutional Review Board (UCF IRB). This research has been reviewed and approved by the IRB. For information about the rights of people who take part in research, please contact: Institutional Review Board, University of Central Florida, Office of Research & Commercialization, 12201 Research Parkway, Suite 501, Orlando, FL 32826-3246 or by telephone at (407) 823-2901.

If you have experienced distress as a result of your participation in this study, a referral list of mental health providers is attached to this document for your use. (Please remember that any cost in seeking medical assistance is at your own expense.)

Please again accept our appreciation for your participation in this study.

Crisis Hotline (24 hour): 1-800-273-8255
Information of mental health professionals in your area: www.goodtherapy.org

**APPENDIX D: DEMOGRAPHICS FORM FOR PROSTATE CANCER
SURVIVORS**

Demographics Questionnaire - Survivors

PLEASE ANSWER THE FOLLOWING QUESTIONS BY CHECKING THE MOST APPROPRIATE ANSWER

1. What is your age? _____ 18-35
_____ 36-45
_____ 46-55
_____ 56-65
_____ 66-75
_____ 76-85
_____ 86-95
_____ 96 or older

2. What is your race? _____ American Indian/Alaska Native
Select all that _____ Asian
apply. _____ Black
_____ Latino(a)
_____ White
_____ Biracial/Multiracial
_____ Other

3. What is your _____ Male
gender? _____ Female
_____ Other

4. What is your _____ Married
current relationship _____ Partnered
status? _____ Divorced

5. What is your sexual _____ Heterosexual/Straight
orientation? _____ Homosexual/Gay
_____ Other

6. What is the highest _____ Grammar school
level of education _____ High school or equivalent
that you've _____ Vocational/Technical school
completed? _____ Associate's Degree
_____ Bachelor's Degree
_____ Master's Degree
_____ Doctoral Degree
_____ Professional Degree

7. What is your annual household income?
- ☐ \$0 - \$9,999
 - ☐ \$10,000 - \$19,999
 - ☐ \$20,000 - \$39,999
 - ☐ \$40,000 - \$59,999
 - ☐ \$60,000 - \$79,999
 - ☐ \$80,000 - \$99,999
 - ☐ Over \$100,000

8. How long has it been since you were first diagnosed with prostate cancer?
- ☐ 0-3 months
 - ☐ 4-6 months
 - ☐ 7-9 months
 - ☐ 10-12 months
 - ☐ 1-3 years
 - ☐ 4-6 years
 - ☐ Over 6 years

9. What is the current stage of your cancer?
- ☐ Zero
 - ☐ One
 - ☐ Two
 - ☐ Three
 - ☐ Four
 - ☐ I don't know

10. Have you been treated for prostate cancer?
- ☐ Yes
 - ☐ No

- 10a. If you selected Yes for question 10, which treatments are you currently in or have completed? Check all that apply.
- ☐ Surgery (removal of prostate)
 - ☐ Prostate removal
 - ☐ Lymph node removal
 - ☐ Radiation Therapy
 - ☐ External
 - ☐ Internal (example: seeds)
 - ☐ Hormone Therapy
 - ☐ Chemotherapy
 - ☐ Biologic Therapy
 - ☐ Other (please describe below) _____
 - ☐ I don't know

- 10b. If you selected Yes for question 10, have you completed prostate cancer treatment?
- ☐ Yes
 - ☐ No

11. Have you been diagnosed with any chronic illness? ☐ Yes
☐ No

For example:

Alzheimer's
disease, cancer,
diabetes,
HIV/AIDS, or other
long-lasting or
lifelong
diseases/illnesses

11a. If you selected
yes to question 11,
please check all that
apply.

- ☐ Alzheimer's disease
☐ Cancer
(if you checked cancer,
please specify which type _____)
☐ Chronic obstructive pulmonary disease (COPD)
☐ Crohn's disease
☐ Diabetes
☐ Heart disease
☐ HIV/AIDS
☐ Osteoporosis
☐ Parkinson's disease
☐ Other
(if you check other,
please specify which _____)

APPENDIX E: DEMOGRAPHICS FORM FOR PARTNERS

Demographics Questionnaire - Partners

PLEASE ANSWER THE FOLLOWING QUESTIONS BY CHECKING THE MOST APPROPRIATE ANSWER

1. What is your age? ☐ 18-35
☐ 36-45
☐ 46-55
☐ 56-65
☐ 66-75
☐ 76-85
☐ 86-95
☐ 96 or older
2. What is your race? ☐ American Indian/Alaska Native
Select all that ☐ Asian
apply. ☐ Black
☐ Latino(a)
☐ White
☐ Biracial/Multiracial
☐ Other
3. What is your gender? ☐ Male
☐ Female
☐ Other
4. What is your current relationship status? ☐ Married
☐ Partnered
☐ Divorced
5. What is your sexual orientation? ☐ Heterosexual/Straight
☐ Homosexual/Gay
☐ Other
6. What is the highest level of education that you have completed? ☐ Grammar school
☐ High school or equivalent
☐ Vocational/Technical school
☐ Associates' Degree
☐ Bachelor's Degree
☐ Master's Degree
☐ Doctoral Degree
☐ Professional Degree

7. What is your annual household income?
- _____ \$0 - \$9,999
 _____ \$10,000 – \$19,999
 _____ \$20,000 - \$39,999
 _____ \$40,000 - \$59,999
 _____ \$60,000 – \$79,999
 _____ \$80,000 – \$99,999
 _____ Over \$100,000

8. Have you been diagnosed with any chronic illness?
 For example:
Alzheimer's
 disease, cancer,
 diabetes,
 HIV/AIDS, or other
 long-lasting or
 lifelong
 diseases/illnesses

_____ Yes
 _____ No

- 8a. If you selected yes, please check all that apply.

_____ Alzheimer's disease
 _____ Cancer
 (if you checked cancer,
 please specify which type _____)
 _____ Chronic obstructive pulmonary disease (COPD)
 _____ Crohn's disease
 _____ Diabetes
 _____ Heart disease
 _____ HIV/AIDS
 _____ Osteoporosis
 _____ Parkinson's disease
 _____ Other
 (if you check other,
 please specify which _____)

APPENDIX F: ADVERTISEMENT FOR ONLINE SUPPORT GROUPS

Prostate Cancer Research

Hello, this is the second advertisement for my dissertation study concerning prostate cancer survivors and their partners. If you have already participated, thank you for your time and please disregard this message. If you have not participated, I ask that you please read the following advertisement and take some time to fill out the survey, if possible. Every couple that completes the survey counts and I am very grateful for your time. Feel free to contact me if you have any questions.

My name is Andrew Wood and I am a doctoral student at the University of Central Florida. I am conducting a study for my dissertation on prostate cancer and how it affects couples. In this study, I am looking at assessments from prostate cancer survivors and their romantic or intimate partners (husband/wife, girlfriend/boyfriend, or significant other). I have contacted the administrator for this page to get approval to post an advertisement for my study and want to thank you for the opportunity to post this message. I understand that the group is used to provide education and support and I do not want to interfere with that in any way, as I consider myself a prostate cancer advocate and want to provide more knowledge to the mental health field as to how couples deal with the disease and how to help make their lives better.

This is an online survey. Both individuals (prostate cancer survivors and their partners) should take it one after the other, but try to keep your own responses private. Either person can initiate the survey, but the other must complete it. The entire survey should take 15-30 minutes in total.

In order to participate in this study, you must be over the age of 18, currently be in a romantic or intimate relationship, and one person must have had a diagnosis of prostate cancer.

For your time, I will be donating \$1.00 for each person that completes the survey (\$2.00 per couple) to the Prostate Cancer Foundation.

If you and your partner would like to take the survey, please follow this link:
http://ucf.qualtrics.com//SE/?SID=SV_aUX3Pc99fJg3QJ7

If you have any questions or concerns about the survey before, during, or after taking it, you can reach me here or at a.wood@knights.ucf.edu and I can provide you with further contact information for my adviser and/or the University of Central Florida Institutional Review Board.

APPENDIX G: SOCIAL IMPACT SCALE

Social Impact Scale

Below is a list of statements. **Please circle or mark one number per question to indicate how much you agree with each statement in regards to your experience with prostate cancer.**

| | Strongly disagree | Disagree | Agree | Strongly Agree |
|---|-------------------|----------|-------|----------------|
| 1. My employer/co-workers have discriminated against me. | 1 | 2 | 3 | 4 |
| 2. Some people act as though I am less competent than usual. | 1 | 2 | 3 | 4 |
| 3. I feel I have been treated with less respect than usual by others. | 1 | 2 | 3 | 4 |
| 4. I feel others are concerned they could “catch” my illness through contact like a handshake or eating food I prepare. | 1 | 2 | 3 | 4 |
| 5. I feel others avoid me because of my illness. | 1 | 2 | 3 | 4 |
| 6. Some family members have rejected me because of my illness. | 1 | 2 | 3 | 4 |
| 7. I feel some friends have rejected me because of my illness. | 1 | 2 | 3 | 4 |
| 8. I encounter embarrassing situations as a result of my illness. | 1 | 2 | 3 | 4 |
| 9. Due to my illness others seem to feel awkward and tense when they are around me. | 1 | 2 | 3 | 4 |
| 10. I have experienced financial hardship that has affected how I feel about myself. | 1 | 2 | 3 | 4 |
| 11. My job security has been affected by my illness. | 1 | 2 | 3 | 4 |
| 12. I have experienced financial hardship that has affected my relationship with others. | 1 | 2 | 3 | 4 |
| 13. I feel others think I am to blame for my illness. | 1 | 2 | 3 | 4 |

| | Strongly disagree | Disagree | Agree | Strongly Agree |
|---|--------------------------|-----------------|--------------|-----------------------|
| 14. I do not feel I can be open with others about my illness. | 1 | 2 | 3 | 4 |
| 15. I fear someone telling others about my illness without my permission. | 1 | 2 | 3 | 4 |
| 16. I feel I need to keep my illness a secret. | 1 | 2 | 3 | 4 |
| 17. I feel I am at least partially to blame for my illness. | 1 | 2 | 3 | 4 |
| 18. I feel set apart from others who are well. | 1 | 2 | 3 | 4 |
| 19. I have a greater need than usual for reassurance that others care about me. | 1 | 2 | 3 | 4 |
| 20. I feel lonely more often than usual. | 1 | 2 | 3 | 4 |
| 21. Due to my illness, I have a sense of being unequal in my relationships with others. | 1 | 2 | 3 | 4 |
| 22. I feel less competent than I did before my illness. | 1 | 2 | 3 | 4 |
| 23. Due to my illness, I sometimes feel useless. | 1 | 2 | 3 | 4 |
| 24. Changes in my appearance have affected my social relationships. | 1 | 2 | 3 | 4 |

APPENDIX H: COUPLES SATISFACTION INDEX

Couples Satisfaction Index (CSI-16)

1. Please indicate the degree of happiness, all things considered, of your relationship.

| Extremely Unhappy | Fairly Unhappy | A Little Unhappy | Happy | Very Happy | Extremely Happy | Perfect |
|----------------------|-------------------|---------------------|-------|---------------|--------------------|---------|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 |

| | All the time | Most of the time | More often than not | Occa- sionally | Rarely | Never |
|--|--------------------|------------------------|---------------------------|-------------------|--------|-------|
| | 5 | 4 | 3 | 2 | 1 | 0 |
| 2. In general, how often do you think that things between you and your partner are going well? | | | | | | |

| | Not at all TRUE | A little TRUE | Some- what TRUE | Mostly TRUE | Almost Completely TRUE | Completely TRUE |
|---|-----------------------|---------------------|-----------------------|----------------|------------------------------|--------------------|
| 3. Our relationship is strong | 0 | 1 | 2 | 3 | 4 | 5 |
| 4. My relationship with my partner makes me happy | 0 | 1 | 2 | 3 | 4 | 5 |
| 5. I have a warm and comfortable relationship with my partner | 0 | 1 | 2 | 3 | 4 | 5 |
| 6. I really feel like <u>part of a team</u> with my partner | 0 | 1 | 2 | 3 | 4 | 5 |

| | Not at all | A little | Some- what | Mostly | Almost Completely | Completely |
|---|---------------|-------------|---------------|--------|----------------------|------------|
| 7. How rewarding is your relationship with your partner? | 0 | 1 | 2 | 3 | 4 | 5 |
| 8. How well does your partner meet your needs? | 0 | 1 | 2 | 3 | 4 | 5 |
| 9. To what extent has your relationship met your original expectations? | 0 | 1 | 2 | 3 | 4 | 5 |
| 10. In general, how satisfied are you with your relationship? | 0 | 1 | 2 | 3 | 4 | 5 |

For each of the following items, select the answer that best describes how you feel about your relationship. Base your responses on your first impressions and immediate feelings about the item.

| | | | | | | | | |
|-----|--------------|---|---|---|---|---|---|-----------|
| 11. | INTERESTING | 5 | 4 | 3 | 2 | 1 | 0 | BORING |
| 12. | BAD | 0 | 1 | 2 | 3 | 4 | 5 | GOOD |
| 13. | FULL | 5 | 4 | 3 | 2 | 1 | 0 | EMPTY |
| 14. | STURDY | 5 | 4 | 3 | 2 | 1 | 0 | FRAGILE |
| 15. | DISCOURAGING | 0 | 1 | 2 | 3 | 4 | 5 | HOPEFUL |
| 16. | ENJOYABLE | 5 | 4 | 3 | 2 | 1 | 0 | MISERABLE |

APPENDIX I: FUNCTIONAL ASSESSMENT OF CANCER THERAPY – PROSTATE

FACT-P (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

| | <u>PHYSICAL WELL-BEING</u> | Not at all | A little bit | Some- what | Quite a bit | Very much |
|-----|--|-----------------------|-------------------------|-----------------------|------------------------|----------------------|
| GP1 | I have a lack of energy | 0 | 1 | 2 | 3 | 4 |
| GP2 | I have nausea | 0 | 1 | 2 | 3 | 4 |
| GP3 | Because of my physical condition, I have trouble meeting the needs of my family | 0 | 1 | 2 | 3 | 4 |
| GP4 | I have pain | 0 | 1 | 2 | 3 | 4 |
| GP5 | I am bothered by side effects of treatment | 0 | 1 | 2 | 3 | 4 |
| GP6 | I feel ill | 0 | 1 | 2 | 3 | 4 |
| GP7 | I am forced to spend time in bed | 0 | 1 | 2 | 3 | 4 |

| | <u>SOCIAL/FAMILY WELL-BEING</u> | Not at all | A little bit | Some- what | Quite a bit | Very much |
|-----|---|-----------------------|-------------------------|-----------------------|------------------------|----------------------|
| GS1 | I feel close to my friends | 0 | 1 | 2 | 3 | 4 |
| GS2 | I get emotional support from my family | 0 | 1 | 2 | 3 | 4 |
| GS3 | I get support from my friends | 0 | 1 | 2 | 3 | 4 |
| GS4 | My family has accepted my illness | 0 | 1 | 2 | 3 | 4 |
| GS5 | I am satisfied with family communication about my illness | 0 | 1 | 2 | 3 | 4 |
| GS6 | I feel close to my partner (or the person who is my main support) | 0 | 1 | 2 | 3 | 4 |
| Q1 | <i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i> | | | | | |
| GS7 | I am satisfied with my sex life | 0 | 1 | 2 | 3 | 4 |

FACT-P (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

| <u>EMOTIONAL WELL-BEING</u> | | Not at all | A little bit | Some- what | Quite a bit | Very much |
|------------------------------------|--|-----------------------|-------------------------|-----------------------|------------------------|----------------------|
| GE1 | I feel sad | 0 | 1 | 2 | 3 | 4 |
| GE2 | I am satisfied with how I am coping with my illness..... | 0 | 1 | 2 | 3 | 4 |
| GE3 | I am losing hope in the fight against my illness..... | 0 | 1 | 2 | 3 | 4 |
| GE4 | I feel nervous..... | 0 | 1 | 2 | 3 | 4 |
| GE5 | I worry about dying..... | 0 | 1 | 2 | 3 | 4 |
| GE6 | I worry that my condition will get worse | 0 | 1 | 2 | 3 | 4 |

| <u>FUNCTIONAL WELL-BEING</u> | | Not at all | A little bit | Some- what | Quite a bit | Very much |
|-------------------------------------|---|-----------------------|-------------------------|-----------------------|------------------------|----------------------|
| GF1 | I am able to work (include work at home) | 0 | 1 | 2 | 3 | 4 |
| GF2 | My work (include work at home) is fulfilling..... | 0 | 1 | 2 | 3 | 4 |
| GF3 | I am able to enjoy life..... | 0 | 1 | 2 | 3 | 4 |
| GF4 | I have accepted my illness..... | 0 | 1 | 2 | 3 | 4 |
| GF5 | I am sleeping well | 0 | 1 | 2 | 3 | 4 |
| GF6 | I am enjoying the things I usually do for fun | 0 | 1 | 2 | 3 | 4 |
| GF7 | I am content with the quality of my life right now..... | 0 | 1 | 2 | 3 | 4 |

FACT-P (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

| <u>ADDITIONAL CONCERNS</u> | | Not at all | A little bit | Some- what | Quite a bit | Very much |
|----------------------------|---|---------------|-----------------|---------------|----------------|--------------|
| C2 | I am losing weight..... | 0 | 1 | 2 | 3 | 4 |
| C6 | I have a good appetite | 0 | 1 | 2 | 3 | 4 |
| P1 | I have aches and pains that bother me..... | 0 | 1 | 2 | 3 | 4 |
| P2 | I have certain parts of my body where I experience pain.... | 0 | 1 | 2 | 3 | 4 |
| P3 | My pain keeps me from doing things I want to do | 0 | 1 | 2 | 3 | 4 |
| P4 | I am satisfied with my present comfort level | 0 | 1 | 2 | 3 | 4 |
| P5 | I am able to feel like a man | 0 | 1 | 2 | 3 | 4 |
| P6 | I have trouble moving my bowels..... | 0 | 1 | 2 | 3 | 4 |
| P7 | I have difficulty urinating..... | 0 | 1 | 2 | 3 | 4 |
| BL2 | I urinate more frequently than usual | 0 | 1 | 2 | 3 | 4 |
| P8 | My problems with urinating limit my activities..... | 0 | 1 | 2 | 3 | 4 |
| BL5 | I am able to have and maintain an erection..... | 0 | 1 | 2 | 3 | 4 |

APPENDIX J: FUNCTIONAL ASSESSMENT OF CANCER THERAPY – GENERAL POPULATION

FACT-GP (Version 4)

Below is a list of statements that other people have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

| <u>PHYSICAL WELL-BEING</u> | | Not at all | A little bit | Some- what | Quite a bit | Very much |
|-----------------------------------|--|-----------------------|-------------------------|-----------------------|------------------------|----------------------|
| GP1 | I have a lack of energy | 0 | 1 | 2 | 3 | 4 |
| GP2 | I have nausea | 0 | 1 | 2 | 3 | 4 |
| GP3 | Because of my physical condition, I have trouble meeting the needs of my family | 0 | 1 | 2 | 3 | 4 |
| GP4 | I have pain | 0 | 1 | 2 | 3 | 4 |
| GP6 | I feel ill | 0 | 1 | 2 | 3 | 4 |
| GP7 | I am forced to spend time in bed | 0 | 1 | 2 | 3 | 4 |

| <u>SOCIAL/FAMILY WELL-BEING</u> | | Not at all | A little bit | Some- what | Quite a bit | Very much |
|--|---|-----------------------|-------------------------|-----------------------|------------------------|----------------------|
| GS1 | I feel close to my friends | 0 | 1 | 2 | 3 | 4 |
| GS2 | I get emotional support from my family | 0 | 1 | 2 | 3 | 4 |
| GS3 | I get support from my friends | 0 | 1 | 2 | 3 | 4 |
| GS6 | I feel close to my partner (or the person who is my main support) | 0 | 1 | 2 | 3 | 4 |
| Q1 | <i>Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box <input type="checkbox"/> and go to the next section.</i> | | | | | |
| GS7 | I am satisfied with my sex life | 0 | 1 | 2 | 3 | 4 |

FACT-GP (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

| <u>EMOTIONAL WELL-BEING</u> | | Not at all | A little bit | Some- what | Quite a bit | Very much |
|------------------------------------|--|-----------------------|-------------------------|-----------------------|------------------------|----------------------|
| GE1 | I feel sad | 0 | 1 | 2 | 3 | 4 |
| GE4 | I feel nervous | 0 | 1 | 2 | 3 | 4 |
| GE5 | I worry about dying | 0 | 1 | 2 | 3 | 4 |
| GE6 | I worry that my condition will get worse | 0 | 1 | 2 | 3 | 4 |

| <u>FUNCTIONAL WELL-BEING</u> | | Not at all | A little bit | Some- what | Quite a bit | Very much |
|-------------------------------------|--|-----------------------|-------------------------|-----------------------|------------------------|----------------------|
| GF1 | I am able to work (include work at home) | 0 | 1 | 2 | 3 | 4 |
| GF2 | My work (include work at home) is fulfilling | 0 | 1 | 2 | 3 | 4 |
| GF3 | I am able to enjoy life | 0 | 1 | 2 | 3 | 4 |
| GF5 | I am sleeping well | 0 | 1 | 2 | 3 | 4 |
| GF6 | I am enjoying the things I usually do for fun | 0 | 1 | 2 | 3 | 4 |
| GF7 | I am content with the quality of my life right now | 0 | 1 | 2 | 3 | 4 |

**APPENDIX K: APPROVAL TO USE SOCIAL IMPACT SCALE FROM
DR. FIFE**

3/5/2015

Re: Social Impact Scale - Andrew Wood

Re: Social Impact Scale

Fife, Betsy L <bfife@iu.edu>

Mon 6/9/2014 9:40 PM

Inbox

To: Andrew Wood <a.wood@knights.ucf.edu>;

You may use the scale if it is to be completed by the person with prostate cancer. You do NOT have permission to re-word for partners. That would not provide valid data.

Sincerely,
Betsy L. Fife, PhD
Senior Research Scientist
Indiana University

Sent from my iPhone

On Jun 9, 2014, at 4:44 PM, "Andrew Wood" <a.wood@knights.ucf.edu> wrote:

Dr. Fife,

Good evening, my name is Andrew Wood and I am a doctoral student at the University of Central Florida. I am gearing up to start my dissertation soon on the topic of stigma's influence on quality of life for older prostate cancer survivors. I am looking to use the SIS as it works as a general illness stigma scale and to my knowledge, no stigma scales exist specifically for prostate cancer.

I was wondering if it was okay with you if I used it. I don't see any official manualization available anywhere, so I am not sure if it is available for use by just anyone.

Also, how do you feel about rewording the questions in order to get a partner's perception of stigma?

For example:

Item 1: My employer/co-workers have discriminated against me.

becomes

Item 1: My partner's employer/co-workers have discriminated against him.

3/5/2015

Re: Social Impact Scale - Andrew Wood

Item 16: I feel I need to keep my illness a secret.

becomes

Item 16: My partner feels that he needs to keep his illness a secret.

I understand that this would essentially make the SIS a new scale, but I was not sure if you have seen anyone else do this to the SIS as I have not. I think it would be valuable to get not only the prostate cancer survivor's feelings of stigma (unchanged SIS), but also the perceived feelings of stigma from a partner (re-worded SIS), to see how stigma of prostate cancer affects the quality of life of both individuals. I note the gender bias in the items (against those who have prostate cancer but don't identify as male) and will look to fix before use.

In any situation, I thank you for your time and your research. Both are greatly appreciated.

All the best,

Andrew Wood, M.S., Registered Mental Health Counseling Intern
Doctoral Student
PhD in Education, Counselor Education Track
University of Central Florida

APPENDIX L: APPROVAL TO USE FACT-P AND FACT-GP FROM FACIT

**License for use of the
FUNCTIONAL ASSESSMENT OF CHRONIC ILLNESS THERAPY (FACIT) system
of Quality of Life questionnaires**

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- 10) Investigator agrees to provide FACIT.org with a copy of any publications which result from this study.

Issued on: June 20, 2014

Lauren Lent, DHA, MS
FACIT.org
381 S. Cottage Hill Avenue
Elmhurst, IL 60126
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REFERENCES

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