Outcomes Assessment within Prostate Cancer Interventions for Couples: A Narrative Review

2016

Andrea M. Siguenza

University of Central Florida

Find similar works at: http://stars.library.ucf.edu/honorstheses

University of Central Florida Libraries http://library.ucf.edu

Part of the Community Health and Preventive Medicine Commons

Recommended Citation

http://stars.library.ucf.edu/honorstheses/118

This Open Access is brought to you for free and open access by the UCF Theses and Dissertations at STARS. It has been accepted for inclusion in Honors in the Major Theses by an authorized administrator of STARS. For more information, please contact lee.dotson@ucf.edu.
Outcomes Assessment within Prostate Cancer Interventions for Couples: A Narrative Review

by

ANDREA M. SIGUENZA

A thesis submitted in partial fulfillment of the requirements for the Honors in the Major Program in Health Sciences (Pre-Clinical) in the College of Health and Public Affairs and in The Burnett Honors College at the University of Central Florida Orlando, Florida

Fall Term, 2016

Thesis Chair: Dr. Michael J. Rovito
ABSTRACT

Current cancer research is beginning to address the psychosocial implications of a prostate cancer (PCa) diagnosis from not just the perspective of quality of life of the patient, but of his partner as well. Such inquiries have created novel intervention programs aiming to alleviate the adverse side effects that a PCa diagnosis may inflict on the couple.

Assessing efficacy of couple-based interventions, however, has been a difficult task due to the lack of homogeneity between studies regarding the operationalization process of primary outcome variables, as well as the instruments being used to measure them. This thesis, in response, aims to provide a detailed assessment of how previous interventions operationalized their targeted variables, the reported psychometric analysis of the instruments of measurement, and which instruments yielded statistically significant results.

A narrative review was conducted using a database search strategy to collect articles regarding couple-based interventions that focused on outcomes related to PCa diagnosis, treatment, and survivorship. Out of the ten articles that passed the screening method, forty-two outcomes were identified, ranging from physical, social, and mental well-being of the couple, to the impact PCa had on their relationship quality. The outcomes were grouped into eight categories: quality of life, appraisal of PCa outcomes, sexual/physical well-being, relationship assessment, coping, mental health, knowledge, and distress. Various scales were used to measure similar outcomes with some articles failing to report on the psychometric properties of their chosen instruments.

This assessment aims to provide future researchers with an indication as to what outcomes have been previously targeted and their corresponding methods of operationalization,
categorization, and analysis. The multitude of assessed outcomes, the lack of uniformity on best practices in PCa couple intervention research, and the general failure to report on reliability and validity of measures may serve as significant barriers to producing high-quality evidence that can inform the development of future research and practice. This review provides the research community an aid in the development of behavioral interventions, and potentially, practice, via offering recommendations on certain outcomes that remain underreported within interventions. It is the ultimate aim of this project to assist in fostering a true public health for all.

Keywords: prostate cancer, couple-based intervention, adverse outcomes
DEDICATIONS

For my mother, who moved mountains so that I could have an education. This is but a small fraction of all that I owe you, and I will not stop here. At twenty-three, you set out to provide a better life for me and at twenty-three, I will set out to provide a better life for you.

For my father, who’s greatest gift to me was loving my mother and making her happy. Thank you for sharing all your wisdom with me and for always celebrating any success of mine, big or small.

For my little sister, who lifted my spirits with her positivity and inspired me to never give up on my dreams, regardless of the circumstances.

For all the amazing friends I made at UCF and all the memories I was able to share. Thank you for endless laughs, sleepless nights of studying, and all the words of encouragement that I received.
ACKNOWLEDGEMENTS

I would like to acknowledge my committee members, Dr. Michael Rovito and Dr. Thomas Wright for their relentless effort to help me succeed with this project. My sincerest gratitude for all the guidance poured into my project and into helping me expand my professional skillset. I would like to especially thank my thesis chair, Dr. Michael Rovito for mentoring me throughout this process and throughout many other academic endeavors. It has been the fondest memory and life-changing experience during my undergraduate career to have learned from you and shared in your passion for male health.
# TABLE OF CONTENTS

INTRODUCTION .......................................................................................................................... 1

Purpose and Importance ........................................................................................................... 1

BACKGROUND .......................................................................................................................... 2

Prostate Cancer ......................................................................................................................... 2

PCa patient specific outcomes ................................................................................................. 3

PCa partner specific outcomes ................................................................................................. 4

Patient-Partner Dyad ................................................................................................................. 5

Objective & Goals ...................................................................................................................... 6

METHODOLOGY ....................................................................................................................... 8

Search Strategy & Data Sources ............................................................................................... 8

Inclusion & Exclusion Criteria ................................................................................................. 8

Screening Assessment .............................................................................................................. 9

Primary Screening .................................................................................................................. 9

Secondary Screening .............................................................................................................. 9

Tertiary Screening .................................................................................................................. 9

RESULTS ................................................................................................................................. 10

DISCUSSION ............................................................................................................................ 23

FUTURE IMPLICATIONS ......................................................................................................... 25
LIST OF FIGURES

Figure 1: Search Strategy and Screening Method................................................................. 10
# LIST OF TABLES

Table 1: Categorization of Outcomes ................................................................................................. 11
Table 2: Quality of Life ...................................................................................................................... 13
Table 3: Appraisal of PCa Outcomes ................................................................................................. 16
Table 4: Sexual/Physical Well-Being ................................................................................................. 17
Table 5: Relationship Assessment .................................................................................................... 18
Table 6: Coping .................................................................................................................................... 19
Table 7: Mental Health ....................................................................................................................... 20
Table 8: Knowledge ........................................................................................................................... 21
Table 9: Distress ................................................................................................................................... 22
INTRODUCTION

Purpose and Importance

Prostate cancer (PCa) is considered the most communal kind of invasive cancer in men (Baade et al., 2009). Despite increases in likelihood of survival, PCa can be a severely disabling disease that may have long-lasting adverse effects on the patient and the partner even after treatments are completed. The adverse outcomes range across a plethora of physical, mental, and emotional well-being, inclusive of erectile dysfunction, psychological distress, and relationship quality (Wittmann et al., 2013; Chambers et al., 2013; Lyons et al., 2016).

Cancer research has begun to shift its focus on not only the biological characteristics of PCa, but also on the psychosocial implications that adverse outcomes may have on the patient and other members of his social support system (Hagedoorn et al., 2008). In other words, the literature demonstrates a pendulum swing of mutual impact from the patient and the partner following a cancer diagnosis to such an extent that couples can either positively or negatively affect each other’s quality of life (QOL).

Despite past and current efforts to implement effective intervention programs for couples dealing with PCa, systematic reviews have concluded on the lack of sound methodological approaches that yield statistically significant results. A common possible explanation for this phenomenon discussed in the research community is the lack of homogeneity of how outcomes are defined and measured. This occurrence may be a possible obstacle for future researchers to design and implement effective intervention programs. In efforts to highlight the heterogeneity of outcomes and their measurements, and to also aid future endeavors of more effective intervention programs, this review provides an assessment of previous targeted outcomes, the
tools used to measure them, and corresponding reported psychometric analyses of the scales. It is from these findings that recommendations for future assessments are offered in order to improve future research, and potentially, practice.

**BACKGROUND**

**Prostate Cancer**

Prostate cancer is the fifth leading cause of all cancer deaths in America (SEER, n.d.). Following lung cancer, PCa is the second leading cause of cancer death in men in the U.S. (American Cancer Society, 2016b). Risk factors, such as older age and African-American or Afro-Caribbean race/ethnic origin, are associated with developing PCa (American Cancer Society, 2016a; Pal, 2013). Other risk factors for the disease stem from lifestyle factors, such as tobacco use and dietary habits (American Cancer Society, 2016a).

PCa screening has decreased prostate-specific cancer mortality within the past three decades, through the use of the prostate specific antigen (PSA) blood test, digital rectal exams, and family history analysis (Bryant & Lilja, 2014). Despite the perceived risk-benefit analysis of early detection practices for PCa, most men who are diagnosed do not die from it. An estimate of one in seven men will be diagnosed with PCa in his lifetime, yet nearly three million of them who have previously been diagnosed are still alive today (American Cancer Society, 2016b).

Although early detection of PCa has a 98.9% five-year survival rate (SEER, n.d.), the process of screening, diagnosis, and treatment can result in many adverse side effects for the patient, ranging from psychological distress to incontinence of the urinary organs and impotence of the reproductive organs. The average age for PCa diagnosis is 66 (SEER, n.d.) and 76.4 for
PCa-free males, meaning if a man gets diagnosed at 66 he may have to cope with the side effects of PCa for at least another ten years.

Baade et al. (2009) reported an improved global survival rate for PCa. With more men getting diagnosed and living with the negative side effects of the detection and treatment process, than men who are dying from PCa, it is imperative for the research community to address the physical and mental well-being of the patients and their families.

**PCa patient specific outcomes.** Many outcomes of PCa treatments have life-long adverse side effects for the patient. For example, Smith et al. (2007) reported that nearly half of diagnosed men experience some extent of unmet psychological need (54/%) and unmet sexuality need (47%). Herr and O’Sullivan (2000) suggests psychological problems may arise, such as anxiety and distress from diagnosis and treatment. Sharpley and Christie (2007) state that incidence rates of depression (16%) and anxiety (12%) in PCa survivors still surpass population norms for older men.

Urinary, bowel, and erectile dysfunction (Lilleby et al., 1999; Sneeuw et al. 2001; Michaelson et al., 2008) are common side effects from invasive procedures such as cryosurgery (freezing of the prostate gland) (American Cancer Society, 2015). Hormonal therapy is known to reduce sexual desire (Canada et al., 2005). Decreased libido (Koeman et al., 1996; Litwin, 2003; Potosky et al., 2004; Dahn et al., 2004) and impotence ((Schover et al., 2002; Potosky et al., 2004) may cause serious psychosocial distress between the patient and the partner as well, all of which can further decrease the patient’s quality of life (Gray et al., 1999; Cliff et al., 2000; Kornblith et al., 1994; Boehmer & Clark, 2001; Eton & Lepore, 2002) and perceived masculinity (Lubeck et al., 1999). Nearly 68% of men experience penile shortening following a radical
prostatectomy which may lead to decreased self-esteem regarding body image (Savoie et al., 2003).

Physical fatigue has been reported by the majority of PCa survivors (Danjoux et al., 2007) as one of the most important symptoms or concerns to monitor (Butt et al., 2008). Cancer treatments can be extremely invasive so as to affect the normative gender role functioning of a household such as the male being too weak to provide for the family for a time being which may lead to financial worries and employment problems (Clark et al., 2003).

PCa partner specific outcomes. Spousal support regarding PCa screening and treatments serves as an important variable for the patient during the decision-making process (Volk et al., 1997). In the process of adjusting to cancer, the patient has an increased emotional dependence on their partner, and having that emotional support was associated with better adjustment for the patient (Helgeson et al., 1996). Krongrad et al. (1996) reported a significantly longer mean survival for men who were married, compared with those who were not, which may indicate longevity’s relationship with spousal presence and/or support.

Boehmer and Clark (2001) examined patients wanting to share their thoughts and concerns regarding PCa exclusively with their spouses, possibly due to the intimate nature of the side effects. Relatedly, social support from other family members or friends cannot suffice or compensate for poor spousal support (Pistrang & Barker, 1995). This indicates the significant role a spouse or partner plays in the quality of life, and perhaps length of life post-diagnosis, among men diagnosed with PCa or undergoing screening for the disease.

The pressure that the partner is under to provide emotional support for the patient while coping with the constant fear of losing them (Maughan et al., 2002; Thomas et al., 2002) may
cause self-neglect in which the partner often fails to address their own feelings and needs (Chung & Hwang, 2012; Lopez et al., 2012). This sacrificial act can increase the risk for varying physical, social, and mental diseases for the partner (Li & Loke, 2014). For example, a growing body of evidence points to increased psychological distress and cancer-specific worries that spouses experience compared to the patients themselves (Kornblith et al., 1994; Braun et al., 2007; Northouse, Mood, Montie, et al., 2007; Segrin & Badger, 2010). Approximately 40% of spouses reported clinically significant levels of depression (Braun et al., 2007). Prevalence of anxiety for the caregivers surpasses reported anxiety levels of the patients themselves (Boyes et al., 2011) and the population norm (Lambert et al., 2013).

**Patient-Partner Dyad**

Hagedoorn et al. (2008) states that the side effects of a diagnosis are known to affect the couple on an individual and dyadic basis. Other research highlights the adverse side effects experienced by the patient and the partner can severally affect relationship quality as well (Couper, Bloch, Love, & Duchesne, et al., 2006; Couper, Bloch, Love, & Macvean, et al., 2006). Distress on the couple, further, begins as early as being able to share the PCa diagnosis news with the spouse and discussing role changes in the household and work (Lopez et al., 2012; Maughan et al., 2002; (Dankoski & Pais, 2007). This is suggestive of a paradigm shift in the body of evidence where research is beginning to address not only the physiological aspects of PCa but the psychosocial implications on the QOL, mental health, and coping mechanisms of the patient and their partner (Kayser et al., 2007; Kim et al., 2008; Northouse et al., 2000). Poor dyadic influence and support are detrimental to the well-being of the patient and the partner when dealing with the distress of PCa. Research has highlighted the importance and necessity of
such a relationship, in which the couple can positively influence and support each other, to exist (Dankoski & Pais, 2007).

**Objective & Goals**

Extant literature suggests the physical, mental, and social well-being of a couple following a PCa diagnosis is a serious public health concern that must be continued to be addressed. Although there have been more intervention programs targeting adverse outcomes for the couple, few report on the efficacy of the intervention or on statistically significant results for targeted outcomes within the interventions. Recent reviews on interventions have either solely focused on male-only intervention programs, have omitted reviewing partner outcomes, or have excluded analysis for interventions of various stages of PCa (see Cockle-Hearne & Faithfull, 2010; Dale et al., 2010).

A recent systematic review of interventions focused on the alleviation of adverse outcomes for both partners and patients, concluded on the difficulty of assessing efficacy of programs due to the inconsistency of results between and within the studies (Chambers et al., 2011). Dale et al. (2010) also reported that lack of homogeneity between studies and poor attention to detail in reporting outcomes hindered their efforts to compare interventions.

Despite efforts to create effective intervention programs, a best practice approach has yet to be identified that addresses the psychosocial necessities of the couple (Chambers et al., 2011). Perhaps if there were increased homogeneity in the targeted outcomes and the tools that are being used to assess said outcomes, there might be less evidence of conflicting results. As of yet, there has not been a systematic review of the literature that compiles PCa outcomes, of couples, as well as the respective tools used to measure them. Following the recommendation of
Chambers et al. (2011) to create intervention programs with measurable outcomes before implementing the program to the target population so as to not waste time and resources for both the researchers and the participants, the objective of this thesis is to use a strength of evidence approach to compile the various measurable outcomes of interventions for couples coping with PCa and the tools that were used to measure adverse outcomes.

The goal of this thesis is to provide an outcomes assessment to the research community that will in turn aid with the creation of effective intervention programs. The more that the research community is aware of how other experts in the field are operationalizing and measuring adverse PCa outcomes for couples, the more congruent the methodological approaches may be to the point where a gold standard may arise. With fewer researchers implementing dissimilar operationalization and analysis approaches, we may get closer to uncovering which intervention programs are working and which ones are not. Addressing the heterogeneity of interventions, and possible reasons for it, is necessary in order to improve the QOL for members of our community.
METHODOLOGY

Search Strategy & Data Sources

The following search strategy of electronic databases was conducted to identify relevant articles of intervention programs: PubMed (MEDLINE) (1948 to 2016), OvidMEDLINE (1946 to 2016), PsychInfo (1806 to 2016), CINAHL (1982 to 2016), Ovid Healthstar (1966 to 2016) and Google Scholar (2000-2016). The keywords that were used are the following: spouse OR couple OR partner AND prostate cancer workshop OR prostate cancer intervention OR prostate cancer education. The reference list of analyzed articles was also evaluated for any related pieces that may have been missed during the search strategy. The abstracts of the search results were first analyzed to confirm that the inclusionary and exclusionary criteria below were met.

Inclusion & Exclusion Criteria

Studies included for analysis were peer-reviewed articles in the English language that specifically looked at interventions for couples that have had a first-time PCa diagnosis. Critical assumptions as to why couple-based interventions were sought after instead of independent patient or partner interventions were the following: 1) PCa does not affect solely the patient but their social network as well, 2) QOL is mutually impacted between the patient and members of their close social network, such as their partner, 3) emotions are inter-reliant (Badger et al., 2011). There were not any exclusions made on the basis of different stages of PCa or the type of treatment for it. However, interventions solely focused on PCa screening were excluded. Studies that analyzed the methodological processes of interventions but did not report on PCa patient-caregiver outcomes were excluded. Articles that were included described relevant intervention processes and outcomes and provided a statistically significant measure for outcomes.
Screening Assessment

The initial search criteria solicited 460 articles. A total of 201 duplicate articles were extracted leaving a total of 259 articles that underwent primary screening. A total of 230 articles did not meet the primary inclusionary criteria, leaving twenty-nine articles to undergo the secondary screening. The secondary screening criteria removed thirteen articles leaving a total of sixteen to undergo the tertiary screening, which excluded out six articles, leaving a total of ten articles for analysis.

Primary Screening. Titles and abstracts of the full-length articles produced from the search criteria were reviewed for relevance. Excluded articles discussed biological processes of PCa and/or employed an intervention that was not PCa specific (included multiple types of cancers) or focused on PCa screening instead of diagnosis and treatment (See Figure 1, below).

Secondary Screening. Full length articles were then reviewed for relevance. Articles with interventions targeted for patients or caregivers independently were excluded. Articles that analyzed the interventions rather than PCa diagnosis and treatment outcomes were excluded.

Tertiary Screening. The third assessment focused on the results for the interventions. Articles that did not include a quantitative measure as a part of the statistical analysis for their outcomes were excluded.
Identified outcomes for couples with a PCa diagnosis or treatment ranged from psychosocial, physical, and emotional health to knowledge and awareness of the disease. A total of forty-two outcomes were identified among the ten relevant articles that remained in the study and were then categorized into eight different groups according to the similarity in topics (see Table 1, below).
Table 1: Categorization of Outcomes

<table>
<thead>
<tr>
<th>Category</th>
<th>Outcome(s)</th>
</tr>
</thead>
</table>
| Quality of Life         | Quality of Life (4)  
|                         | Spousal Quality of Life (2)  
|                         | General Quality of Life (1)  
|                         | Caregiver Quality of Life (1)  
|                         | Health-related Quality of Life (1)  
|                         | Disease-Specific Quality of Life (1)  |
| Appraisal of PCa Outcomes | Uncertainty (1)  
|                         | Hopelessness (1)                                                                                                                                 |
|                         | Benefit Finding (1)  
|                         | Illness Appraisal (2)  
|                         | Appraisal of Illness or Caregiving (1)  |
| Sexual/Physical Well-Being | General Symptoms (1)  
|                         | Sexual Satisfaction – Male (1)  
|                         | Levels of Physical Intimacy (1)  
|                         | Sexual Satisfaction – Female (1)  
|                         | Sexual Supportive Care Needs (1)  
|                         | Menopausal Symptom – Female (1)  
|                         | Urinary and Bowel Symptoms – Male (1)  
|                         | Erectile Dysfunction & Help Seeking Attitudes (1)  
|                         | Utilization of Medical Treatment for Erectile Dysfunction (ED) (1)  |
| Relationship Assessment | Marital Satisfaction (1)  
|                         | Relationship Quality (1)  
|                         | Relationship Satisfaction (2)  
|                         | Relationship Functioning (2)  
|                         | Dyadic Communication about PCa (1)  |
| Coping                 | Coping (1)  
|                         | Self- efficacy (2)  
|                         | Dyadic Coping (1)  
|                         | Communication (1)  
|                         | Individual Coping (1)  
|                         | Coping Strategies (1)  |
| Mental Health          | Anxiety (1)  
|                         | Depression (2)  
|                         | Mental Health (1)  |
| Knowledge              | Knowledge on PCa Sexual Problems and Sexual Recovery (1)  |
| Distress               | Psychological Distress (2)  
|                         | Cancer-Specific Distress (2)  
|                         | General Symptom Distress (1)  
|                         | PCa- specific Symptom Distress (2)  
|                         | Spousal PCa Symptoms Distress (2)  |
Outcomes grouped under each category were organized on the basis of conceptual similarities. For example, in order to be grouped under the “Quality of Life” category, the outcome had to relate to an overall assessment of physical, mental, and social state of health. Outcomes under the “Appraisal of PCa Outcomes” category were related to how the patient or partner reflected about the cancer.

The “Sexual/Physical Well-Being” category encompassed outcomes that pertained to anything related to the implications that PCa has had on the sexual or physical well-being of the couple. Outcomes that were related to the state of the relationship between the patient and their partner were grouped under the “Relationship Assessment” category. Outcomes that were associated with methods of coping were placed under the “Coping” category. The “Mental Health” category contained outcomes that solely focused on the psychological implications of a PCa diagnosis. The “Knowledge” category only had one entry regarding knowledge of sexual problems and sexual recovery of PCa. The final category “Distress” embodied outcomes that were related to any form of distress that was caused from PCa on the couple.

The following are the individual tables for each of the categories and their corresponding outcomes. Within each table, the articles pertaining to each outcome were organized from most recent intervention to the oldest, so as to show if any changes in how outcomes were measured had occurred and if any older scales still continued to be used or if new ones were preferred. Scales that were used more than once by different articles are in bold. Psychometric analyses that were reported ranged from scores of internal consistency and retest reliability using the appropriate tests for each.
Six different articles identified QOL as a targeted outcome (see Table 2, below). A total of seventeen different scales were used to measure patient/partner general quality of life and disease-specific quality of life. Of those six articles, general patient QOL was measured using fourteen different scales. Partner QOL was measured using six different scales; however, only three articles chose to give the partner a “caregiver/spousal-specific” scale (Lambert et al., 2016; (Song et al., 2015; (Northouse, Mood, Schafenacker, et al., 2007) to assess QOL. Disease/health-specific QOL was measured using two different scales, the 52-item Prostate Cancer Quality of Life Instrument (PCQoL) and the 36-item Short Form Health Survey (SF-36). Two different articles used the same scale (SF-36) to measure a general QOL outcome (Giesler et al., 2005) and a health-related QOL outcome (Canada et al., 2005). Of the seventeen scales used, six did not have any corresponding psychometric analysis reports. Only half of the six articles reported statistically significant results for their interventions (Northouse, Mood, Schafenacker, et al., 2007; Badger et al., 2011; Lambert et al., 2016).

### Table 2: Quality of Life

<table>
<thead>
<tr>
<th>Article</th>
<th>Outcome</th>
<th>Scale</th>
<th>Psychometric Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Badger et.al., 2011)</td>
<td>Quality of Life</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression * #</td>
<td>20-item Center for Epidemiological Studies-Depression Scale (CES-D)</td>
<td>$\alpha \geq 0.88$</td>
<td></td>
</tr>
<tr>
<td>Positive affect &amp;</td>
<td>20-item Positive and Negative Affect Schedule (PANAS)</td>
<td>$\alpha &gt; 0.87$</td>
<td>(positive)</td>
</tr>
<tr>
<td>Negative affect *</td>
<td></td>
<td></td>
<td>$\alpha \geq 0.86$</td>
</tr>
<tr>
<td>Perceived stress*</td>
<td>10-item Perceived Stress Scale (PSS)</td>
<td>$\alpha \geq 0.88$</td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Fatigue</strong> *#</td>
<td>20-item Multidimensional Fatigue Inventory (MFI)</td>
<td>$\alpha \geq 0.89$</td>
<td></td>
</tr>
<tr>
<td><strong>Prostate specific health–related QOL</strong></td>
<td><strong>urinary, bowel, sexual functioning subscales from the UCLA Prostate Cancer Index</strong></td>
<td>$\alpha \geq 0.74$</td>
<td></td>
</tr>
</tbody>
</table>

**Social**

| **Social well-being** *# | 8-item social well-being scale (modified) | $\alpha \geq 0.78$ |
| **Social support – family** *# | 20-item Perceived Social Support-Family scale (PSS-FA) | $\alpha \geq 0.79$ (patients) |
| **Spiritual well-being** *# | 8-item spiritual well-being subscale of the Quality of Life-Breast Cancer version | $\alpha = 0.78$ (patients) |

(Lambert et al., 2016) | **Quality of Life** *# | Physical and mental subscales of the Assessment of Quality of Life - 8 Dimensions (AQoL-8D) | ---- |

(Lambert et al., 2016) | **Caregiver Quality of Life** | four subscales of the QOL Index-Cancer (CQOLC) | $\alpha = 0.91$ |

(Song et al., 2015) | **Quality of Life** | 27-item Functional Assessment of Chronic Illness Therapy-General (FACT-G) scale | $\alpha = 0.9$ |

(Song et al., 2015) | **Spousal Quality of Life** | FACT-G spousal version w/ modified wording | $\alpha = 0.9$ |

(Northouse, Mood, Schafenacker et al., 2007) | **Quality of Life** * | 27-item Functional Assessment of Cancer Treatment (FACT-G) (version 4) – patient | ---- |

(Northouse, Mood, Schafenacker et al., 2007) | **Spousal Quality of Life** * | FACT-P (Prostate Specific Quality of Life Scale)-patient only | ---- |

(Giesler et al., 2005) | **Disease-Specific Quality of Life** * | 52-item Prostate Cancer Quality of Life Instrument (PCQoL) | $\alpha = 0.70-0.90$ |
Four different articles targeted variables related to PCa appraisal of outcomes (see Table 3, below). A total of seven different scales were used to measure variables related to PCa appraisal outcomes across the different studies. The outcome “Illness appraisal” was measured by two separate articles. Lambert et al. (2016) chose to use three different scales to measure illness appraisal, whereas Wittmann et al. (2013) chose to use only one scale to measure illness appraisal. Northouse, Mood, Schafenacker, et al. (2007) and Chambers et al. (2013) reported statistically significant results nevertheless, they did not report any psychometric analysis on the tools that measured their targeted outcomes. Only two articles reported psychometric analysis for their measurement tools (Wittmann et al., 2013; Lambert et al., 2016). Almost all the articles reported statistically significant results for their outcomes (Northhouse, Mood, Schafenacker, et al., 2007; Chambers et al., 2013; Lambert et al., 2016).

Five different articles targeted outcomes related to sexual and physical state (see Table 4, below). A total of nine different scales were used to measure the reported outcomes. Of the nine scales that were used, four did not have any reported psychometric analysis. Three of the articles reported statistically significant results for their intervention (Canada et al., 2005; Chambers et al., 2013; Wittmann et al., 2013).
Table 3: Appraisal of PCa Outcomes

<table>
<thead>
<tr>
<th>Article</th>
<th>Outcome</th>
<th>Scale</th>
<th>Psychometric Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Lambert et. al., 2016)</td>
<td>Illness Appraisal *#</td>
<td>Mishel’s Uncertainty in Illness Scale (MUIS)</td>
<td>α = 0.64–0.92</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Kessler’s Cognitive Appraisal of Health Scale (CAHS)</td>
<td>α &gt; 0.70</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Appraisal of Caregiving Scale (ACS)</td>
<td>α &gt; 0.85</td>
</tr>
<tr>
<td>(Wittmann et. al., 2013)</td>
<td>Illness Appraisal</td>
<td>Protective Buffering Scale</td>
<td>α &gt; 0.70</td>
</tr>
<tr>
<td>(Chambers et. al., 2013)</td>
<td>Benefit Finding *</td>
<td>The Post-traumatic Growth Inventory (PTGI)</td>
<td>---</td>
</tr>
<tr>
<td>(Northouse, Mood, Schafenacker et al., 2007)</td>
<td>Appraisals of illness/caregiving*#</td>
<td>27-item Appraisal of Illness or Appraisal of Caregiving Scales.</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>Uncertainty*#</td>
<td>28-item Mishel Uncertainty in Illness Scale</td>
<td>---</td>
</tr>
<tr>
<td></td>
<td>Hopelessness #</td>
<td>20-item Beck Hopelessness Scale</td>
<td>---</td>
</tr>
</tbody>
</table>

* Statistically significant results for the patient according to guidelines of the intervention
# Statistically significant results for the partner according to guidelines of the intervention
---- No psychometric analysis reported

Six different articles targeted outcomes related to the relationship of the couple (see Table 5, below). A total of seven scales were used to measure the seven outcomes.

Relationship/Marital satisfaction was targeted by three different articles and measured by three different scales (Lambert et al., 2016; Song et al., 2015; Canada et al., 2005). Relationship functioning was an outcome of interest for two different articles, each of which chose different scales to measure the outcomes (Couper et al., 2015; Giesler et al., 2005). All the scales that
were used reported corresponding psychometric analysis results. Only one study produced statistically significant results with their intervention (Couper et al., 2015).

**Table 4: Sexual/Physical Well-Being**

<table>
<thead>
<tr>
<th>Article</th>
<th>Outcome</th>
<th>Scale</th>
<th>Psychometric Analysis</th>
</tr>
</thead>
</table>
| (Lyons et al., 2016)            | Levels of Physical Intimacy                         | Four affectionate and two sexual behaviors on a 1 (none of the time) to 4 (most or all of the time) scale | Affectionate: $\square$  
  $a=0.90-0.94$  
  (husband)  
  $a=0.86-0.92$  
  (wife)  
  Sexual:  
  $a=0.82-0.91$  
  (husband)  
  $a=0.80-0.84$  
  (wife) |
| (Song et al., 2015)             | General Symptoms (i.e. fatigue, pain)               | 21-item symptom scale                                                | $a = 0.76-0.84$                                                                       |
| (Wittmann et al., 2013)         | Erectile Dysfunction and Help Seeking Attitudes *    | Erectile Dysfunction Help-Seeking Scale                              | $a = 0.65$ (erectile dysfunction)  
  $a = 0.84$ (help-seeking) |
| (Chambers et al., 2013)         | Sexual Supportive Care Needs * #                    | Sexuality needs subscale of the Supportive Care Needs Survey        | ----                                                                                  |
| (Canada et al., 2005)           | Sexual Satisfaction – Male *                        | 15-item International Index of Erectile Functioning (IIEF)           | $a = 0.86-0.93$                                                                      |
| (Canada et al., 2005)           | Sexual Satisfaction – Female #                      | 19-item Female Sexual Function Index (FSFI)                          | $a = 0.89-0.97$                                                                      |
| (Canada et al., 2005)           | Utilization of Medical Treatment for Erectile Dysfunction (ED) | Utilization of medical treatment of ED                               | ----                                                                                  |
| (Canada et al., 2005)           | Urinary and Bowel Symptoms - Male                   | urinary and bowel symptom scales from the UCLA Prostate Cancer Index (UCLA PCI) | ----                                                                                  |
| (Canada et al., 2005)           | Menopausal Symptom - Female                         | 7-item menopausal symptom scale derived from the Breast Cancer Prevention Trial (BCPT)Symptom Checklist | ----                                                                                  |

* Statistically significant results for the patient according to guidelines of the intervention  
# Statistically significant results for the partner according to guidelines of the intervention  
---- No psychometric analysis reported
### Table 5: Relationship Assessment

<table>
<thead>
<tr>
<th>Article</th>
<th>Outcome</th>
<th>Scale</th>
<th>Psychometric Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Lambert et. al., 2016)</td>
<td>Relationship Satisfaction</td>
<td>Revised-Dyadic Adjustment Scale (R-DAS)</td>
<td>$\alpha = 0.89$–$0.95$</td>
</tr>
<tr>
<td>(Lyons et al., 2016)</td>
<td>Relationship Quality</td>
<td>15-item Mutuality scale</td>
<td>$\alpha = 0.95$</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Husbands)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$\alpha = 0.93$</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Wives)</td>
</tr>
<tr>
<td>(Song et al., 2015)</td>
<td>Relationship Satisfaction</td>
<td>7-item Relationship Assessment Scale</td>
<td>$\alpha = 0.73$–$0.9$</td>
</tr>
<tr>
<td>(Song et al., 2015)</td>
<td>Dyadic Communication about PCa</td>
<td>21-item, five-point Likert-type Mutuality and Interpersonal Sensitivity Scale</td>
<td>$\alpha = 0.9$–$0.94$</td>
</tr>
<tr>
<td>(Couper et al., 2015)</td>
<td>Relationship Functioning**</td>
<td>12-item Family Relationship Index (FRI)</td>
<td>$\alpha = 0.57$–$0.65$</td>
</tr>
<tr>
<td>(Canada et al., 2005)</td>
<td>Marital Satisfaction</td>
<td>7-item abbreviated for of the Dyadic Adjustment Scale (A-DAS)</td>
<td>$\alpha = 0.96$</td>
</tr>
<tr>
<td>(Giesler et al., 2005)</td>
<td>Relationship Functioning</td>
<td>Subscales: Dyadic Satisfaction and Dyadic Cohesion from the 32-item Spanier Dyadic Adjustment Scale (DAS)</td>
<td>$\alpha = 0.86$</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Satisfaction)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>$\alpha = 0.73$</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(Cohesion)</td>
</tr>
</tbody>
</table>

* Statistically significant results for the patient according to guidelines of the intervention
# Statistically significant results for the partner according to guidelines of the intervention
---- No psychometric analysis reported

Three different articles targeted outcomes related to coping (see Table 6, below). A total of eight different scales were used to measure the targeted outcomes. The outcome “self-efficacy” was measured by two different articles using the same scale. However, Lambert et al. (2016) included an additional scale to measure self-efficacy. From those two articles only Northouse, Mood, Schafenacker, et al. (2007) reported statistically significant results for self-efficacy. The Brief COPE scale was used by two separate articles, both of which reported statistically significant results however there was discordance on the psychometric analysis of
the scale across the studies (Lambert et al., 2016; Couper et al., 2015). Three out of the ten scales did not have any reported psychometric analysis. All articles produced statistically significant results for certain outcomes.

Table 6: Coping

<table>
<thead>
<tr>
<th>Article</th>
<th>Outcome</th>
<th>Scale</th>
<th>Psychometric Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Lambert et. al., 2016)</td>
<td>Self-efficacy</td>
<td>Lewis Cancer Self-Efficacy Scale (LCSES)</td>
<td>α = 0.97</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3 subscales of the Communication and Attitudinal Self-Efficacy for Cancer (CASE-Cancer)</td>
<td>α = 0.76- 0.77</td>
</tr>
<tr>
<td>(Lambert et. al., 2016)</td>
<td>Dyadic Coping **</td>
<td>nine subscales of the Dyadic Coping Inventory (DCI)</td>
<td>α = 0.63–0.93</td>
</tr>
<tr>
<td>(Lambert et. al., 2016)</td>
<td>Individual Coping *</td>
<td>Brief COPE' derived from Coping Orientation to Problems Experienced Scale</td>
<td>α = 0.60–0.90</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Global Adaptive Coping Scale</td>
<td>α = 0.85- 0.87</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Problem-focused coping and emotion-focused coping subscales</td>
<td>----</td>
</tr>
<tr>
<td>(Northouse, Mood, Schafenacker et al., 2007)</td>
<td>Coping Strategies</td>
<td>28-item Brief Coping Orientations to Problems Experienced scale</td>
<td>----</td>
</tr>
<tr>
<td></td>
<td>Self-efficacy#</td>
<td>17-item Lewis Cancer Self-Efficacy Scale (LCSES)</td>
<td>----</td>
</tr>
<tr>
<td></td>
<td>Communication*</td>
<td>32-item Lewis Mutuality and Interpersonal Sensitivity Scale</td>
<td>----</td>
</tr>
</tbody>
</table>

* Statistically significant results for the patient according to guidelines of the intervention
# Statistically significant results for the partner according to guidelines of the intervention
---- No psychometric analysis reported

A total of three different articles measured outcomes related to mental health (see Table 7, below). Three different scales were used to measure the aimed outcomes. The depression outcome was measured using two different scales (HADS-D and the 20-item Center for Epidemiologic Studies-Depression Scale) and neither study produced statistically significant
results for the depression outcome (Lambert et al., 2016; Giesler et al., 2005). All the articles reported psychometric analysis results for their respective chosen scales. Only one study reported statistically significant results for that patient and partner regarding anxiety (Lambert et al., 2016).

**Table 7: Mental Health**

<table>
<thead>
<tr>
<th>Article</th>
<th>Outcome</th>
<th>Scale</th>
<th>Psychometric Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Lambert et. al., 2016)</td>
<td>Anxiety*#</td>
<td>Hospital Anxiety and Depression Scale (HADS-D)</td>
<td>$\alpha = 0.68-0.93$</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>Hospital Anxiety and Depression Scale (HADS-A)</td>
<td>$\alpha = 0.68-0.93$</td>
</tr>
<tr>
<td>(Couper et. al., 2015)</td>
<td>Mental Health</td>
<td>38-item Mental Health Inventory (MHI): 10-item psychological well-being and psychological distress subscales</td>
<td>$\alpha = 0.80-0.97$</td>
</tr>
<tr>
<td>(Giesler et. al., 2005)</td>
<td>Depression</td>
<td>20-item The Center for Epidemiologic Studies-Depression Scale</td>
<td>$\alpha = 0.85-0.90$</td>
</tr>
</tbody>
</table>

* Statistically significant results for the patient according to guidelines of the intervention
# Statistically significant results for the partner according to guidelines of the intervention
---- No psychometric analysis reported

Only one article, out of the ten that were analyzed, looked at knowledge regarding sexual consequences involved with PCa (see Table 8, below). Wittmann et al. (2013) used only one scale to analyze the targeted variable. The scale was self-made, and although there were reported statistically significant results for the partner and the patient, the psychometric analysis of the instrument was not reported.

Five different articles targeted various outcomes related to distress (see Table 9, below). A total of six different scales were used to measure the outcomes. Psychological distress was measured by two separate scales (BSI) and (IES-R) in two different articles and only Chambers
et al. (2013) reported statistically significant results regarding the patient’s psychological distress.

<table>
<thead>
<tr>
<th>Article</th>
<th>Outcome</th>
<th>Scale</th>
<th>Psychometric Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Wittmann et. al., 2013)</td>
<td>Knowledge on PCa Sexual Problems and Sexual Recovery*#</td>
<td>Sexual Recovery Questionnaire</td>
<td>----</td>
</tr>
</tbody>
</table>

* Statistically significant results for the patient according to guidelines of the intervention
# Statistically significant results for the partner according to guidelines of the intervention
---- No psychometric analysis reported

Two different articles used the same scale (4-item EPIC) to measure spousal symptoms of distress regarding PCa (Song et al., 2015; Northouse, Mood, Schafenacker, et al., 2007). The IES-R scale was used by three different articles and measured cancer-specific distress (Lambert et al., 2016; Couper et al., 2015) and psychological distress (Chambers et al., 2013). There was some discordance with the reported psychometric analysis of the IES-R scale across the three studies, with one study not reporting any reliability or validity results (Chambers et al., 2013). Only three out of the five studies reported psychometric analysis (Lambert et al., 2016; Song et al., 2015; Couper et al., 2015).
<table>
<thead>
<tr>
<th>Article</th>
<th>Outcome</th>
<th>Scale</th>
<th>Psychometric Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Lambert et. al., 2016)</td>
<td>Cancer-Specific Distress</td>
<td>Impact of Event Scale-Revised (IES-R)</td>
<td>$a = 0.78-0.96$</td>
</tr>
<tr>
<td>(Song et. al., 2015)</td>
<td>Symptom Distress Related to PCa-specific Symptoms</td>
<td>26-item Expanded Prostate Cancer Index Composite (EPIC)</td>
<td>$a = 0.74-0.9$</td>
</tr>
<tr>
<td>(Song et. al., 2015)</td>
<td>Spousal PCa Symptoms Distress</td>
<td>four-item EPIC</td>
<td>$a = 0.74-0.9$</td>
</tr>
<tr>
<td>(Couper et. al., 2015)</td>
<td>Cancer Distress</td>
<td>22-item Impact of Events Scale-Revised (IES-R)</td>
<td>$a = 0.84-0.92$</td>
</tr>
<tr>
<td>(Chambers et. al., 2013)</td>
<td>Psychological Distress</td>
<td>The Revised Impact of Events Scale (IES-R)</td>
<td>----</td>
</tr>
<tr>
<td>(Northouse, Mood, Schafenacker, et al., 2007)</td>
<td>Spousal PCa Symptoms Distress</td>
<td>the 4-item spousal version of the EPIC</td>
<td>----</td>
</tr>
<tr>
<td>(Northouse, Mood, Schafenacker, et al., 2007)</td>
<td>Prostate cancer -specific Symptoms Distress</td>
<td>50-item Expanded Prostate Cancer Index Composite (EPIC)</td>
<td>----</td>
</tr>
<tr>
<td>(Northouse, Mood, Schafenacker, et al., 2007)</td>
<td>General Symptom Distress</td>
<td>16- item Symptom Scale of the Omega Screening Questionnaire (OSQ).</td>
<td>----</td>
</tr>
<tr>
<td>(Canada et.al., 2005)</td>
<td>Psychological Distress</td>
<td>Brief Symptom Inventory (BSI)</td>
<td>----</td>
</tr>
</tbody>
</table>

* Statistically significant results for the patient according to guidelines of the intervention
# Statistically significant results for the partner according to guidelines of the intervention
---- No psychometric analysis reported
DISCUSSION

As mentioned previously, more cancer-related research is focusing on the couple as a unit, a term referred to as caregiver-patient dyad, rather than patients or caregivers as individuals (Fletcher et al., 2012). Continued efforts to provide a methodologically sound and effective intervention program for couples has proven to be a difficult task, due to the lack of homogeneity across studies regarding targeted outcomes, how to measure them, and what results are produced. This review further suggests that identifying a singular definition and method of measurement for the listed outcomes has been a challenge as previously stated by Chambers et al. (2013). Table 1 provides indication to the extent of differing outcomes that have been targeted from past interventions.

The sporadic reports on statistically significant results is also disconcerting. Given the nature of intervention programs, much about the methodology can influence the obtainment of significant results. Nevertheless, across all outcomes there was an inconsistency for a recurrent obtainment of statistically significant results of a single outcome across the ten different articles. Variability of outcomes might be hindering the research community in their efforts to create novel intervention programs with effective and statistically significant results.

The multitude of outcomes and their chosen measurement tools (with varying reported validity and reliability properties) may also explain the lack of congruency across results for different studies. Chambers et al. (2013) reported statistically significant results for the outcome “Benefit Finding”; however, without reported results of psychometric analysis there is less confidence in the validity and reliability of the scale. The same holds true for Wittmann et al.
(2013) that out of the ten articles, they were the only ones who analyzed knowledge on PCa and only covered knowledge regarding sexual recovery and satisfaction.

Given that spouses are an influential factor during the PCa treatment decision making process (Volk et al., 1997), knowledge on the disease, treatment options, and adverse side effects and how that information is discussed between partners are important to know prior to life-changing decisions. The categories “Relationship Assessment” and “Mental Health” were the only ones that reported psychometric analysis on all pertaining scales. The lack of psychometric analysis of some scales is concerning, given that without reported satisfactory results of validity and reliability, the final results must be tested again for consistency.

The inconsistency with employing particular assessments may contribute to the effectiveness of interventions. Across select pieces of the reviewed literature, similar outcomes were measured differently, which in turn may impact the results such as the case of the following outcomes: illness appraisal, relationship/marital satisfaction, relationship functioning, self-efficacy, depression, and psychological distress. Vice versa, there were circumstances in which the same scale was used to measure distinctive outcomes such as using SF-36 for both a general and a health related QOL assessment and the IES-R scale to measure both cancer-specific distress and psychological distress. There were some situations in which the same scale was used to measure the same outcome across studies such as the BRIEF Cope scale being used to measure coping, and the 4-item EPIC scale which measured spousal symptoms of PCa-induced distress.

Recent intervention reviews (Baik et al., 2011; Regan et al., 2012; Hopkinson et al., 2012) and a meta-analysis (Badr & Krebs, 2013) have concluded that anxiety, depression, and
improvement of quality of life were supported to be effective in the couple-based interventions that were analyzed. As evident through the information provided in this paper, anxiety, depression, and quality of life compose a small portion of the overall outcomes that couples face with a PCa diagnosis.

**FUTURE IMPLICATIONS**

This paper aims to provide the research community with a detailed assessment of the various outcomes related to PCa and the tools used for their measurement. The assessment strengthens previous discussions made from reviews of couple-based PCa interventions on the lack of homogeneity of outcomes and their measurements. The assessment of outcomes also provides an in depth look at what outcomes are more reoccurring, raising the possibility of the implemented priority of certain outcomes and the underrepresentation of others. Furthermore, the assessment may also highlight the need for the creation of more innovative intervention programs for this at risk population.

From the 259 original articles only ten passed basic screening measures (i.e. couple-based intervention, statistically significant results) and were analyzed suggesting that there is a need for more attempts at intervention programs for this target population. Of the ten articles that were analyzed, not all outcomes that were measured produced statistically significant results, thus highlighting the need for improvements in the operationalization, measurement and statistical analysis of PCa outcomes.

More emphasis needs to be placed on interventions that incorporate a knowledge of PCa as an outcome of interest, given that only Wittmann et al. (2013) included a knowledge outcome into their intervention. Knowledge about PCa treatments and corresponding outcomes can be
very useful for a couple when making life-changing decisions. Another outcome that was evidently lacking from the intervention programs was spousal communication. Given previous research on the positive effects that spousal/partner communication during a cancer diagnosis (Sterba et al., 2011; Badr et al., 2010) can have on the QOL of the couple, future intervention programs should incorporate communication into their targeted outcomes.

Future researchers may use this work as a guide for what outcomes remain to be assessed, what outcomes have been previously assessed and improved, and what are the best scales to use for their measurement. With the assessment provided, future interventions can be designed with more attention to detail of the methods of operationalization and on improving previous efforts of measuring certain outcomes and including understated outcomes as well.
LIST OF REFERENCES


breast and prostate cancer survivors and their spousal caregivers. *Annals of Behavioral Medicine, 35*(2), 230-238.


months post-diagnosis. *Supportive Care in Cancer*, (1), 75. doi:10.1007/s00520-012-1495-7


Northouse, L. L., Mood, D. W., Montie, J. E., Sandler, H. M., Forman, J. D., Hussain, M., . . .


