COUPLES' SEXUAL RECOVERY AFTER SURGERY FOR PROSTATE CANCER: THE DEVELOPMENT OF A CONCEPTUAL MODEL

By

Daniela Wittmann

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ABSTRACT

COUPLES' SEXUAL RECOVERY AFTER SURGERY FOR PROSTATE CANCER: THE DEVELOPMENT OF A CONCEPTUAL MODEL.

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The goal of this multiple-manuscript dissertation is to addresses a gap in the literature on couples' sexual recovery after surgery for prostate cancer in order to arrive at a testable conceptual model of couples' sexual recovery. The three manuscripts are independent in their research questions and methodologies, but are related in their exploratory nature and in their effort to examine different aspects of couples' sexual recovery. In Chapter I, the theoretical framework of the research is described and a preliminary model of couples' sexual recovery is proposed. It is a biopsychosocial model of sexuality, with grief as a process through which couples work on recovery. In Chapter II, a qualitative study describes couples' anticipation of the sexual recovery and their actual experience after surgery. The study findings support the theoretical framework in which couples experience the affect of the side-effects of prostate cancer surgery on the biopsychosocial aspects of sexuality and cope more or less successfully with the sexual losses through grief and mourning, which starts at diagnosis. Female partners' interest in sex, regardless of menopausal status of their sexual function, makes a contribution to the recovery. Chapter III presents the second study, also qualitative, and describes patients' and partners' view of the role of the partner in the sexual recovery. Men and partners have many common perceptions of the role, including the importance of the partner's interest in sex regardless of menopause. However, the men generally are not aware of partners' sexual needs and needs of support; partners are not certain about help-seeking. The third study, described in Chapter IV, is a quantitative study that uses validated measures to trace the change in patients'

and partners' sexual function, sexual satisfaction, and dyadic satisfaction from before surgery to 18 months after surgery, on average. In spite of the patients' improving sexual function, sexual satisfaction of patients as well as partners decreased. Female partners' dyadic satisfaction appears to depend on the partner's sexual satisfaction and the couple's level of income. The author integrates the three studies' findings into extant research literature and, based on the findings of the dissertation research, proposes a conceptual model of couples' sexual recovery after surgery for prostate cancer that can be tested in confirmatory, hypothesis driven research.

DEDICATION

This dissertation is dedicated my parents Marie and Ervin Wittmann whose courage in life is my model, and to my children Madeleine and Spencer Amdur, as well as to my brother George Wittmann, whose faith in me gives me confidence. It is dedicated to my husband Jonathan Cohn, whose love, irrepressible enthusiasm for my work, intellectual companionship, and delicious meals helped propel me through graduate school.

It is also dedicated to Jim Montie, whose commitment to prostate cancer patients has been an inspiration, and whose mentorship and uncanny ability to see what I was capable of, even before I could see it, has lit the road on which I am now traveling.

Finally, this dissertation is dedicated to all the patients who gave me the privilege of entering into their lives and who taught me everything I know.

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CHAPTER I

AN OVERVIEW OF THE DISSERTATION RESEARCH

The dissertation comprises five chapters organized in a multiple manuscript format. Three manuscript chapters follow an Abstract; these chapters are designed to conform to a format suitable for submission to a peer-reviewed journal. The Integration of Findings chapter summarizes the research findings.

Chapter I introduces the key concepts relevant to couples' sexual recovery after prostate cancer surgery and provides a review of the research literature on the sexual side-effects of prostate cancer, men's experience, partners' response, and the effect of men's sexual problems on couples. The introductory chapter identifies the gap in the research literature and serves to frame the research questions motivating the dissertation research. The author describes the research's data collection, which includes two waves of interview and survey data available from a previous study on barriers to couples' sexual recovery after surgery for prostate cancer, and a third wave of data collection from the same sample during the dissertation phase. The author proposes the rationale for using mixed methodology in the dissertation research and explains the significance of the topic studied. A preliminary theoretical model that has guided the dissertation research is presented.

Chapter II, entitled "Couples' Sexual Recovery After Surgery for Prostate Cancer: Shared Experiences," describes the findings from a study which used pre- and post-operative interviews with 20 couples to understand couples' experiential perspectives on the anticipation of and coping with the sexual side-effects of prostate cancer surgery. In this study, the author used existing interview data from a previous study of barriers to couples' sexual recovery after surgery for prostate cancer. Using the analytic induction method, she re-analyzed the interviews

qualitatively according to the dissertation research questions. A revised version of the preliminary model summarizes the study findings. Clinical implications of the findings, as well as suggested next-steps in research, conclude the chapter.

In Chapter III, entitled "The Role of the Partner in Couples' Sexual Recovery After Surgery for Prostate Cancer", the author presents findings about the role of the partner in the man's recovery of erectile function and the couple's recovery of their sexual relationship from both the patient's and partner's points of view. New interview data were collected during the dissertation phase, this time from men and partners separately, to ensure participants of the confidentiality of their particular perspective. The interviews were conducted and analyzed qualitatively using Grounded Theory. The findings extend current knowledge about partners' roles in the couple's sexual recovery and point to specific partners' needs that have been identified to date. The chapter concludes with a description of the relevance of the findings to clinical practice and poses research questions that stem from the findings.

The third study, reported in Chapter IV and entitled "Couples' Trajectory During the First Year After Prostate Cancer Surgery: Change in Sexual Function, Sexual Satisfaction, and Dyadic Adjustment", reviews quantitative studies describing the impact of men's erectile dysfunction on couples after surgery for prostate cancer. It presents the research questions that guide this study, as derived from the gap in the literature. Two waves of survey data from the pre- and post-operative periods of participants in the previous study on barriers to couples' sexual recovery after prostate cancer surgery are used for this study's analyses. A third phase of data collection was initiated during the dissertation phase. With questionnaire data from three time points, i.e., pre-operative, post-operative, and approximately 18 months after surgery, trajectories are presented of men's erectile function, women's sexual function, men's and women's sexual

satisfaction, and couples' dyadic adjustment. Multilevel analysis is used to identify statistically significant change in these functional variables over the three time points in an attempt to identify potential predictors for the change. Given the significant limitation of small sample size, the study findings are used to triangulate those of the qualitative analyses of the interviews, described in the previous two chapters. Potential implications for social work practice are discussed.

Chapter V, titled "Integration of Findings," combines the qualitative and quantitative findings into a coherent representation of the experience of couples' sexual recovery after prostate cancer surgery. It relates the findings of the dissertation research to the extant literature and revises the preliminary model of couples' sexual recovery based on those findings. The author comments on the significance of the findings and describes potential clinical implications for social work practice. She suggests that the dissertation research can be considered a pilot study and the findings exploratory in nature. She also discusses the distinction between transferability and generalizability of findings to the population of prostate cancer survivors and their partners, with a suggestion for further, confirmatory research necessary to validate the derived model of couples' sexual recovery after prostate cancer surgery.

Introduction

During the last five decades, early detection and successful treatment of many cancers has extended patient survival for years, and even decades. In 2012, an estimated 241,740 men would be diagnosed with prostate cancer (Siegel, Naishadham, & Jemal, 2012). Ninety-eight percent of these men would be expected to survive five or more years. This dissertation research will focus on men who undergo definitive surgical treatment (treatment whose goal is to totally

eradicate the cancer) for localized prostate cancer with the expectation of long-term survival for the majority.

Long-term survival means the absence of cancer, but the victory over cancer is not without its price. Harsh and definitive surgical treatments, such as surgery or radiation therapy, can result in short- and long-term side-effects whose nature and responsiveness to interventions are not yet fully understood. In response to the recognition that long-term survivors may experience reduced quality of life as a result of cancer and cancer treatment, the Institute of Medicine published a recommendation that psycho-social support be available to cancer survivors (Adler & Page, 2008). Sexuality, while addressed in a limited way, is recognized as one of the aspects of survivors' lives that require assessment and treatment.

The sexual side-effects and recovery process after surgery for prostate cancer have shown themselves to be challenging to men, partners, and their relationships. The available research literature demonstrates that men experience erectile dysfunction, that they are unhappy with their level of recovery of erectile function, that partners experience distress, and that couples do not work well together to recover their intimate lives. Although sexual problems of prostate cancer survivors and their partners have been studied to some degree and some interventions do exist, couples' experiences of sexual recovery are not well understood. There is no existing model that integrates the dynamics of the biopsychosocial aspects of couples' sexual recovery. There is also no model of the recovery process through which couples attempt to re-establish their intimate lives after prostate cancer surgery. Without a theoretical model, interventions are fragmented and often meet with limited success. At this time, we do not even know for certain what the end points in the recovery process are and as such, when and what support couples need.

This study begins with a definition of sexuality as a biopsychosocial experience; it seeks to understand couples' anticipation of and response to the losses within their sexual relationship that are a consequence of the loss of men's erectile function after surgery. Further, the study aims to elucidate the process through which couples cope and recover, or perhaps do not recover, sexual intimacy. The study is longitudinal, i.e., it begins with an effort to identify couples' pre-existing, long-term 'couple' strengths that facilitate recovery, as well as describing hindrances that impede sexual recovery and may have to be overcome in the recovery process. The study places couples' sexual recovery in the theoretical framework of grief theory (Parkes, 1971, 1998) and seeks to identify characteristics that lead to a successful recovery. Finally, the study hopes to contribute to the emerging research on post-cancer thriving, which comes from the literature on young adult survivors of childhood cancer (Parry & Chesler, 2005).

Definitions

The consensus definition of "sexual function" is based on Helen Singer Kaplan's model of the human sexual response. This model emphasizes "a temporal sequencing and coordination of several phases, including sexual desire (libido), arousal (excitement), orgasm and satisfaction" (Basson et al., 2000). Sexual function is considered to be a stable trait with endurance over time (Wilmoth & Tingle, 2001). It can be thought of as the physiologic or biologic aspect of sexuality.

"Sexual dysfunction" is defined in both the International Classification of Diseases, 9th Revision (ICD-9) and the Diagnostic Statistical Manual, 4th Edition (Text Revision) (DSMIV) as "the various ways in which an individual is unable to participate in a sexual relationship as he or she would wish", including lack or loss of sexual desire, sexual aversion disorder, failure of genital response (erectile dysfunction, rapid ejaculation, poor vaginal lubrication), orgasmic

dysfunction, nonorganic vaginismus, nonorganic dyspareunia, and excessive sexual drive (Vroege, Gijs, & Hengeveld, 1998).

"Sexuality" is an overarching concept that is a part of our biological, psychological, and social imprint. Former Surgeon General, David Satcher (2001) described sexuality as "an integral part of human life . . . (which). . . can foster intimacy and bonding as well as shared pleasure in our relationships. . . ." (Satcher, 2001).

"Sexual health" is defined by the World Health Organization (WHO) (2002) as "a state of physical, emotional, mental and social well-being in relation to sexuality." WHO recognizes that sexual health can be affected by chronic and acute illness and may require intervention at an individual, family, and community level throughout the lifespan (WHO, 2002).

For the purpose of this research, the definition of "sexuality" will combine the above definitions and integrate sexual function with the personal and partnered experience of sex because such a definition best reflects the biopsychosocial aspects of the way in which people live their sexual lives.

"Recovery" is a concept best known in the fields of mental health and substance abuse. It is defined as "a process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential" (Substance Abuse and Mental Health Services Administration, SAMHSA, 2011). This is a definition that is easily applied to couples' sexual recovery because health, wellness, self-directed life or self-efficacy, and full potential are also the goals that couples pursue as they try to rebuild their intimate lives after prostate cancer surgery. It is important to note that recovery does not necessarily imply return to baseline.

Review of the Literature

Prostate cancer is a highly prevalent disease with one in six men having a chance of being diagnosed with it in his lifetime. Upward of 90% of men survive for 15 or more years (Siegel et al., 2012). Men, while well adapted otherwise, continue to be bothered by sexual losses after surgical treatment (Hollenbeck, Dunn, Wei, Sandler, & Sanda, 2004; Sanda et al., 2008; Wei et al., 2002). The primary sexual loss is the loss of erectile function (Matthew et al., 2005; Schover et al., 2002a). Men speak of feeling less manly, of avoiding relating to women, of grief, and of the loss of quality of life (Bokhour, Clark, Inui, Silliman, & Talcott, 2001; Hedestig, Sandman, Tomic, & Widmark, 2005; Katz, 2005).

Descriptive studies suggest that men's sexual difficulties affect partners, too, and have an impact on the couple relationship. Partners evidence a high level of distress (Couper et al., 2006a). Differently timed experience of distress between partners can lead to marital dissatisfaction (Couper et al., 2006b). Couples do not communicate effectively about their sexual problems (Ptacek, Pierce, Ptacek, & Nogel, 1999) and do not seek help for sexual recovery (Miller et al., 2006; Schover et al., 2004). Little is known about how couples process sexual changes due to prostatectomy.

The majority of intervention research in prostate cancer has focused on promoting the recovery of physiologic (erectile) function. Penile rehabilitation, an emerging early intervention strategy, is designed to maximize erectile recovery (Mazzola & Mulhall, 2011; Mulhall, Bella, Briganti, McCullough, & Brock, 2010; Raina, Pahlajani, Agarwal, & Zippe, 2007). Medical aids such as phosphodiesterase-5 inhibitors, penile suppositories and penile injections of alprostadil or prostaglandin E, and non-medical erectile aids such as vacuum erectile devices have shown efficacy in aiding erectile function (Incrocci, Slagter, Slob, & Hop, 2006; Montorsi et al., 2010;

Raina et al., 2005). However, men try medical aids infrequently and discontinue their use early despite unhappiness with sexual problems (Miller, et al., 2006).

Most studies that focus on psychosocial interventions do not address sexual issues directly. They have emphasized: (a) psycho-education (Manne, Babb, Pinover, Horwitz, & Ebbert, 2004); (b) combined psycho-education and offer of erectile aids (Canada, Neese, Sui, & Schover, 2005; Davison, Elliott, Ekland, Griffin, & Wiens, 2005; Titta, Tavolini, Moro, Cisternino, & Bassi, 2006); and (c) relationship enhancement (Manne et al., 2011). A review of interventions to help couples with sexual problems secondary to prostate cancer treatments found that psychosocial interventions primarily promoted psychological adjustment, with sexual recovery as a secondary goal (Latini, Hart, Coon, & Knight, 2009). The authors propose the need for a biopsychosocial model of recovery responsive to survivors' sexual concerns.

Acknowledgement of the biopsychosocial nature of the effect of cancer on sexuality has begun in the past few years. Tierney (2008) described the three dimensions of sexuality affected by cancer and its treatment: physiology, psychology, and relationship. She suggested that these three dimensions are interdependent and interactive and must be addressed together in interventions. Similarly, Bober and colleagues (2012), in a review of current knowledge about cancer and sexuality, described the impact of the illness upon the same three dimensions of sexuality and added the dimensions of ethnicity, religion, and culture as well. Wittmann (2011) proposed a model of the process of recovery through grief and mourning; however, this model has not been studied empirically. A well designed, recently published study comparing online and in-person couple intervention to promote sexual recovery after prostate cancer treatment does include biopsychosocial components of sexuality and additionally addresses menopause of

the female partner (Schover et al., 2011). However, the study does not address the process of recovery as such.

Gap in the Literature

Given the fact that prostate cancer is diagnosed in mid- or later life, it is surprising that certain contextual and psychological issues are not included as significant contributors to the post-prostatectomy couples' experience with altered sexuality. In fact they are neglected. Such contributors include: (a) developmental changes that have an impact on sexual physiology and function in midlife, including menopause and pre-operative erectile dysfunction; (b) couples' emotional response, including grief and mourning, to the loss of familiar sexual relationship after menopause and prostatectomy; and (c) couples' construction of the role of sexuality in their relationship and its reconstruction based on the female partner's menopause and the man's altered sexual function post-prostatectomy. These contextual and psychological issues potentially have an impact on couples' long-term coping with the sexual changes after surgery for prostate cancer.

Men's aging-related erectile dysfunction and female partners' post-menopausal sexuality.

We do not know how couples cope with developmental changes in their sexual relationship. Despite erectile dysfunction due to aging or co-morbidities, most men preserve sexual desire and are motivated to continue to be sexually active. Loss of estrogen lowers women's desire for sexual activity and creates difficulties in lubrication. A modified approach to sexuality is needed for the female partner to stay engaged sexually (Basson, 2004). While men have the ability to use medications to maintain erectile function, it is unclear how couples understand post-menopausal women's sexual potential: they may give up on sex prematurely.

The role of grief and mourning.

Age-related sexual losses usher in emotional responses, including grief and mourning, and a need to construct a new sexual relationship. The emotional adjustment of couples to developmental sexual changes when the man has prostate cancer and the level of confidence that couples have regarding solving sexual problems have not been examined empirically. The author's clinical experience in working with couples after prostate cancer surgery suggests that, while female partners can be sexually re-engaged and couples can develop greater intimacy as they work on retaining their sexual relationship, both female partners and men can experience feelings of loss of former sexuality. Extant interventions designed to promote sexual recovery have not addressed couples' loss and grief, nor their motivation and ability to maintain the viability of the female partner's post-menopausal sexuality. If interventions are to address the complex, dynamic needs of recovering couples, a model of sexual recovery must include these aspects of the couple's sexual relationship.

The role of the partner.

Studies suggest that the partner has a critical role in the sexual recovery of the prostate cancer survivor (Soloway, Soloway, Kim, & Kava, 2005; Wootten et al., 2007). However, survivors' and partners' own attitudes and feelings about the partner's role have not been examined. If couples are to be helped in their sexual recovery, the partner's role must be better understood. Partners may need support, particularly if post-menopausal female partners have their own, unaddressed sexual concerns during the men's sexual recovery after prostate cancer surgery.

Couples' construction of the role of sexuality in their relationship.

There is a need for research that recognizes that couples' sexual recovery is interactional by nature, and that understanding the perceptions from the patient's and partner's points of view are crucial. The interactional nature of couple emotional intimacy has been proposed to some extent in the breast cancer recovery research literature. Manne and colleagues (2004) proposed that couple relationship (i.e., emotional) intimacy could enhance or harm couples' recovery after cancer treatment (Manne et al., 2004). However, an intervention based on this model, with couples in which the man had prostate cancer, did not address the physiologic and psychological issues in prostate cancer and did not have a discernible effect on couples' emotional intimacy and disclosure (Manne et al., 2011). The intervention was primarily helpful to couples having fewer psychological resources. We currently do not know how men and their partners interact in relation to the losses inherent in the sexual changes of middle age, how they reconstruct sexuality after these developmental changes, and the value they put on recovering sexual intimacy after prostate cancer surgery.

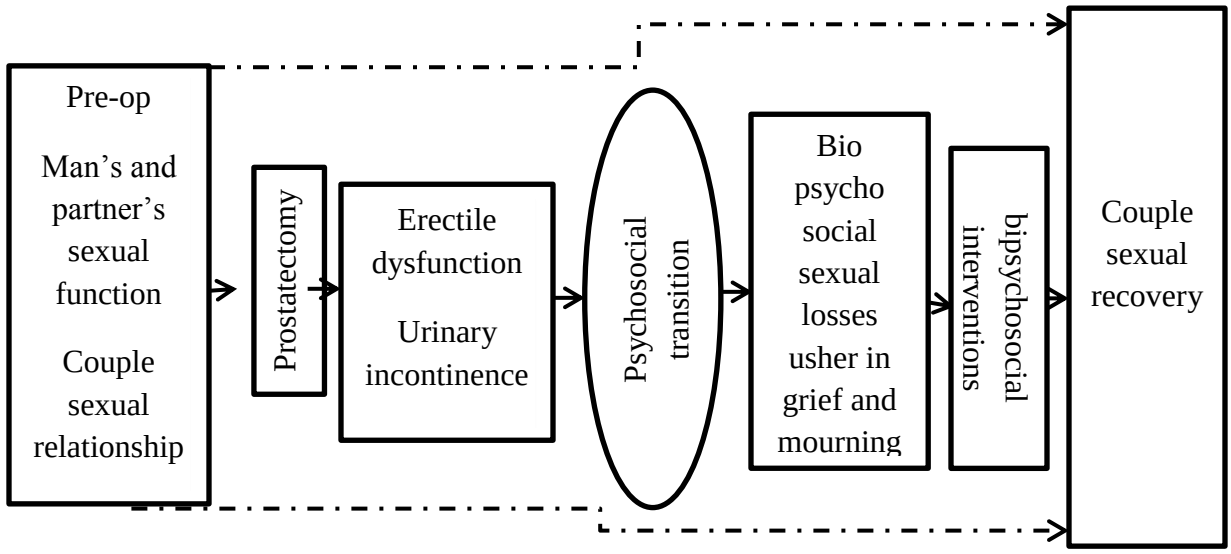
Preliminary Model of Couples' Sexual Recovery

In order to anticipate a model of sexual recovery after prostate cancer surgery, the author has developed a preliminary model. It adopts the biopsychosocial theory of sexuality that resonates with a biopsychosocial theory of social work (Simpson, Williams, & Segall, 2007). The model conceptualizes the sexual side-effect of surgery for prostate cancer as a sexual loss, which parallels a schema of sexual loss and altered sexuality developed theoretically in breast cancer research (Wilmoth, 2001).

In this preliminary model, the diagnosis of prostate cancer and the treatment-related side-effects usher in a 'psycho-social transition' whereby a life-altering event begins the process of adaptation and recovery. Psycho-social transition, a construct first described in the sociology and

grief literature, is a moment in time when assumptions about the world are unalterably changed by a new experience. The transition requires that the person or couple give up an emotional attachment to the way things were in order to begin the process of acceptance of the new situation and the development of new functioning in that context (Parkes, 1971). By definition, a psycho-social transition involves loss. In order to be overcome, a loss must be grieved and mourned (Worden, 1996). In this model of sexual recovery after surgery for prostate cancer, the diagnosis of prostate cancer forces the couple to recognize that the man's sexual function and the couple's sexual relationship will be irrevocably altered by prostate cancer surgery. The change represents loss and recovery begins when the couple is able to grieve and mourn the loss of the man's sexual function and the changes in the sexual relationship (Figure 1.1). Pre-operative sexual and couple functioning mediate the couple's sexual recovery; physiologic and psychosocial interventions interact with the couple function and influence each other's effect on the sexual recovery.

Figure 1.1 Preliminary Model of Couples' Sexual Recovery After Prostate Cancer Surgery



Because it is impossible to anticipate how an individual man will recover his erectile function, the loss is ambiguous. Boss (1999), in her book on ambiguous loss, illuminates the special difficulty which ambiguous loss poses, i.e., uncertainty, expressed as a combination of hopeful longing and deep fear.

Overarching Research Questions

The dissertation research attempts to answer the following research questions: How do couples anticipate sexual recovery after prostate cancer surgery? How do they work through the tasks of recovery as a couple? How do they describe their strengths and the challenges in the process? What is the role of the partner in the sexual recovery of the couple as viewed by both the men and the partners? As the man's sexual function changes, is the couple's dyadic adjustment/satisfaction affected? What is the trajectory of their recovery as measured by sexual function, sexual satisfaction, and dyadic satisfaction measures?

Methodology

The dissertation research is exploratory and uses a mixed-methods longitudinal design. As so little is known about how couples recover sexual intimacy after surgery for prostate cancer, the goal of the research was to discover concepts that could be used to shape a model of sexual recovery. Interviews with couples before and after surgery provided data for two of the included studies and these data were analyzed qualitatively. In addition, validated measures were analyzed quantitatively in the third study to assess functional outcomes relevant to the sexual recovery process, i.e., sexual function and sexual satisfaction for both members of the couple, as well as dyadic adjustment/satisfaction.

The first dissertation study used data from a previous mixed-method study on barriers to couples' sexual recovery, which was in progress at the University of Michigan ('Barriers' study).

In the ‘Barriers’ study, couples were included if the man had prostate cancer and a partner, if both were willing and able to sign Informed Consent, and if both were not disqualified because of cognitive or language comprehension issues. These couples were interviewed using semi-structured interview schedules at two time points (before the surgery and three months after the surgery). Transcripts from both sets of interviews were available for the dissertation research. The interview guide questions about sexual recovery were open-ended, and the data collected could be re-analyzed in response to the research questions of the dissertation research.

During the dissertation period, a new wave of data collection was initiated after the University of Michigan Institutional Review Board approved an amendment to the protocol Participants from the previous study were asked to consent to filling out the same surveys they had filled out during the previous study. They were also asked to consent to being interviewed regarding the role of the partner in the sexual recovery. The data from these interviews were analyzed for the second study.

Validated measures assessments of men’s and partners’ sexual function, sexual satisfaction, and dyadic satisfaction were obtained during the pre- and post-operative time points of the ‘Barriers’ study, as well as during the dissertation phase, totaling three time points in all. Demographic data from the first time point were used for this study. These data were analyzed for the third dissertation study.

One hundred and eight couples were eligible and 30 couples were enrolled in the study (38% response rate). Thirty-one patients did not return calls. Reasons given by those who declined participation included partner not interested (10), patient not interested (8), distance (9), no time (5), choice of radiation treatment (2), and miscellaneous others (13). Prior to surgery,

one couple dropped out because of the close proximity of the scheduled research interview to surgery. This reduced the pre-operative sample to 29.

After surgery, 20 couples were available for the study. Reasons given by couples for dropping out during the post-operative phase included a choice of radiation treatment rather than surgery (3), absence for more than five months (1), and lack of time because of the man's return to work or the couple's return to retirement activities (5).

These couples did not anticipate the third wave of data collection, but 10 men and nine partners were willing to participate in the study described in Chapter III. Sixteen men and partners returned surveys. The reasons given by the couples for non-participation were death of the patient (1), and the couples' feeling that they were now at a distance from the surgery and did not wish to prioritize participation in the study (4). One couple returned to the study for the third time point although they did not participate during the post-operative phase. The survey data from all three time points were used in the study described in Chapter IV.

The findings from all three studies were integrated in order to develop a model of couples' sexual recovery after surgery for prostate cancer. The qualitative and quantitative methodologies complemented each other and triangulated each other's findings. The findings of this research will be considered transferable, but not generalizable to the population of prostate cancer survivors and their partners.

Significance

This research on couples' sexual recovery after surgery for prostate cancer is innovative in that, for the first time, it gives voice to the couples who are actually going through the experience of sexual recovery after surgery for prostate cancer. It is also innovative because it explores the couples' experience of sexual recovery from *before* the surgery, thus providing new

information about couples' anticipation of sexual recovery, which has not been available until now. Finally, the longitudinal nature of the study and its use of mixed methodology enables the researcher to trace measurable aspects of the couples' relationship over time to provide a prospective, real-time sense of the impact of prostate cancer surgery on couples' functioning in several domains – sexual function, sexual satisfaction, and dyadic satisfaction.

The long-term goal of this research is to build a model that can be confirmed through hypothesis-driven studies with larger samples. If confirmed, the model can serve as a theoretical platform for the development of interventions to empower couples, offering them a biopsychosocial roadmap to sexual recovery with which they can identify and which they can embrace. Although the recovery of a sexual relationship after other cancers may have unique elements, it is likely that this model could be adapted for other cancer survivor populations to build interventions for couples who want to work on recovering their intimate lives after treatment.

CHAPTER II

COUPLES SEXUAL RECOVERY AFTER SURGERY FOR PROSTATE CANCER: SHARED EXPERIENCES

Abstract

Background: Couples' expectations and coping strategies that lead to the recovery of sexual intimacy after prostatectomy are not well understood. This study sought to understand couples' common experiences of sexual recovery after surgery for prostate cancer and to empirically assess a proposed model of couples' sexual recovery. Method: Audiotaped and transcribed semi-structured interviews with 20 couples before and three months after surgery were available from a previous study. Using the qualitative methodology of Analytic Induction and NVivo 9 software, interview data were systematically examined to test a preliminary theoretical model. Results: Ninety-five percent of couples were sexually active before surgery. They came to surgery with worry about cancer, and with anticipatory grief regarding the expected loss of urinary and sexual function. All said sexual recovery was important to them. Based on appraisal of their couple strengths, motivation to work on sexual recovery and on their surgeon's competence, couples had high expectations for erectile recovery, yet expressed dislike of erectile aids. After surgery, most men required erectogenic assistance. Nearly 50% of couples were not sexually active. They experienced feelings associated with loss and grief and found sexual recovery arduous. Men felt less masculine. Partners adopted a supportive role although some were ambivalent about their sexual role. Positive coping included good communication, ongoing sexual activity, partner's positive attitude to sex regardless of menopause, and acceptance of lower sexual function. Barriers to recovery included dislike of erectile aids, complicated by grief; partner's disinterest in sex,

and relationship problems. Conclusions: The study confirmed and extended the preliminary model of sexual recovery after surgery for prostate cancer.

Background

Couples' recovery of sexual intimacy after prostate cancer surgery has not been studied empirically despite the well-known fact that men's erectile dysfunction, a side-effect of prostate cancer surgery, has an impact on men, partners, and the couple relationship. This study was designed to explore this gap in the research in order to provide a model for the development of interventions addressed to couples.

Prostate cancer is a highly prevalent disease, with one in six men having a chance of being diagnosed with it in his lifetime. Upward of 90% of men treated definitively for localized prostate cancer survive for 15 or more years (Siegel et al., 2012). Men's difficulties with the sexual side-effects of prostate cancer treatment have been well described (Benson, Serefoglu, & Hellstrom, 2012; Gomella, 2007; Hollenbeck, Dunn, Wei, Sandler, & Sanda, 2004; Incrocci, 2006). Erectile dysfunction, the primary side-effect, is most dramatically experienced by men immediately after surgical treatment and is slow to remit. For most men, erections do not return to their baseline function; for some, erectile dysfunction becomes a way of life (Schover et al., 2002). Healing of the damaged nerves responsible for erectile function is considered to be complete or nearly complete after two years, and men are told that the degree of erectile function attained at two years after surgical treatment is likely to be the extent of their erectile recovery (Miller et al., 2005).

Longitudinal studies of the quality of life in prostate cancer have used validated measures to describe the trajectory of erectile function recovery for up to five years (Penson et al., 2005, 2008; Potosky et al., 2004; Wei et al., 2002). In some measures, one item assesses "bother",

which quantifies the degree to which men are upset by the loss of erectile function. A study by Sanda and colleagues (2008) indicated that up to 50% of men were bothered or very bothered by the loss of erectile function two years after surgery (Sanda et al., 2008). The inclusion of the "bother" in quality of life measures, such as the Expanded Prostate Index Composite (Wei et al., 2000), to ascertain men's psychological reaction to erectile dysfunction is a useful first step toward identifying the man's psychological response as an important aspect of the sexual recovery experience. As a one-item measure, however, it fails to elucidate either the meaning of loss of erectile function to men or the effect of that loss on men's sexual relationships with their partners.

Over time, qualitative studies designed to further understanding of men's experience gave voice to men's concerns. The theme of changed sexual bodies and sexual losses emerged consistently across the studies. Men's sorrow about their sexual relationships with partners surfaced as a concern in some studies (Bokhour, Clark, Inui, Silliman, & Talcott, 2001; Bokhour, Powel, & Clark, 2007; Hedestig, Sandman, Tomic, & Widmark, 2005; Katz, 2005, 2007; Navon & Morag, 2003).

Research on couples has been cross-sectional in nature; it has focused primarily on couples' stress and coping (Northouse, Mood, Montie, et al., 2007; Northouse, Mood, Schafenacker, et al., 2007; Ptacek, Pierce, & Ptacek, 2007), communication (Boehmer & Clark, 2001; Manne, S., 1999; Manne, S. et al., 2004; Manne, S. et al., 2008), or marital satisfaction (Couper et al., 2006) after prostate cancer treatment. However, these studies did not focus on sexual issues per se. Many studies have used a measure of dyadic satisfaction. The Dyadic Adjustment Scale (DAS) (Sharpley & Cross, 1982) has only one item that asks about agreement

or disagreement about sex and, therefore, cannot be considered to be a satisfactory assessment of the couple's sexual relationship.

A few studies have attempted to address sexuality both pre- and post-operatively in prostate cancer couples. Soloway and colleagues (2005) examined sexual, psychological, and dyadic functioning of the prostate cancer 'couple' pre-operatively. The researchers found that partners were more sexually satisfied in the relationship and endorsed higher sexual function than patients. Partners also estimated men's sexual function to be lower than the men estimated it themselves. Patients were not asked to rate partners' sexual function (Soloway, Soloway, Kim, & Kava, 2005). These sexual function findings are surprising because many partners of prostate cancer patients are post-menopausal and have consequent sexual challenges. The study does not include a discussion of the possibility that men's high level of sexual dysfunction (78%) is due to the negative effect of the cancer diagnosis on sexual function, not an uncommon finding in clinical practice. A study by Neese and colleagues (2003) looked at motivators and barriers to help-seeking for sexual problems in a sample of men and partners of those men who consented to have partners interviewed. They found that partners did not encourage men to seek help for sexual problems and assumed that sex was over after prostatectomy (Neese, Schover, Klein, Zippe, & Kupelian, 2003). The study has limitations due to interviewing men and partners separately rather than as couples, and to developing survey questions about motivators and barriers to help-seeking for sexual problems without input from patients or partners. Garos and colleagues (2007) used validated measures to study the effect of partners' dyadic satisfaction, sexual self-esteem, sexual depression (feeling disappointed and discouraged about one's sex life), sexual preoccupation, life satisfaction, and satisfaction with mental health services on men. They found that partners' depression and sexual depression were predictive of men's sexual

satisfaction (Garos, Kluck, & Aronoff, 2007). The study design did not include assessing the effect of men's factors on female sexual satisfaction, without which there is a danger of "blaming the partner" for the difficulty with adjustment without accounting for the mutual effect that the man and the partner have on each other. Finally, two studies described couples' sexual recovery through surveying the men after prostate cancer treatment. Wootten and colleagues (2007) found that men's use of emotion-based coping to solve sexual problems was negatively related to marital satisfaction, and positively related to mood disturbance (Wootten et al., 2007). The authors do not account for the possibility that the men may have used emotion-based problem-solving because they were grieving sexual losses. Navon and Morag (2003) reported that after treatment for advanced prostate cancer, men not only lost sexual function and libido, but also general vitality, which resulted in their giving up what they saw as masculine family roles such as management of finances (Navon & Morag, 2003).

An individual experiences sexuality in three domains or dimensions: physiologically, emotionally or psychologically, and in the relationship with a partner. The extant research is gradually reflecting the recognition that after prostate cancer treatment, men are affected in all three domains of sexuality: the body, the psychological response, and the sexual relationship. The biopsychosocial nature of sexuality has been recognized both by the Surgeon General, David Satcher (Satcher, 2001) and by the World Health Organization (WHO, 2002). Gradually, biopsychosocial models of the effect of cancer on the three domains of sexuality are emerging. Tierney (2008) described the effect of cancer and its treatment on the physiology of sexual function, the emergence of distress, feelings about changes in body image and uncertainty in response to those changes, and distress in the relationship that ensues. More recently, Bober & Sanches-Varela (2012) proposed a biopsychosocial model of the effect of cancer on sexuality

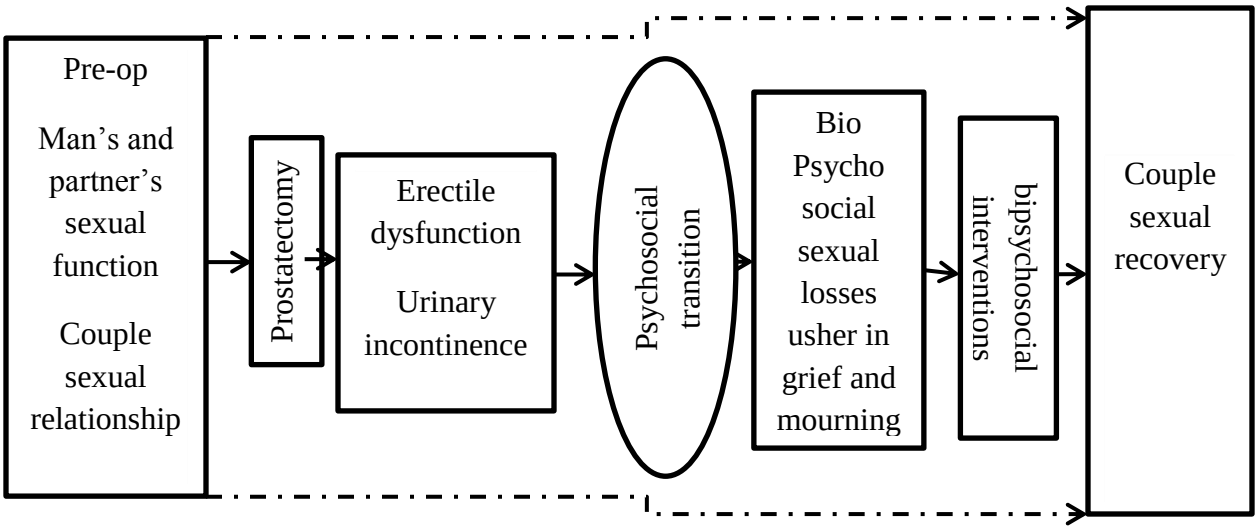
that includes cultural values, religious beliefs, and social norms. However, these models are not based on empirical evidence. In addition, none of the models have a process variable that would elucidate how couples move from the effects of cancer and its treatment on sexuality toward the recovery of sexual intimacy after prostate cancer. The role of grief and mourning after prostate cancer has been offered theoretically, postulating that losses engendered by prostate cancer treatment must be grieved and mourned before or while sexual recovery begins. An inability to grieve can interfere with sexual recovery; suppression of feelings about any losses may suppress libido as well (Wittmann, Foley, & Balon, 2011). A definition of what couples might consider to constitute a sexual recovery is not specified in the research literature.

Preliminary Model of Couples' Sexual Recovery After Surgery for Prostate Cancer

A preliminary model of couples' sexual recovery incorporates the biopsychosocial nature of sexuality, as well as grief and mourning as aspects of the recovery process (Figure 2.1). Surgery for prostate cancer is conceptualized as a 'psychosocial transition' (Parkes, 1971), a life altering event that creates loss (of sexual function and familiar sexuality) and ushers in grief and mourning as a way of processing the changes and of recovering sexual intimacy by developing a new sexual intimacy.

The concept of "recovery" is best known in the fields of mental health and substance abuse. It is defined as "a process of change through which individuals improve their health and wellness, live a self-directed life and strive to reach their full potential" (Substance Abuse and Mental Health Services Administration, SAMHSA, 2011). This definition is easily applied to couples' sexual recovery; health, wellness, self-directed life/self-efficacy, and full potential to the extent possible given sexual losses, are also goals that couples pursue as they try to rebuild

Figure 2.1 Preliminary Model of Couples' Sexual Recovery After Prostate Cancer Treatment



their intimate lives after prostate cancer surgery. It is important to note that recovery does not necessarily imply return to baseline. Rather, recovery includes acceptance of lower sexual function, use of aids to function sexually if needed, and sexuality not focused on penetrative sex only. It is described by Reese and colleagues (2010) as more 'flexible coping' with sexual concerns (Reese, Keefe, Somers, & Abernethy, 2010).

The aim of this study was to test this model by asking couples about the way in which the physiologic changes/losses of familiar sexual function and sexual relationship (bio) would be experienced by the man and partner psychologically (psycho) and result in the couple's working on a new sexual relationship (social). The study was longitudinal in nature; it traced the process of couples' sexual recovery. Although some concepts, such as the role of menopausal changes in heterosexual partners and men's overly optimistic expectations, have been seen as possibly influential (Shindel, 2005; Symon, 2006; Wittmann, 2011), the goal of this study was to learn whether couples' descriptions of their recovery would confirm these concepts in a 'couple'

context empirically. In addition, the study sought to discover new concepts regarding the challenges of sexual recovery after surgery for prostate cancer, based on the expertise of those who were actually living the experience in real time.

The following research questions motivated this study:

1. How do couples anticipate, prior to surgery, their sexual recovery from the man's loss of erectile function after surgery for prostate cancer?
2. How do couples describe their experience and cope with sexual changes related to surgery side-effects three months after surgery in the biopsychosocial domains of sexuality?
3. Are grief and mourning an aspect of the psychological experience?

The nature of the study was exploratory, with an interest in seeking empirical support for the previously discussed model. A formal hypothesis is not stated; rather, the model represents an exploratory hypothesis that is iteratively tested in the methodology used for this study.

Method

The study was based on a re-analysis of interviews collected for a previous study focused on barriers to couples' sexual recovery (Wittmann et al., 2012). Semi-structured interviews queried couples about anticipation and experience of sexual recovery associated with surgical treatment of prostate cancer. Interviews were conducted pre-operatively and three months post-operatively. The aim of the original study was to discover pre- and post-operative barriers to couples' sexual recovery. The current study examined the same interview data with a focus on the couples' expectations for sexual recovery pre-operatively and their actual experience after surgery, with a special interest in the role of grief and mourning in the recovery.

Study Sample

In the previous study, a purposive sample of thirty couples was recruited through a criterion sampling strategy (the criterion being the man's diagnosis with prostate cancer) in a large Midwestern academic medical center between January and August 2010. All couples participated in the same clinical program offered to men treated with surgery for prostate cancer. The couples signed an informed consent, and all procedures were reviewed and approved by the university's institutional review board.

Procedure

Pre- and post-operative data from twenty heterosexual couples were available for the data analysis. Couples had been interviewed at the medical center's Cancer Center. Interviews lasted an hour on average and were carried out by the author. They were digitally recorded and transcribed. Some examples of questions asked of couples were:

> As you are getting ready for surgery, can you describe your thoughts about it and any concerns?
>
> Are you aware that you will be experiencing side-effects that affect urinary control and the ability to have erections? What are your thoughts about those side-effects?
>
> What do you expect will happen to you sexually?
>
> Do you think that the side-effects affect just the man or both of you as a couple?
>
> Can you tell me about your experience of recovering your sexual relationship since the surgery?
>
> Where are you from the point of view of bladder control? Have urinary problems interfered with your efforts to get your sex life back?
>
> How is the experiment going – are you able to try new things sexually? What have you tried?

Demographic data were surveyed with an eleven-item questionnaire that included questions about race/ethnicity, education level, income and length of partnership. Comorbidities

were ascertained with the use of the Charlson Comorbidities Index (Charlson, Pompei, Ales, & McKenzie, 1987) which predicts the risk of death from comorbid conditions and is widely used in the research literature.

Data Analysis

Analytic Induction (Robinson, 1951; Znaniecki, 1934) was used as a method of data analysis. The Analytic Induction method builds theory from qualitative data. It rests on the examination of an explanatory hypothesis, while checking each case for conformity to the hypothesis. Any negative or deviant case can lead to potential rejection or alteration of the hypothesis until a sufficient number of examined cases leads to the generation of typical characteristics of a phenomenon, and hence, a theory that explains the phenomenon. This research examined a preliminary biopsychosocial model of couples' sexual recovery after surgery for prostate cancer, with grief as a process variable. Interviews from the 'Barriers' study were then analyzed, using the research questions of the current study. Initial open codes stemmed from identifying word groupings that represented concepts reflective of couples' experience of sexual recovery after prostate cancer surgery. In the course of the analytic process, each case was re-examined in the light of previous findings. The next step in the analysis was grouping related codes into categories, based on the preliminary model. For example**,** when people spoke about no longer having erections or having sex rarely, these statements were coded as bio and social sexual losses, later categorized into overall sexual losses. The themes were then further categorized at a higher conceptual level to identify common experiences of sexual recovery. For example, expectations and worries were categorized as 'uncertainty'. Finally, the categories were organized into a narrative based on the biopsychosocial paradigm, with special reference to the role of loss and grief in couples' adaptation to loss of sexual function. The author remained open

to new categories or concepts beyond the study's theoretical orientation in order to discover cases that did not fit into the hypothesized model and to find potential new characteristics that could be equally significant, or perhaps even more significant, than the ones hypothesized. The model was then revised based on the findings. NVivo software (NVivo 9) was used to complete qualitative analysis.

Assurance of Data Quality

Several factors secured the trustworthiness of the data and the analysis process during the original study; these included the author's 5-year clinical experience (prolonged exposure), checking transcripts randomly for accuracy, memoing after each interview, keeping an audit trail throughout the 'Barriers' study, making reflexive statements throughout the project, and consensus of the analytic team. During the dissertation phase, quality of data was secured through regular consultation with the qualitative research mentor, keeping an audit trail throughout the project, memoing, and making reflexive statements throughout the project.

Results

Sample Characteristics

The demographic characteristics of the sample are described in Table 2.1. The mean age of the men was 60.2 (SD = 6.0). The mean age of partners was 57.6 (SD = 6.9). The couples had been partnered, on average, more than 30 years. Seventy percent of the men and 50% of partners were educated beyond high school. Mode family income was 90 K (30K-90K). The patients' characteristics reveal a very homogeneous sample in terms of ethnicity, education, and income. These couples were in long-term relationships although patients and partners recall the length differently as seen in the differences in mean scores.

Table 2.1 Sample Demographic Characteristics

Characteristic	N	%
Ethnicity		
White		
Patient	19	95
Partner	19	95
Hispanic		
Patient	0	0
Partner	1	4
Chinese American		
Patient	1	4
Partner	0	0
Completed education beyond HS		
Patient	14	70
Partner	10	50
	Mean	SD
Age at baseline		
Patient	60.2	6.0
Partner	57.6	6.9
Length of relationship (years)		
Patient	31.5	7.7
Partner	35.0	8.1
	Mode	Range
Income		
Patient and Partner	> $90,000	<$30,000-$90,000

Patients' clinical characteristics (Table 2.2) show a relatively healthy sample of patients, mostly with localized prostate cancer. Pathological findings revealed a more aggressive prostate cancer in two patients. Surgery for those two patients necessitated more damage to their

neurovascular bundles because of the extent of their cancer, auguring a less successful recovery of erections. All men in this sample could anticipate long-term survival.

Although they were not formally assessed regarding mental health and some participants were on antidepressants, none of them suffered from identifiable mental illness or abused substances. All were functioning sufficiently well psychologically to fulfill their roles in their

Table 2.2 Patients' Clinical Characteristics

Characteristic	n	%
Gleason Sum		
≤ 6	4	20
7	13	65
≥ 8	3	14
Clinical Stage		
T1c	17	85
T2a	2	10
T2b	1	0.5
Pathological Stage		
T2a	5	25
T2b	11	55
T3a	3	14
T3b	1	0.5
Nerve Sparing		
Bilateral	18	90
Partial	2	10
None	0	0
Charlson Co-morbidity Score (Median/Range)	0	0-4

jobs and in their relationships. The couples described themselves as coping well despite worry about the cancer and surgery.

Interview Findings

Couples' pre- and post-operative experiences are described below. They reflect and extend the framework of the preliminary model of couples' sexual recovery. It is important to note that the study baseline is the pre-operative, but post-diagnosis period. As a result, couples were already affected by the fact that the man was diagnosed with cancer; cancer concerns influenced their attitude to sexual recovery. After the surgery, cancer concerns were minimal, while preoccupation with the side-effects of surgery was much more in the forefront.

Characteristics of the pre-operative experience.

The themes that emerged were reflective of the couples' stage in the life cycle, of the many years that these couples had spent together, and of the confidence that most felt, in spite of the challenges and worries about this experience, that they would come out relatively intact. These themes can be described within the biopsychosocial paradigm. The themes are described in greater detail below and illustrative quotes from the couples are summarized in Table 2.3.

Bio: Already changed sexual function and relationships.

Although all but one couple (95%) were sexually active to some degree, frequency had decreased in the years prior to the diagnosis of prostate cancer, and 60% of couples reported that sex was not their highest priority. Seventy percent of men reported interest in sex, but declining erectile function. Menopause had led some female partners (50%) to be less interested in sex. These changes were due to aging and co-morbidities. Thirty percent of couples reported desire discrepancy.

Psycho: Worry and anticipatory grief, high expectations of sexual outcomes and ability to cope, dislike of sexual aids and recovery activities.

Table 2.3 Patients' and Partners' Statements in Anticipation of Surgery

	Patient	**Partner**
Bio		
Already changed sexual function and relationship	". . . I have difficulty maintaining an erection through the full sexual activity."	". . . dried up and no urges"
Psycho		
Worry and anticipatory grief	"I mean I think I have some feelings of grief in regard to, um, the sexual aspect because I think we have a good sexual like I think that it's an important part of our relationship or bonding . . . "	"I don't think , as much as I love or care for my husband, I'd never change his diapers and wipe his butt"
High expectations of sexual outcomes and of ability to cope	Patient: "I'm so comfortable with being here (in the medical center), . . . I am just very, very confident that when I walk out of here I'm going to be fine."	"I don't think of it as being a year, I think of it as being less than that cause I think of him as being a vibrant, healthy, normal person . . . "
	Patient: "It won't diminish me, erectile function doesn't define me."	
Dislike of sexual recovery aids and sexual experimentation	" . ..yeah as of now, I'm still of the optimistic thinking that we're not going to need that, it would be my preference not to have to do that (use aids)."	"It's scary for me (sexual experimentation) . I'm very conventional , because it's different, it would be different. . . . "
Social		
Sex is important to us	"Well, I think we both agree that we are not as interested as we used to be but . . . It's still a part of our lives and we still enjoy it and . . .we wouldn't like to lose it if we didn't have to."	Patient: "I'm anticipating . . . um. . .um . . . " Partner: "trying new things . . . chuckle, laugh) Patient: ". . .phase II, yeah, trying new things . . . "
Couples' sense of self-efficacy in coping with sexual recovery		". . . because I think we have a terrific relationship, we have so much that we do together, we work together."

All couples expressed a variety of worries as they anticipated surgery. The worries focused on the possibility that the surgery would not eradicate the cancer (65%), the danger of surgery itself (65%), urinary incontinence (80%), and the effect of surgery on sexual function (60%). Many couples did not directly speak about grief, but nearly all (95%) had feelings about potential losses.

While citing their awareness of nerve damage and a period of recovery, 90% of the couples expected the men to more or less return to pre-operative function. They based their expectation on the quality of care they were receiving, healthy living habits, hard work on penile rehabilitation, or simply on the opportunity to address sexuality after prostate cancer surgery. All the men said that erection loss would not affect their identity as men. In this manner, couples hoped that they would be relatively unaffected by the surgery.

Despite their eagerness to work actively on sexual recovery, 85% of couples expressed dislike of one or more of the rehabilitation activities: use of sexual aids, sexual experimentation, talking about sex, and masturbation. They hoped and expected that they would not have to use erectile aids.

Social: Sex is important to us, we can work hard to recover it, the partner will have an important role in the recovery.

Forty-five percent of the couples described sex as an important part of their relationship, and 90% of couples were willing to work on some aspects of sexual recovery, such as accepting recommended procedures, accepting the side-effects of medications, or the need to experiment sexually in the absence of easily obtained erections and intercourse to regain sexual intimacy. In some cases, couples saw the post-prostatectomy focus on sexuality as an opportunity to improve sexual intimacy, even to re-kindle an already abandoned sexual relationship.

Although couples evidenced vulnerabilities, such as the men's tendency to be impatient and problems within the relationship, they prided themselves on strengths they had developed through longevity and through successfully navigating previous past challenges. They expressed confidence in their ability to cope well with sexual problems after prostatectomy, no matter what the outcome. At the same time, they did not plan; 80% of the couples postponed thinking about the recovery.

Without exception (100%), partners spoke about becoming protective during the pre-operative period and expected to continue it after surgery. They saw themselves as being supportive, but also as having to enforce adherence to rehabilitation, manage the men's frustration, and in some cases, to provide requisite sexual stimulation for the men as a part of the recovery. Men accepted this role; some men explicitly relied on the partners to know them better than they knew themselves and regarded them as arbiters of decisions about their medical and emotional needs.

Characteristics of the Post-Operative Experience

Table 2.4 presents the post-operative themes of the interviews. All couples had to face the man's loss of erectile function and change in their sexual relationships. Sixty-percent of couples were now sexually active as opposed to the 95% that were sexually active before surgery. All acknowledged the challenge, especially the fact that sex became "work".

Bio: Functional sexual losses and sexuality as it is now.

In addition to erectile loss and loss of the ejaculate, some men reported loss of orgasmic experience (50% had satisfactory orgasms), loss of desire, and unhappiness due to a need for longer stimulation. Menopausal symptoms continued to play a role in the partners' low sexual interest or discomfort with intercourse. On the other hand, 75% of the men recovered some

tumescence and this encouraged them. Nearly half of the couples were not sexually active, and an equal number reported decreased frequency in sexual activity. Seventy-five percent of couples reported feeling unhappy about the loss of spontaneity in sex or some aspect of familiar sexual interactions. Sex was more work now and this was frustrating to the couples.

Nearly a third of the men had some urinary incontinence that was interfering with sexual activity. Fifty-percent of the men had satisfactory orgasms, and some couples felt that work on sexual recovery brought them closer together. The participants spoke about the difference that the man's loss of erectile function made to their sexual relationship. A few partners saw that a smaller penis affected their ability to be orgasmic with intercourse. Even where erectile function was returning, worry about performance, satisfying the partner, the partner's sexual role, and self-consciousness led to decreased frequency of sexual interactions.

Psycho: Ambiguous loss and grief.

Feelings associated with grief were reported by 90% of the couples. The emotion experienced by nearly half of the men was frustration, sometimes hopelessness. While the majority of couples had said, pre-operatively, that the men were not defined by their erectile function, 75% of the men experienced a feeling of loss of manhood, 50% of the men rued a loss of sexual performance, and 25% said they lost sexual confidence. Anxiety about performance dominated their thinking now. They were not sure how definitive their losses would be in the long run. The men who had more extensive nerve damage and were not recovering tumescence or libido were particularly upset. Some partners also felt frustrated. However, only about 10% of the couples felt either hopeless or regretful about their treatment decision. Worry about cancer spread was almost absent, but worry about urinary incontinence (75%), sexual

Table 2.4 Patients' and Partners' Statements 3-4 Months After Surgery

Theme	Patient	Partner
Bio		
Functional sexual losses	" . . and plus my orgasms are diminished I can't get an erection and I can't have an orgasm."	"I also feel like reaching an orgasm is just like, oh really hard for me (due to menopause). And it was hard for me before. But now with all this apparatus and everything else we are bringing in and this Astroglide and this and that and all this paraphernalia, it just doesn't seem worth it to me."
Sexuality now	" There is a response but it's not, probably not what I would say is enough for penetration."	"Well, that seems like another apparatus that it's like so much work, you know. . ."
Psycho		
Ambiguous loss and grief	"It's a part of my being that has changed . . . this is something that is life changing."	"I know. I like threw the vibrator across the bed. I am sick of this. Sick of it. Sick of it."
Social		
Couples' coping - positive	" . . . In that sense the quality is improved. And I think you focus more on your partner than you did in the past."	"I think it's been pleasant, I mean it's now there's stages you can't achieve, but it's not diminished our being intimate or being physical. . . . "
Couples' coping - negative	" . . . the electric pump device I find sort of alienating it's you know it's mechanical and rigid and kind of aggressive and I mean it certainly works but . . . you know it's not very appealing . . ."	"I think the therapy is up to him because it is not something that I don't think he wants me to participate in."
Partner's role in sexual recovery	" . .she's always act like I'm the focus of, of her life and our relationship and she knows what I need and so she's going to give that and she, she knows that I need someone to lean on someone to be strong while I'm having my fearful time that that's the role that's going play I would count on her to do that ."	" . . .he's doing great and it is going great for me, you know, but I am feeling more guilt because I feel that I should be initiating and I just can't pull myself to do that because the motivation isn't there, yeah, and it should be cause he needs it."

performance (50%), and partner sexual satisfaction (50%) was dominant. The feeling of hardship of sexual recovery was clear in all the couples, even those who said that they were coping well because sex was now intentional, not spontaneous. One patient noted that he was not grieving sexual losses; this represented a negative case, a case that did not conform to the preliminary model. Upon further exploration, he explained that aging had already robbed him of his love of athletics; losing sexual function was less significant. For this man, the loss of sexual function opened up grief about earlier, more meaningful functional losses.

Social: Couples' coping and the role of the partner.

After surgery, couples reported that pleasure required work and longer stimulation, that sometimes the man's body had a different sensitivity, and that aspects of sexuality were missing. Although 50% of the couples continued to feel that their sexual relationship was important to them, sexuality was now characterized as being 'different'. Couples used strategies that appeared to help them in their recovery, as well as strategies that made coping with their feelings of loss and frustration more difficult. In this context, coping is defined as attitudes and behaviors in which couples engaged in response to the man's sexual function and altered sexual relationships.

Coping strategies that helped the recovery process.

These included being optimistic, using humor, reframing the experience in the larger context of beating cancer, invoking the strength of the relationship, acceptance of low sexual function, affection, patience, communication about sexual changes, the man's participation in rehabilitation activities, the partner's interest in sex, regular sexual activity, and willingness to experiment sexually and use sexual aids.

Coping strategies that made recovery less successful.

For couples in this sample, these included feeling hopeless, difficulty accepting sexual losses, lack of communication about the losses of emotional intimacy, the men's worry about sexual performance and urinary incontinence, and the partner's low interest in sex. Dislike of sexual aids hindered the work on sexual recovery and led to avoidance. A significant loss of sexual function (including loss of desire, erection, or orgasm) led to loss of sexual intimacy, even in couples whose relationships were otherwise harmonious and mutually supportive.

As they anticipated, partners took on encouraging patients to engage in rehabilitation activities, reminding them about appointments and medications, and managing their feelings of frustration with reassurance. At times, they felt they had to be strong for the men, and men appeared to rely on their partners for strength. Partners had their own feelings about their role, particularly about their expectation that they should be sexually available during the patients' recovery. The demands of the partner role remained mysterious even to the partners themselves.

Couples' definition of sexual recovery.

Couples defined sexual recovery in different ways, sometimes thinking of it as fully recovered erection, at other times wishing to simply be sexually engaged, no matter what aids they might have to use. One couple defined sexual recovery very eloquently, in a way that could probably speak for all the couples who were recovering their sexual relationships after prostatectomy. This couple described a longing for being able to be unselfconscious during sexual activity again. For most couples, loss of spontaneity and self-consciousness were interfering with sexual pleasure and intimacy.

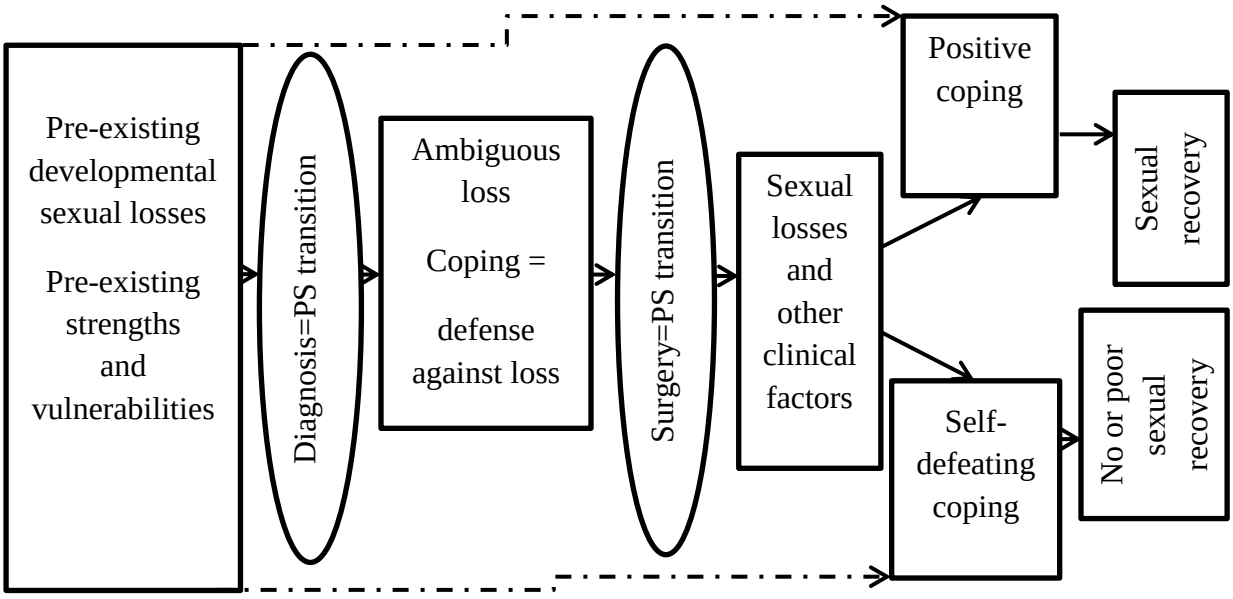
Discussion

The goals of this study were twofold: one was to discover whether couples' reflections on their anticipation of and experience of sexual recovery after prostate cancer surgery would provide empirical evidence to support a hypothesized biopsychosocial model of couples' sexual recovery after surgery for prostate cancer. The other was to learn whether grief was a process in this model through which couples moved toward recovering their sexual intimacy. The findings of this study support the presence of both aspects of the model. However, as represented in Figure 2.2, couples experience not one, but two psychosocial transitions: cancer diagnosis is the first life-altering event they must face; the loss of function after surgery is the second. Sexual recovery after prostate cancer surgery is a complex process governed by many influential factors. Some are pre-existing; others emerge at the time of diagnosis and/or after surgery. Couples are affected physiologically, psychologically, and in their sexual relationship. They are also required to cope in all three domains. They do it through the process of grief and mourning. It should be noted that, while not all participants endorsed the language of 'grief and mourning', all expressed emotions or actions that are commonly associated with grief, such as sadness, anger, frustration, helplessness, and giving up.

Couples' Anticipation of Sexual Recovery Before Surgery

Couples said that their sexual relationships were important to them, even though they had already experienced loss of sexual function prior to surgery, and sex was not always the highest priority. They expressed confidence about sexual function outcomes and about their ability to overcome adversity. Patients' high expectations of return of sexual function had been previously described in the literature (Symon et al., 2006; Wittmann et al., 2011). In both these studies, patients' expectations did not match the actual outcomes. In most cases, patients were

Figure 2.2 Revised Model of Couples' Sexual Recovery After Surgery for Prostate Cancer



Pre-existing developmental sexual losses: erectile dysfunction, post-menopausal symptoms.
Pre-existing strengths: long-term relationships, success coping with challenges.
Pre-existing vulnerabilities: relationship problems, stressors, dislike of unspontaneous sex.
Post-diagnosis coping: anticipatory grief, faith in surgeon skill and couple strengths, willingness to work hard on recovery, minimization of nerve damage, belief that using sexual aids will be unnecessary.
Post-surgery positive coping: on-going sexual activity, acceptance of sexual losses, normal grief and mourning, use of sexual aids, flexible sexuality, partner's positive interest in sex regardless of menopause.
Post-surgery self-defeating coping: no or infrequent sexual activity, relationship problems, inability to grieve sexual losses, stressors, inflexible sexuality, partner's low or no interest sex regardless of menopause.

hoping for a better recovery than they obtained. In our sample, not only patients, but partners were equally optimistic, and couples did not think it necessary to anticipate the recovery. In this way, couples participated in mutual reinforcement of high expectations.

Of concern is the fact that these couples based their expectations on factors which have only some influence on the actual outcome, i.e., the expertise of providers, their own healthy

living, pre-existing sexual function (not always optimal), and their willingness to work hard on recovery as a couple. They relied, in their thinking, on their self-efficacy and the efficacy of the providers, without sufficiently taking into account the physiologic damage that occurs during even the most skilled surgery. Thus, they may have unwittingly positioned themselves to not only experience a greater than expected loss of sexual function and familiar sexuality, but also loss of self-efficacy during the recovery process.

There was a notable incongruence between couples' stated willingness to work on sexual recovery and to experiment sexually on the one hand, and their dislike of devices and medications that they would have to use during the recovery period on the other. An explanation may lie in the already mentioned high expectations with which couples approached the surgery and recovery, and in their decision not to anticipate the recovery period: if erections returned to baseline, they would not need to use the medications or devices and deal with the emotions associated with them. This approach is consistent with the first stage of grief when the acknowledgement of losses is resisted, especially when the loss is ambiguous (Boss, 1999).

Couples' Experience of Sexual Recovery

After surgery, couples reported losses in all three domains of sexuality. With respect to physiology, all but one man experienced erectile dysfunction after surgery. Some experienced other losses, such as poor penile sensitivity, inability to reach orgasm, and loss of desire for sex. It is important to note that clinical recovery parallels sexual recovery and is influential. In these couples, ongoing urinary incontinence created problems for sexual recovery. Additionally, while this was a relatively healthy sample, prostate cancer survivors and partners are generally older, and other illnesses and their treatment can have a significant impact on sexual recovery.

All couples used some positive and some self-defeating strategies to cope with the changes in their sexual relationships. Couples who seemed to be likely to move forward more successfully were those that had some recovery of erectile function; could grieve, share, and accept the loss; could collaborate openly on sexual recovery, and could use aids to sexual functioning. They were able to engage in 'flexible' sexual interactions, as posited by Reese and colleagues (Reese, Keefe, Somers, & Abernethy, 2010). These couples remained engaged in sexual activity on an on-going basis, without waiting for the spontaneity of a hormonal surge. This intentional approach, relevant to men with post-prostatectomy erectile dysfunction, is well represented by Basson's model of female sexual arousal in which the woman subjectively decides to engage sexually, based on her closeness to her partner and her ability to focus away from environmental distractions (Basson et al., 2004).

Regardless of post-menopausal sexual function, couples with partners who were interested in sexual recovery were poised for a more successful recovery. This is an important finding that contrasts with previous research suggesting that a man's sexual recovery after prostatectomy is dependent on the female partner's sexual function (Moskovic et al., 2010; Shindel, Quayle, Yan, Husain, & Naughton, 2005). It suggests that relationship factors (including sexual relationship factors), not biological ones, are more influential in couples' ability to recover sexual intimacy after prostate cancer surgery.

Couples who did not cope as well tended to have pre-existing relationship problems, had partners who were less interested in sex, were more pessimistic, communicated poorly, and disliked aids to sexual functioning. They also had more stressors in their lives. In two cases, couples with very good pre-existing relationships were greatly affected by the men's significant sexual losses due to more nerve damage. In those couples, the men were unable to grieve

effectively and move beyond those losses at the time of the 3-month interview, and the couples experienced a loss of sexual and emotional intimacy.

Grief

Grief proved to be a salient aspect of the experience of coping with sexual losses, although not all participants called it by its name. In the pre-operative period, couples experienced anticipatory grief, but also found it difficult to absorb what was coming. After surgery, couples often endorsed individual feelings such as frustration, sadness, and anger without fully associating them with the grief process. Two men gave up on sex with profound sadness and appeared unable to work through their feelings of loss. To the degree that couples communicated about their sexuality and sexual recovery, they did communicate about the losses. In those couples where losses were such that they overwhelmed the men, feelings of loss and grief were not shared.

Recovery of sexual intimacy was important to these couples. Some defined it in terms of return to sexual activity with or without sexual aids. The most poignant, and probably most apt definition was a return to being unselfconscious during sexual activity. As was anticipated, sexual recovery did not mean a return to baseline. Acceptance of changed sexual function and of changed sexual relationship through the process of individual and shared grief and mourning led to more flexibility in sexual expression for those couples who recovered sexual intimacy.

Study Strengths and Limitations

The study has several strengths. The large sample allowed for theoretical saturation. Studying couples from the pre-operative to the post-operative stage gives a new and unique insight into the process of recovery. The qualitative nature of the study has given couples a voice with which to educate clinicians about their experiences and concerns. The study has identified

grief as a necessary aspect of couples' recovery after prostate cancer surgery and provides a biopsychosocial model of sexual recovery after prostate cancer surgery.

There are several limitations. The study is a pilot that allows for transferability of findings, but not for generalizability. As the post-operative interviews occurred three months after surgery, the physiologic recovery of erectile function was only just beginning. A recent study suggests that early recovery predicts later outcomes (Abdollah et al., 2012**)**, but the accepted wisdom in research and clinical practice recognizes a process of recovery that can last two years (Miller et al., 2005). The study sample was very narrow in terms of diversity of ethnic, economic, and sexual orientation characteristics. It may have been biased in the sense that couples chose to be in the study because they were interested in sexual recovery.

Implications for Social Work Practice

From a clinical perspective, we have to recognize that couples have a variety of responses to the ways in which prostatectomy disrupts their intimate lives. Some may accept the loss and replace sex with other meaningful couple activities that they associate with aging and companionship. These couples were not present in our study, likely because they would not have chosen to participate in a study on couples' sexuality. Other couples will work on recovery and achieve a new intimacy. But the more vulnerable couples, those ostensibly interested in sexual recovery but unable to proceed, will need to be identified early and given assistance. In fact, intervention research suggests that couples who have more problems benefit most from interventions (Manne et al., 2011; Molton et al., 2008; Schover et al., 2011).

Urologic research and typical urologic care for prostatectomy patients focus on erection recovery. The offer of penile rehabilitation, while critical from a physiologic point of view, collides with couples' capacity for dealing with sexual losses individually and as a couple. The

need to address loss, grief, and mourning, while touched upon by some authors, has been largely neglected in the psycho-social literature on prostate cancer. The nearest effort in this direction is the attention to restructuring negative attitudes about sexual dysfunction and aids to erectile function that has been an aspect of some interventions (Manne, et al., 2011; Schover, et al., 2011). Our study supports the notion that grief begins prior to an anticipated loss. When the loss is ambiguous and the outcome is uncertain, there is room to postpone coping and to reach for overly optimistic expectations. Many of the couples in this study did not use the language of grief, only emotions associated with it. It is therefore important to provide education about loss and grief pre-operatively to help couples anticipate their responses to sexual losses and normalize them. Since grief about sexual losses is experienced both by the men and their partners, partners need equal assistance in this area. Couples in this study reinforced each other's high optimism and relied on psychological and couple strengths to reassure themselves about coping with sexual changes after prostatectomy. They did not factor in sufficiently the biological effects of the surgery. They were thus poised for deep disappointment and a sense of powerlessness when their outcomes do not match their expectations. Faced with the loss of familiar sexual interaction and self-efficacy, some couples may become paralyzed.

A treatment approach that includes the biopsychosocial domains simultaneously is critical. In the physiologic domain, penile rehabilitation is already offered in many urologic practices as a way of mitigating loss of erectile function. Patients' and partners' underestimation of the impact of the biological damage to their neurovascular bundles can be best addressed by urologists pre-operatively and reinforced throughout post-operative care. Recognition of the role of biology can help patients and partners feel less responsible for the slow speed of recovery despite their best efforts.

Psychological interventions should address both the man's and the partner's losses and help couples face and work through grief and mourning. Men may need to be helped to accept their vulnerability and their grief as well as support without feeling diminished (Wall & Kristjanson, 2005). Partners' grief about sexual losses needs to be viewed as legitimate. When grief emerges, as is normally the case after a loss, dealing with sexual losses for some couples brings up other losses, sexual or otherwise, in their relationships; they may need an opportunity for more intensive, longer-term sex therapy to work through them. Social workers are trained to understand human development and losses that are commonly experienced during the life cycle. Their clinical training includes attentiveness to grief and mourning, particularly in medical social work where loss of function is a usual aspect of adjustment to chronic illness. Including sexual losses in their clinical purview would be critical in the psycho-social care of prostate cancer patients and their partners.

In the social or relationship domain, comfortable communication enhances the process of mourning and recovery. Some couples have to learn this as a new skill not in their repertoire. In addition to communication, couples need guidance and support for their post-prostatectomy sexual activity. Acceptance of non-penetrative sex during the initial phases, widening of sexual repertoire, and sexual experimentation can be encouraged. The partner's role in the sexual recovery needs to be studied further so that appropriate support can be provided. Social workers can help patients and partners understand the importance of working on sexual recovery and provide a referral for a consultation with a certified sex therapist to help couples work on the relationship aspects of the sexual recovery. Clinical experience suggests that, for many couples, expert support need not be intensive or long term, but its availability can build on couples' self-efficacy and help them restore sexual intimacy after prostate cancer surgery.

Future Research

The findings of this study, which describe the effect of surgery for prostate cancer on couples' sexual recovery, should be confirmed with a larger and more diverse sample, using validated measures of sexual function, complicated mourning, self-efficacy, and couple coping. Couple coping will require a more substantive definition. The development of a brief screening measure that addresses potential barriers to sexual recovery would help identify couples who will need assistance in sexual recovery. The development and evaluation of interventions that address all three domains of sexuality as well as the process of grief and mourning are needed in order to maximize couples' post-prostatectomy sexual recovery. It would be important to learn which couples would most benefit from such interventions. Couples should be followed for up to two years so that the recovery process can be observed within a more meaningful timeframe.

Conclusion

Surgery for prostate cancer affects the three domains of sexuality, i.e., biological, psychological, and social or relational. Couples' sexual recovery depends on their ability and willingness to work in all three domains. Penile rehabilitation helps with physiologic recovery, while grief and mourning help men and partners accept sexual losses. Communication, sexual experimentation, and collaboration are critical to the couples' ability to restore sexual intimacy. If this model can be shown to be valid in studies with large samples, patients and their partners should be alerted to the multifactorial nature of sexual recovery after prostate cancer surgery. Interventions that address all three domains should be developed and tested.

CHAPTER III

EXPLORING THE ROLE OF THE PARTNER IN COUPLES' SEXUAL RECOVERY AFTER SURGERY FOR PROSTATE CANCER

Abstract

Background: Heterosexual partners of patients with prostate cancer have been shown to be distressed, sometimes more than the patients themselves. Their reactions to prostate cancer revealed feelings of depression in response to the loss of emotional intimacy and sexuality. Partners' sexuality has been studied primarily as a factor in men's recovery of erectile function, however, patients' and partners' perspective on the role of the partner in the sexual recovery has not been studied empirically. The purpose of the study was to elucidate the role of the partner in the couple's sexual recovery from both the patient's and the partner's point of view. Method: Ten men and nine partners were interviewed separately about the role of the partner. Grounded Theory was the analytic method and NVivo software aided the analysis. Results: Men and partners agreed on many aspects of the role. They perceived the partner's own interest in sex as being an important positive factor in the recovery. Men did not have a sense of the partner's sexual needs or needs for support. Partners expressed both kinds of needs, but were unsure of what kind of help they needed and whether they would accept help. They expressed eagerness to fulfill their role, but also uncertainty and frustration in their role. Conclusion: Partners' importance in the recovery is recognized by both men and partners and should be acknowledged in usual care for men with prostate cancer. Partners' needs should be assessed and support provided in the context of couples' sexual recovery after surgery for prostate cancer.

Background

Although caregiver involvement and caregiver distress have been found to be inextricable components of the cancer experience, partners' role in couples' sexual recovery after surgery for prostate cancer has not been studied to date (Given & Northouse, 2011; Palapattu et al., 2004). In prostate cancer, partners' dual role as caregivers and sexual partners may pose unique challenges.

Much of the early literature focuses on partner distress, anxiety, and depression. Couper and colleagues (2006a) reviewed the literature on partners in prostate cancer and found them to be more distressed than the men; in a study that followed men and partners for a year, the authors discovered that men become distressed later than partners (Couper et al., 2006b). Several studies concluded that partners had significant psychosocial morbidity. Cliff & MacDonagh (2000) measured depression and anxiety in patients and partners, using the Hospital Anxiety and Depression Scale (HADS) (Carroll, Kathol, Noyes, Wald, & Clamon, 1993) and a measure of psychosocial morbidity in prostate cancer validated by the authors in previous research. They found that 49.6% of partners experienced marginal or definite anxiety or depression as measured by the HADS, while only 20.7% of patients' anxiety could be similarly described. The HADS scores were highly correlated with worry related to cancer and some social anxiety (Cliff & MacDonagh, 2000). A recent study by Thomas (2012) and colleagues compared 19 partners of men with prostate cancer with 26 partners of men who were healthy. They assessed the participants with the Structured Clinical Interview for DSM IV (Spitzer, 1990) and concluded that partners of men with prostate cancer, unlike healthy controls, suffered from sub-threshold post-traumatic stress disorder (Thomas et al., 2012). This research suggests that partners' emotional adjustment to the threat of cancer and to the sequelae of prostate cancer is a significant component of the couple's adjustment to the prostate cancer experience overall.

Partners' concerns and role in men's sexual outcomes are addressed in some research that focuses on quality of life of men who have prostate cancer. Sanda and colleagues (2008), in a study of men who chose several different treatment options for prostate cancer, found that up to 44% of female partners of men who chose surgery were unhappy with the men's sexual outcomes (Sanda et al., 2008). Garos, Kluck, and Aronoff (2007), in a postal survey, evaluated general depression, sexual depression (depression about sexual relationships), anxiety, sexual function, and relationship satisfaction of 77 prostate cancer patients and 57 partners who were on average more than two years post-diagnosis and treatment. They found that while there were many similar outcomes for patients and partners, partners evidenced greater depression and greater sexual depression. Partners' depression and unhappiness with their sex lives were also significant predictors of the patients' depression and satisfaction with their sex lives (Garos, Kluck, & Aronoff, 2007). Since this was a cross-sectional study, a serious limitation of the study was the inability to assess changes in the relationships based on the surgery outcomes. Moskovic and colleagues (2010) had pre-operative sexual function data on 27 heterosexual couples. After surgery, patients who were unable to obtain erections were encouraged to engage in various forms of penile rehabilitation. The researchers found that the pre-operative sexual function of the female partner had a significant effect on the man's compliance with penile rehabilitation activities (Moskovic et al., 2010). The relationship aspects, including sexual relationship aspects, of the patient's erectile recovery and compliance with penile rehabilitation were not explored. Of note is the fact that in the two later studies, female partners' sexuality was conceptualized as a variable that was influential in men's erectile recovery without attention to the role of male sexuality or sexual dysfunction in the female partners' sexual satisfaction or sexual depression. Only one study focused on the female partners' sexual concerns; Schover and colleagues (2002)

interviewed men and partners during the first post-treatment year and found that the women were concerned about their post-menopausal symptoms (Schover et al., 2002a).

Research focused specifically on partners has been exploratory. In a qualitative study by Bruun and colleagues (2011), five partners of men diagnosed with "incurable" prostate cancer described their experience as entailing: (a) aspects of loneliness which included men's silence about their feelings about their cancer and partners' self-imposed decision to live with the silence; (b) informal care which described the partners' devotion to physical care of their male partners, sometimes at the cost of self-care; and (c) acceptance of relationships which were based on affection. Sexuality is not mentioned. Partners coped by turning to family support, mutual love with their partners based on physical care, finding meaning in that care, and faith. The researchers recommended recognizing these issues, particularly partners' loneliness, so that partners could be supported emotionally (Bruun, Pedersen, Osther, & Wagner, 2011**)**. Although this is a study of partners of men coping with a terminal illness, the lack of attention to sexuality is surprising. Sexual expression can provide a sense of connection and comfort during advanced stages of illness, as described by Blagbrough (2010) in her study of patients' sexual needs during palliative care. It is likely that treatment and worry about the cancer would have affected men's and partners' sexual relationships in a way that would have been meaningful at least to some of the partners. Tanner and colleagues (2011) asked two open-ended questions of partners' during eight years of follow-up: How has prostate cancer affected your life? Is there anything else you'd like to add? One hundred and thirteen partners responded and data analysis revealed three themes: (a) coping with life in the face of cancer which included feeling overwhelmed with many stressors, yet grateful for the good care the men were receiving; (b) encountering difficult emotions which included worry, feeling helpless, scared and sad; and (c) learning to live with

relationship changes. The participants acknowledged anger about losing their sexual relationships, lack of success in recovering them, and uncertainty about how to cope with an emotionally vulnerable partner. In these circumstances, partners reported difficulty communicating, primarily by the male partner. In their discussion, the authors place the partners' "difficult emotions" into the context of other literature that has found partners to be distressed, depressed, and evidencing psychosocial morbidity. The discussion appears to view emotions typically associated with the grief process, such as distress, anxiety, despair, and hopelessness, as evidence of declining mental health. The authors recommend listening support and referral to other healthcare providers. Only one study explores partners' sexual needs in couples coping with a variety of cancers when penetrative sex is no longer an option. The ability to negotiate greater flexibility in defining sexuality beyond penetrative sex and the ability to communicate was critical in couples' ability to maintain a sexual relationship (Gilbert, Ussher, & Perz, 2008). There is, in the extant literature, therefore, recognition that women tend to be first responders to the distress about cancer, and that they feel affected emotionally by their male partners' sexual dysfunction, sexual worries, and tendency to withdraw. As Schover et al. (2002a) indicate, female partners have their own sexual challenges related to menopause, but these are primarily addressed as factors in the men's recovery of erectile function, rather than as issues meaningful to the partners themselves. Female partners appear to be experiencing feelings of grief in response to sexual losses and uncertainty about how to cope, yet these are regarded in the research as a group of symptoms rather than a process. They feel excluded by their male partners who keep to themselves their worry about their health and sexual function, but it is not clear how well female partners communicate about their own concerns to the patients. The female partners' sexual needs are not explored, nor are their views as to whether recovery of sexual intimacy is

important to them or how it has been attempted. Their perceptions about their role in their 'patient' partners' recovery of erectile function or couple sexual recovery are not explored. Rather than focusing on empowering women to find resources that would help them address the relationship and sexual issues, as well as the instrumental exigencies of their role, most researchers suggest only support for female partners in their current state. Gilbert and colleagues (2010) suggest, in addition, that communication between patient and partner should be facilitated.

We may wonder whether the partners' distress reflects an outcome rather than a correlate of the couple's sexual recovery after prostate cancer. Is it possible that the studies reflect a very difficult adjustment of the partner who may experience significant stress and uncertainty in the post-operative period, as she or he faces the expectations (imposed and self-imposed) for the partner role in the sexual recovery of the patient? The majority of men who are diagnosed with prostate cancer are in their 50s and 60s (Jemal, Siegel, Xu, & Ward, 2010). Most are partnered with women who are menopausal or post-menopausal, thus experiencing their own challenges with loss of libido, vaginal dryness, and changes in sensitivity. Although some studies and some writers have addressed the developmental influence of menopause on the sexual relationship of couples by providing psycho-education about aids to post-menopausal sexual function (Canada, Neese, Sui, & Schover, 2005; Davison, Elliott, Ekland, Griffin, & Wiens, 2005; Schover et al., 2011), the effect of menopause is by no means an accepted and well developed variable in a model through which to view couples' post-prostatectomy process of sexual adjustment after surgery.

Many questions remain: How does the partner experience his/her role? What is going on for the partner sexually as the patient experiences sexual losses due to prostate cancer surgery?

Does the partner experience grief? Does the partner experience a burden in the roles of caregiver and of sexual partner? Those questions must be asked and answered before a model of sexual recovery can be credibly described and tested. My clinical experience has shown that men and partners may view the partner's role differently from one another. The anecdotal nature of clinical work, however, does not provide sufficient evidence that this is a prevalent phenomenon.

Because the distress of partners of men who undergo surgery for prostate cancer has been well documented in the research literature, their mental health will not be a focus in this study. Instead, the aim of this study is to explore empirically the role of the partner in the man's erectile recovery and the couples' sexual recovery from the point of view of the men and their partners. The research was motivated by the following research questions: Do patients and partners see the partner as having a role in the couple's sexual recovery? If so, how do patients and partners view it? Is there congruence between the patients' and partners' perspectives? Hypotheses were not stated because this is an exploratory study that hopes to discover new concepts and to build theory of couples' sexual recovery after prostate cancer surgery.

Method

Qualitative methodology was used to explore and describe men's and partners' perception of the partner role in the man's recovery of erectile function and the recovery of the couple's sexual relationship. The subject is a new area of discovery and relevant concepts have not been identified. The decision to interview men and partners separately was based on the notion that it would give men and partners the opportunity to speak freely, unhindered by the consideration of the other partner's feelings if he or she were present in the conversation.

Participants were recruited from a previous study on barriers to sexual recovery after surgery for prostate cancer (the "Barriers" study). A study amendment was submitted and it was

approved by the Institutional Review Board of the University of Michigan. Participants were asked to sign a new Informed Consent if they agreed to participate in this phase of the study.

Study Sample

Twenty-eight couples from the "Barriers" study (the full original sample) were contacted for further interviews for this study. In the original study, couples in which the man had chosen surgery as prostate cancer treatment were included if both members of the couple were willing to sign Informed Consent, were not cognitively impaired, and were able to participate in interviews in English. The goal of this study was to recruit 10-15 men and partners, not necessarily in the same partnership, to interview separately about the role of the partner in the sexual recovery after prostate cancer surgery. This number was expected to be optimal for the achievement of theoretical saturation (Guest & Johnson, 2006).

Procedure

Separate interview guides were developed for men and partners. Participants were asked about the stage of erectile recovery and couple sexual recovery to learn about the context in which the partner role was explored. Men and partners were then asked questions about the partner, appropriately phrased for each cohort, such as:

> "If you were to look back, what would you say your major contribution to your partner's and to your sexual recovery as a couple has been?"
>
> "What went on for you sexually during that period?", "If you were to weigh the 'benefits' and the 'toll on you' that your role has taken, what would you say?"
>
> "What kind of help/support do you think partners need during the couples' sexual recovery after prostate cancer?"

Iterative process was used during the interviewing in such a way that data from each interview were be used to modify further interviews. Interviews were digitally recorded and

transcribed. Data analysis proceeded along with data collection. Interviews continued until categories were developed and theoretical saturation was achieved.

Data Analysis

The demographic data were summarized with descriptive statistics in order to describe the sample. Modified Grounded Theory was used for the analysis (Charmaz, 2006; LaRossa, 2005). Open coding was used to identify men's and partners' observation of the partner's role in the man's recovery of erections and the sexual recovery of the couple. Open codes were organized into groups of related themes. These themes were further categorized into higher-level concepts descriptive of the men's and partners' perceptions of the partner's role. The men's and partners' perceptions were then compared to identify the extent to which they were congruent with one another. NVivo 9 software was used to complete data analysis.

Assurance of Data Quality

The quality of the data and analysis were secured based on prolonged exposure (the researcher's five years of experience with this population of men and partners), checking transcripts randomly for accuracy, and consulting with a qualitative research mentor. An audit trail was kept throughout the project, and memos that included reflexive statements were written after each interview.

Results

Sample Characteristics

Ten men and nine partners consented to participate in the study. Eight men and partners were couples (seven were heterosexual, one was in a same-sex partnership). Two men participated without their partners; in both cases, the partners had indicated their lack of interest in sex, one due to menopausal symptoms and the other as a chronic issue. One female partner

participated without her male partner. He had initially agreed to participate, but later did not respond to calls to schedule appointments. He had previously indicated a loss of libido after prostatectomy and urethral discomfort after radiation therapy. Table 3.1 provides a description of the participants' demographic characteristics.

Table 3.1. Sample Demographic Characteristics

Characteristic	N	%
Ethnicity		
White		
Patient	9	90
Partner	9	100
Chinese American		
Patient	1	10
Partner	0	0
Completed education beyond HS		
Patient	8	80
Partner	9	89
	Mean	SD
Age at baseline		
Patient	62.2	4.4
Partner	58.3	2.3
Length of relationship		
Patient	31.3	8.6
Partner	34.5	6.4
	Mode	Range
Income		
Patient and partner	> $90,000	<$30,000-$90,000

The men's mean age was 62.2 (SD = 4.4), the partners' median age was 58.3 (SD = 2.3). Eight (80%) of the ten men and eight of the nine partners (89%) had higher than high school education. The mode income for these couples was higher than $90,000 (range $30,000-$90,000+).

All men had localized prostate cancer. One man's prostate cancer was more aggressive (Gleason 8) and required additional radiation treatment. This man's surgical treatment also resulted in more nerve damage, which augured poorer erectile recovery. One man had residual urinary incontinence. Three men and two partners had chronic conditions other than prostate cancer. The couples, on average, were together for more than 30 years. The men in this sample were, on average, 14.3 months (range 6-24) past their surgeries. The partners in this sample were, on average, 13.6 months (range 6-21) post the surgery of the patients. The discrepancy in time periods after surgery between the men and partners is explained by the fact that the two men who participated without their partners were further post-surgery than some of the others, 24 and 12 months, respectively.

Interview Findings

Context: Couples' sexuality and sexual recovery as it is now.

Erectile function.

At more than one year after the patient's surgery for prostate cancer, all but one participant was recovering some tumescence. All but one were using aids to erectile function such as vacuum erectile devices or PDE-5 inhibitors. Although most of them had engaged in penile rehabilitation to some degree (taking pro-erectile medication and using vacuum devices to create blood flow in the penis), for most, it was an ambivalent involvement. Several did not like using vacuum devices, like Rob, who said, "The uh, uh (. . .) electric pump which I never liked, I mean that was, it was sort of aggressive and alienating". Or Chad, who described his experience

in the following way: “I used the pump for the first three months as part of that process of rehab, and it’s such a pain to go through all that assembly and disassembly, and it’s just too much monkey motion for me.”

Attitudes about erections and expanded sexual expression.

Men continued to value erectile function above all. Most men also denied expanding their sexual repertoire as a way of enjoying various aspects of sexuality in the face of erectile dysfunction. But Peter was able to say that he and his partner did expand ways of making love: “We do more stroking; more exploring of the body, other parts of the body . . . there is more appreciation of it (sexual interaction).” Generally, men coped with the sexual losses by conflating them with aging, as James put it: “. . . the fact that there’s no ejaculation, I don’t think makes any difference, but there hasn’t seemed to me . . . I don’t have the impression that that’s a consequence of the surgery, it was starting, you know, to be more difficult even before this all came up, so it’s just a function of age, I’d assume . . . .” Barry joked: “We cannot help but feel sorry, but it’s almost, you know, like an old convertible that you once had and it’s also a process of getting older . . . and certain things happen, so I think you have to kind of live with that and just you have to make light of it . . . .” Partners were more accepting of erectile dysfunction. Olivia expressed her thinking about it: “I mean I guess that, I can certainly accept that (erectile dysfunction).”

Menopause.

Two men who participated in the study without their female partners spoke of having lost their sexual relationships even before the surgery, one because of his wife’s surgically induced menopause, the other because of his wife’s pre-existing lifelong lack of desire and ability to experience pleasure, which was exacerbated by menopause. Although all but two

partners in this sample were post-menopausal, all nine were interested in retaining their sexual relationships and reported being able to experience pleasure. Lower interest in sex than their male partners was true of some female partners and of one pre-menopausal partner. However, some partners retained robust sexuality despite menopause, like Denise who was quietly proud: "I don't know whether I'm just sensual or whether a lot of women are like me, I don't know, I mean, I'm 70 but I still enjoy sex." The partners' sexual interest was thus variable regardless of menopause status.

Changes in sexual relationships.

All men in this sample retained sexual desire after surgery. However, they acknowledged a decrease in the frequency of sexual activity and feelings of grief about sexual losses. Chad, who did not recover any tumescence, said that he was "disappointed, disappointed, disappointed, from the sexual side of it. From the physical side of it, I never thought that I was sick to begin with, but umm , , , yeah, just, ah. I wish I, I never even thought that there was the potential loss of everything." Because some of the men were uncomfortable with using aids to erectile function, in a few cases, this was a barrier to sexual activity. Others had trouble tuning out worries about sexual performance and partner satisfaction; for example, James said, ". . . It's the part of the fear of trying you know, what if it doesn't work . . . ? You worry about, are you satisfying your partner?" Partners also acknowledged sexual losses and decrease in frequency, but were philosophical about it, like Mary who reasoned, ". . . I say, you can't get discouraged because sometimes it works, sometimes it doesn't. That's just a matter of how it is, and I'm just not that way where it just bothers me. . ."

Recovery of sexual relationship.

Four of the ten men and corresponding partners saw themselves as either having recovered or recovering their sexual relationships. John made the following statement: "I think we've kind of gone back to a similar pattern in relationship as we had before." Peter put it this way: "I think we're pretty close to coming back full circle, but um, you know, I think it's still a little developing . . . ." Julia expressed contentment: ". . . You know, life is good, and I think that our sex life is good. Like I say, it's not like it was, but things happen as you get older anyway. We've come to more of an understanding, we've become closer. . . ."

Nearly all men endorsed the importance of communication about sexual needs and their feeling that it was not well developed in their relationships. Carl complained, "She'll say, umm oh, I thought about it a couple of hours ago but you were gone . . . and that's why I never have sex with you. We get mixed messages." Partners thought that good communication and on-going sexual activity were more important than intact sexual function. Rose said, to clarify this point: ". . . It was always like, you know, are you satisfied? Is this something for you? And I would let him know that, too, because otherwise how do you know?" Mary thought communication could be reassuring: "I think you just have to, um, let the partner know that, um, you know the strength or length of an erection is not the most important thing, that the most important thing is that you can be intimate with one another and give each other pleasure, um, and just feel closeness and love." The partners who were couples with an ability to talk about the sexual challenges, including feelings about sexual changes and worries about performance, found that it was beneficial and moved the relationship forward.

Couples who were communicating well and felt a continued sexual connection also found that taking focus away from worry about erectile function and performance was helpful. While most denied changes in repertoire, at least two couples either added more foreplay or the partner

allowed herself to be more sexually spontaneous, which was very stimulating to her 'patient' partner. James said, "I think she's more a little more wilder then she used to be . . ." In this way, they indicated that communication and adding new forms of satisfying sexual activity fostered sexual pleasure, emotional intimacy, and a sense of trust.

Men and partners who reported a lack of current sexual connection with their partner and who felt that sexual recovery was stalled, described their relationships as having additional obstacles. Some identified pre-existing stressors, such as caring for needy family members. Brad commented on his wife's recent sexual unavailability: ". . . The only thing that has slowed her down probably is her mother . . ." Others brought up relationship problems. Steven said, almost puzzled, ". . . and the funny thing about it is, the issues that came up were more related . . . more to our relationship issues than the physical issues." Deborah spoke about the patient's unsupportive response to a stressor: "I've often told him before (laugh,) it really does mean a lot, how you also treat me out of the bedroom. You can't just expect me to (snap of fingers), you know, turn on to you when I've got anger issues about that." In one couple, urinary incontinence hindered sexual recovery and added to an already existing conflict; as Carl pointed out, "Well, she states that's the only reason she tried twice – yeah, because of urine everywhere, all over the bed." In a separate interview, his wife reinforced this view: ". . .yeah. it was because umm . . . when we tried to have sex he's continually peeing." Two partners described their 'patient' partner's withdrawal because of immense sadness about the loss of sexual function, and said that they felt they could not pursue it (sexual activity) out of sensitivity to the patient's feelings, "I wonder whether he stays down because he knows how I feel (interested in sex) and he doesn't want to come to bed because of that. I might be wrong, but I don't question him over that either." Chad, who was the husband of one of those partners, spoke with sadness: ". . . I thought it was

always just going to be . . . a period of time, not understanding what the mechanical things would do (mechanical aids to erections) . . . I just wanted the real thing, that experience to come back again, yeah, and now it's not. . . ." In two cases, mentioned above, the female partners had pre-existing disinterest in sexual activity, and thus, were not truly available as sexual partners during the recovery phase. The couples who were experiencing difficulty with recovery were sad and frustrated.

Most of the men and partners said they wanted to continue to work on recovering their sexual relationship. Two partners and one man said that they were trying to adapt to a relationship that did not include partnered sex.

Men's perception of the partner role.

The men's perception of the partner role is represented in Figure 3.1. Of the ten men, two did not expect a role for their partners in their own recovery of erection. One said he did not wish to impose on a wife who lost pleasure after surgical menopause: "She is willing any time I have a feeling of being romantic . . . even though she might not get anything out of it." The other saw himself as generally self-sufficient: "Well, I don't think she could help my recovery; it was something I would have to." One man experienced the partner as uninterested" "I just don't see much interest, period." The remaining seven men saw partners as critical to the recovery of erectile function. These men saw partners as providing emotional support, help with frustration, and assistance with appointments. Some examples of men's appreciation of the partner's role are: "Well, I mean I think she's instrumental in my recovery and the rapidity in which that activity has been restored", or "Yeah well, yeah, she noticed that I was more irritable, then I went on this sleep apnea thing so I'm doing the, um, C-PAP machine so that seems to be helping with that, but I also went to counseling, um, (and) went on the Prozac."

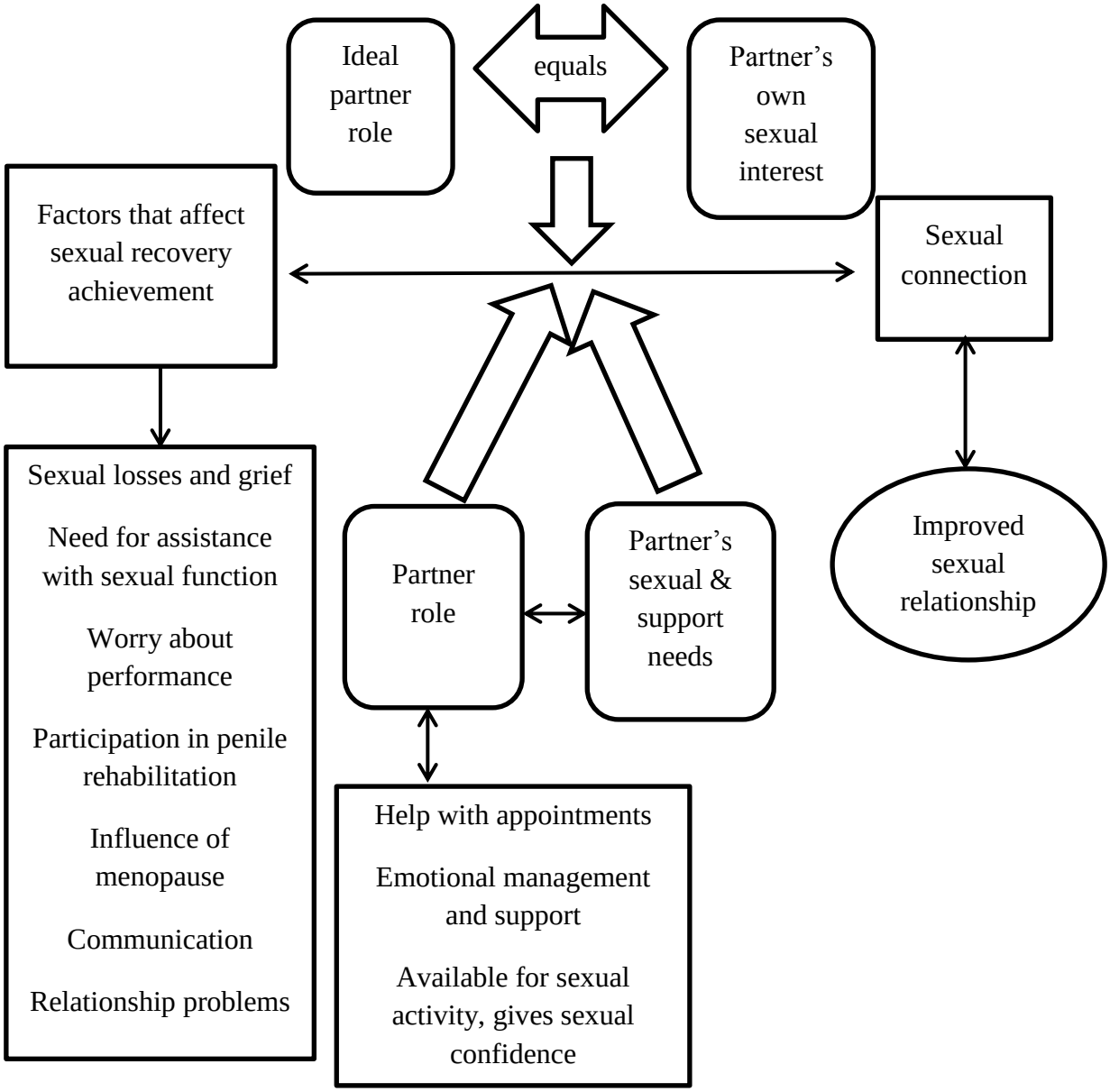
In their minds, the partner's sexual availability and sexual interest were key components of the success of the recovery of their sexual relationship. As Carl put it, "Whenever we were involved, she was really interested in it." Talking about sex, including about their worries, with their partner was helpful and resulted in greater emotional intimacy, as well as in a better sexual relationship. Carl summarized it well: "It's more of a deeper . . . it's more than just an orgasm, it's . . . our relationship is better."

The men were asked about what they envisaged as an ideal partner role. All men wished for a partner that would have either sexual interest of her or his own, or be aware of their needs and take initiative in sexual activity -- but be gentle about it. Chad said, "Well I think, number one, it has to be supportive, uh, but not demanding, uh, it has to be, uh, as a coach, uh, as one of those improving the situation, understanding what the situation is, um, but not the drill instructor . . ." Peter described the following scenario: "If . . . physically you need the aids, then you would have a partner that would say, 'Honey why don't you take a Viagra. I'll see you later', you know or something like that." Carl added an emotional component: "Someone who could bring me out, make me better understand my fears, and also one, once you did get in the sex act, be willing to do whatever it took to really turn me on." In three of the four couples that were recovering their sexual intimacy well, partners were, in fact, active participants. David gave an example: "It wasn't just, you know, as part of the protocol to the procedure, you know, there was true, uh, true interest and true arousal which was a, you know, kind of picking up where you left off. " None of the men mentioned a wish for another or younger partner; all wished to be engaged with their own partners.

When asked about their awareness of their partners' sexual needs or needs for support during the recovery period, most men were uncertain about their partners' sexual interest; while

at least four men understood that their partners experienced hardship during the recovery period, they had difficulty answering the question about whether partners needed support for themselves. Most thought that partners did not get support.

Figure 3.1. Patient's View of the Partner's Role in the Couple's Sexual Recovery after Surgery for Prostate Cancer



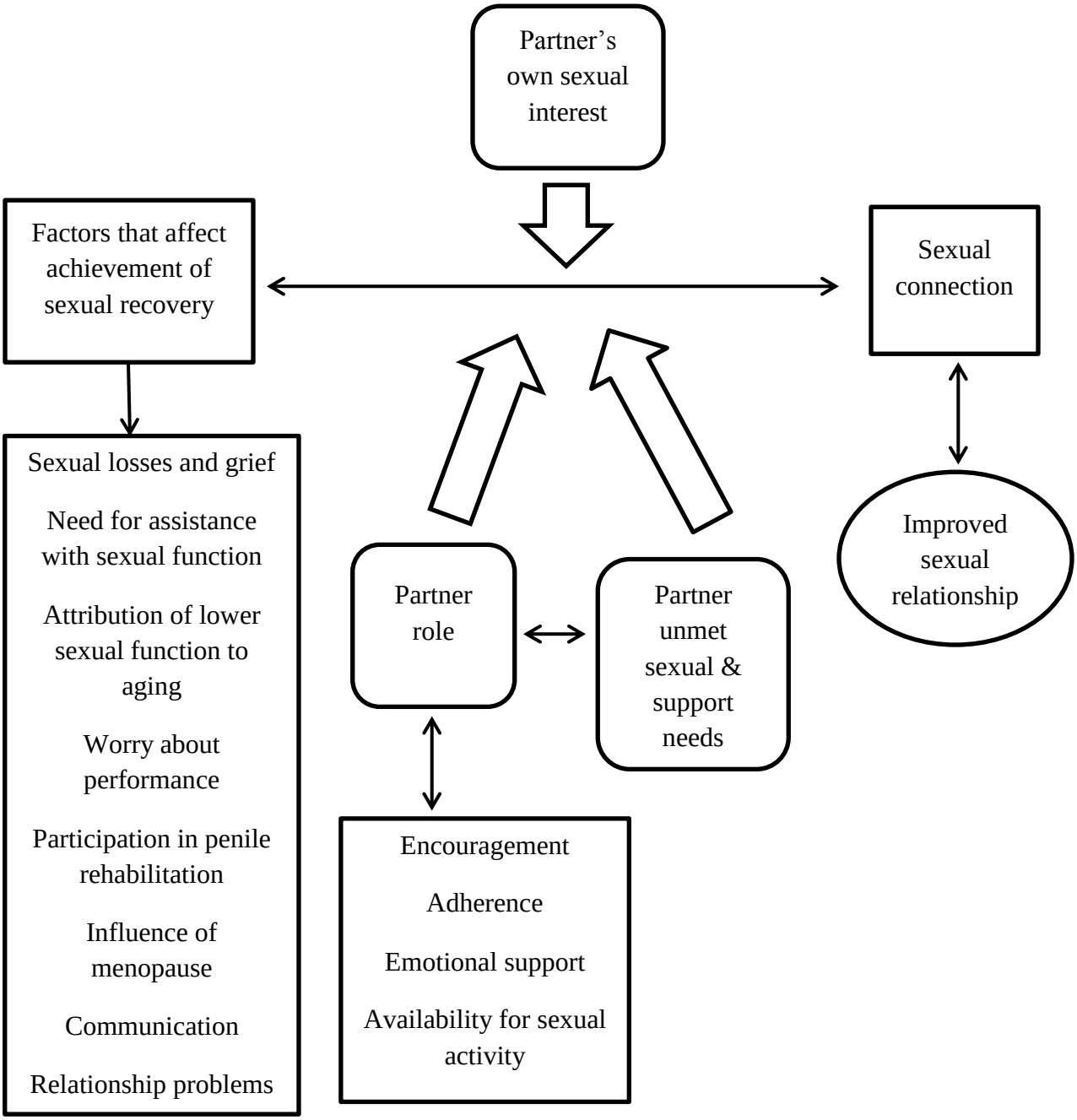
Partners' perception of the partner role.

All nine partners saw their role in the men's recovery of erections as providing emotional support and encouraging men to engage in rehabilitation activities (Figure 3.2). Julia put it this way: "Especially in the beginning . . . I felt like I was almost nagging him to, you know, 'practice'." Olivia said, "I'd like to think that he recognizes that I'm there for him no matter what . . . ." Partners also thought that making themselves available for sexual activity was necessary, like Mary who said, "My role is to be there when he wants to have intercourse or wants to try." This was true for all partners in spite of their own diminished libido due to menopause.

In addition to providing support to the men in their recovery of erectile function, all partners attempted to resume sexual relationships either by being available or more actively. In their effort to engage sexually with their 'patient' partners, partners sometimes found their sexual role complicated. More than half of them had been responders rather than initiators of sexual activity prior to surgery; now they found themselves having to take more initiative as they saw that the men were struggling with worry about performance. For most, this was a necessary transition, even when it was not easy. One partner, Martin, said: "I think that it's something that I actually need to work on more, because I do sense, um, that it's a little more difficult for him to initiate because of what he's going through." At least one partner, Deborah, found the role reversal so challenging that she was unable to initiate in spite of her awareness that her husband was hoping for it: ". . . so that all of the sudden those roles have changed where I should be the more aggressive one, and now, you know, he's to be the passive one . . . so I don't do it, you know. . . old habits are hard to break." Three of the partners who were willing to initiate did not always find their sexual interest welcome. They believed that the men were too worried about performance to respond. Carol said: "I did actually speak to him and said, 'You know, even if

you can't make love, just remember that the touching is still part of it.' I mean, um, I have in the past ruffled his hair at the back and I'll put my hand on his knee if we sit down and things like

Figure 3.2. Partners' View of the Partner's Role in the Couple's Sexual Recovery After Prostate Cancer Surgery



this, and he tended to drift away totally." This left the partners with a sense of loss and sadness, and somewhat uncertain about how to fulfill their sexual role in the recovery.

Five of the nine partners, (three post-menopausal, one pre-menopausal, and one male), said that they had active sexual needs while their 'patient' partner was recovering. Four partners turned to masturbation as a way of reaching sexual satisfaction when partnered sexual activity was not available. The remaining four partners who did not have active sexual needs still said that their sexual relationships and sexual recovery were important to them. The following statement is representative of many of the partners, even those who had less interest in sex: "I would like him to be happy and, you know, I have needs. I was not as sexually active as he was, or. . . but I yeah, it was very important."

Partners were asked to identify their needs for support for their role. Many had a wish for some form of counseling or peer support, although not all were sure they would have participated. Two partners said they did not want to discuss personal matters with others. Three partners thought that the urology survivorship program was a good source of support, and that even just participating in the study was helpful. Several said that the study facilitated a conversation about sex. Olivia said, "I think that was a good thing that we did the study because you get, all this is brought out . . ." The desire for support was there in general, but the wish for a specific type and desire to use it were not uniform.

Five partners said they felt happy with the way they were fulfilling their role in their 'patient' partner's sexual recovery after surgery for prostate cancer. They thought that the men were appreciative of their support. One partner hoped so, but was not sure. Two partners thought that their husbands did not appreciate their contribution; one thought that she did not do much to help and perhaps should have done more.

Discussion

The purpose of this study was to elucidate the role of the partner in the man's recovery of erectile function and in recovery of the couple's sexual relationship. Men and partners spoke about the partner role in the context of their recovering sexual relationship. There was variation in the way in which couples were recovering sexually after the man's surgery for prostate cancer. At more than one year after surgery, most men no longer suffered from urinary incontinence, but most continued to have some degree of difficulty with erections. They struggled with regaining sexual confidence and their partners were very much aware of it. As a result, partners adopted a caregiving role and wanted to offer as much of themselves as possible to be helpful. Recovering the feeling of being sexually comfortable and connected with each other has eluded some men and partners, while others felt more intimate because of overcoming the challenges of the recovery.

The factors that appeared to facilitate couples' sexual recovery were the ability to communicate about sexual losses and concerns, acceptance of suboptimal erectile function, and willingness to not focus on erectile function. Most couples did not expand their sexual repertoire to other activities, although more foreplay was evident for some. This combination of factors led to even better, more intimate sexual relationships for some than they had prior to surgery. Acceptance of erectile dysfunction was easier for the partners than the men, as has been shown in other research (Wittmann et al., 2013), and partners often adopted a reassuring role. In their recovery, these couples were able to adopt what Reese and colleagues call "flexible sexuality" (Reese et al., 2010).

Discomfort with erectile aids, female partners' loss of libido and sexual sensitivity due to menopause, life's stressors, overwhelming grief about the loss of erectile function, a partner's

difficulty in assuming a more active sexual role, and relationship problems were some of the cited barriers to these participants' ability to reclaim their sexual relationships.

Both men and partners had a perspective on the partner's role and involvement in the man's recovery of erections and the couple's sexual recovery. They were mostly in agreement, but there were also some differences. Both men and partners regarded the role of the partner in the man's recovery of erections as important. Both men and partners thought that encouragement and emotional support were helpful. In addition to providing emotional support, partners saw their role as making sure that the men were diligent in their rehabilitation activities, something that men did not see as the partner's role. Partners' role in the recovery of the couple's sexual relationship was also seen as critical. The partner's sexual availability was a seen as instrumental in building men's sexual confidence. However, partners' sexual availability sometimes did not mesh well with the men's worry about performance, leaving both parties sad and frustrated.

When asked about what would an ideal partner in sexual recovery be like, men invariably spoke of a partner who would be sexually interested in his/her own right, sensitive to the recovering patient's sexual and emotional needs, and who would take initiative in sexual activity. The outcomes in our sample indicate that, for the dyads who were feeling intimate again, the partners' participation fit this description. This is a particularly interesting finding because the men were not describing an ideal partner as one who was younger, with intact sexual function. Female partners' higher sexual function has been described as a predictor of men's success in sexual recovery in previous research (Schover, et al., 2011; Shindel, Quayle, Yan, Husain, & Naughton, 2005). The majority of female partners in this sample were post-menopausal and the male partner had post-prostatectomy erectile dysfunction. Our findings suggest that partners who were in sexual relationships that had emotional intimacy with at least some ability to

communicate about sexual issues, were able to continue to have sexual interest and enjoy their sex lives despite a compromised physiologic substrate of their sexuality. These findings confirm Gilbert's findings from a study of 20 Australian partners (Gilbert, Usser & Perz, 2010). In that sense, we may hypothesize that relationship factors potentiate the couple's desire and ability to continue a satisfying sexual relationship, in spite of age and prostate cancer treatment-related physiologic challenges.

The difficulty that some partners evidenced in a movement from a passive, receptive sexual role to a more active one indicates that the viability of some couples' sex lives depends on the man's libido and erectile function. When the man struggles with confidence and does not initiate sexual activity after surgery for prostate cancer, these couples are at risk for poor recovery of sexual intimacy. It is an aspect of post-surgery couple sexual functioning that must be taken into account when considering the development of interventions for couples in their sexual recovery.

We found that the patients' and partners' major difference in perspective on the partner role lies in their appreciation of the partners' needs. While the patients recognized that partners experienced some hardship in their role, they were not aware of the partners' sexual needs, and had difficulty articulating ideas about how partners might be supported. Partners were able to describe, for the most part, their willingness to help the patients as caregivers and as sexual partners, even beyond their own sexual needs. For some who did have sexual needs, those needs went unmet in the relationship. Partners struggled with their role and wished for support, although they were not always certain about what kind of support would be most helpful or would be acceptable. This finding suggests that partners in long-term relationships desire to fulfill their dual role as caregivers and sexual partners after their 'patient' partner's surgery for

prostate cancer. However, this dual role is not well understood either by the patient or the partner. Partners take on the role despite its lack of definition and their uncertainty about how it should be fulfilled. Most try and persist even when they encounter frustration, lack of success, and lack of support. This uncertainty, lack of fulfillment of their own needs, and lack of support may be some of the factors implicated in partner distress already described in the research literature. In the review of the research, the author suggests that partners are typically viewed in studies as instrumental to the men's sexual recovery. If they are similarly viewed and experience themselves as thus objectified in usual prostate cancer care, this perception could add to their stress and even to resentment in their care-giving and sexual role. If their own needs are not recognized and supported, partners may begin to experience a burden in their role that can impede the sexual recovery of the couple.

Study Strengths and Limitations

This study brings new insights to men's and partners' experience of and perspective on the partner's role in couples' sexual recovery after the man's surgery for prostate cancer, particularly about (a) the men's wish for a sexually interested partner regardless of menopause rather than a partner with intact sexual function who does not have post-menopausal sexual challenges with libido and vagina dryness, (b) partners' willingness to be both caregivers and sexual partners, and (c) partners' unmet needs in their role. If these findings are confirmed in larger studies, they can have the benefit of enriching clinical practice and achieving better outcomes for couples that are working on recovering sexual intimacy.

The results of this study can be regarded as preliminary because the sample was small and lacking in diversity. As participants were recruited from a sample of a previous study, the sample may have been biased. The wide-ranging post-operative time frame (6-21 months) for the

participants also may have limited the validity of the findings. Although saturation was achieved, the findings are transferable, but not generalizable, to the population of prostate cancer survivors and partners.

Implications for Social Work Practice

Partners have a critical role in the man's recovery of erectile function and the couples' sexual recovery. Partners have been seen as factors in the man's sexual recovery, but not in their own right. This study suggests that they are legitimate stakeholders in the men's and couples' sexual recovery, and that they can experience uncertainty about how to be helpful, have their own unmet sexual needs, and have needs for emotional support for themselves. These unrecognized needs can create partner burden and lead to a difficult adjustment for the partner, as well as interfere with couples' recovery of sexual intimacy. Both patients and partners can be educated about the issues that affect partners who support men after surgery for prostate cancer. Interventions developed to help couples recover sexual intimacy should address partner needs.

Couples who had been dependent on the man's libido and erectile function in their sexual activity need even more support. Partners can be encouraged to learn more about post-menopausal sexuality and to recognize that they can have a positive impact on their sexual relationships; if they take responsibility for their own sexuality and sexual interest, they may be able to increase the viability of their sexual relationships when men are too worried to continue their sexual leadership role.

Future Research

There is a need to design future studies with larger samples to confirm the current study's findings. Understanding of partners' need for support particularly needs further elucidation. The research should include a question about partners' perception of the way they are seen and

responded to by providers who treat the patients for prostate cancer. Their distress and readiness for dual care-giving should be evaluated with measures developed to capture their unique position. This research is necessary not only as a precursor to the development of effective interventions that will support partners, but also as a step toward helping men understand their partners' needs in the context of sexual recovery after surgery for prostate cancer. Partners' desire to have information and to be included in decision-making about prostate cancer treatment is already documented in the research literature (Mason, 2005). Increasingly, partners are involved in decision making as a result. Research that helps further elucidate the partner role and the partner's need for support in fulfilling the role in the man's and couple's sexual recovery after surgery can lead to more comprehensive care in prostate cancer.

Conclusion

Partners have a critical role in the sexual recovery of the couple after surgery for prostate cancer. Their needs and challenges are not well known and their post-menopausal sexual viability has been misunderstood. Preventing partners from becoming burdened by their dual role as caregivers and sexual partners should be included in interventions designed to help couples recover sexual intimacy after treatment for prostate cancer.

CHAPTER IV

COUPLES' SEXUAL RECOVERY TRAJECTORY DURING THE FIRST TWO YEARS AFTER SURGERY FOR PROSTATE CANCER: CHANGE IN SEXUAL FUNCTION, SEXUAL SATISFACTION, AND DYADIC SATISFACTION

Abstract

Background: Couples' sexual recovery has not been studied prospectively. Studies have demonstrated discrepancy in men's and partners' sexual function and distress, both before and after surgery. Partners are often seen as influential factors in the men's sexual recovery. The present study sought to follow men's and partners' sexual function, sexual satisfaction, and dyadic satisfaction from before surgery to nearly two years after surgery. Method: Couples' survey data were available at three time points: 28 at baseline (T1), 20 three months after surgery (T2), and 16 at 18 months on average (T3). The Expanded Prostate Index Composite assessed erectile function and urinary incontinence; the Sexual Experience Questionnaire assessed men's satisfaction with erections and individual and couple sexuality; the Female Sexual Function Index assessed female sexual function, and the Dyadic Adjustment Scale assessed partnership satisfaction. Demographic data were obtained at baseline. A multilevel analysis was used to with time as Level 1, man and partner comparison as Level 2, and inclusion of covariates such as age, education, income, comorbidities (other illness conditions) and urinary incontinence as Level 3. Results: Erectile function declined after surgery and then improved at T3, while men's sexual satisfaction declined after surgery, but did not rebound at T3. Female partners' sexual satisfaction declined at T2 and continued to decline at T3. Partnership satisfaction was greatest when female partners were sexually satisfied, and the couple's income was reasonably high. Conclusion: Both men's and partners' sexual satisfaction decline after prostate cancer surgery,

even as erectile function begins to rebound. Female sexual satisfaction and income level appear to be influential factors in couples' partnership satisfaction during the recovery of sexual intimacy after surgery for prostate cancer.

Background

Prostate cancer is the second most prevalent cancer in men. Approximately 40% of male cancers are accounted for by prostate cancer, with one in six men having a chance of being diagnosed with it each year (Hewitt & Stovall, 2006). In 2010, it was estimated that 217,730 men would be diagnosed with prostate cancer (Siegel et al., 2012). Ninety- eight percent of men with prostate cancer were expected to survive five or more years; men who are diagnosed and treated for localized disease have a 98% chance of 15-year survival (Siegel et al., 2012).

Although survivors and their partners can think of prostate cancer as a "good cancer" because survival after definitive treatment is very likely (Maliski, Heilemann, & McCorkle, 2002), they pay a price. All prostate cancer treatments have side-effects, which can become long-standing and not resolved for some (Benson et al., 2012; Hollenbeck, Dunn, Wei, Sandler, & Sanda, 2004; Matthew et al., 2005; Wei et al., 2002). Surgical treatment for prostate cancer (prostatectomy) ushers in two major side-effects: urinary incontinence and erectile dysfunction. Urinary incontinence typically becomes a short-term frustration for most. More than 90% of men return to normal bladder control within the first year of treatment, some earlier (Sanda et al., 2008). Erectile dysfunction is a much more persistent side-effect, with a slow resolution over two or more years without returning to pre-surgery level (Miller et al., 2005; Schover et al., 2002). For some men, erectile dysfunction is a permanent outcome, with the need to use medical or non-medical aids to erections. This makes sexual activity much less spontaneous and, in fact, likely

leads to diminution or cessation of sexual activity for some men, as evidenced by men's infrequent use of aids to erections (Miller et al, 2006).

The loss of erectile function affects men's ability to function sexually, which in turn affects their sexual relationships with their partners. Post-prostatectomy sexual recovery requires that men and partners develop a new sexual paradigm that may include the use of aids to sexual function. Since men who are treated for prostate cancer are often partnered with post-menopausal female partners, adaptation of sexual interactions already may have either taken place or added to distress regarding the sexual relationship.

Research on couples in prostate cancer began in the 1990s. In a seminal study, Kornblith, Herr, Ofman, Scher, & Holland (1994) surveyed 172 prostate cancer survivors and 83 partners and found that partners were more distressed than patients, and wondered whether culturally, men and women differed in their expression of distress. The recognition of the importance of the partner and the desire to understand the differences in men's and female partners' expression of distress encouraged the effort to look at patients recovering from cancer in the context of their relationships.

There is very little literature on the change that couples experience in their sexual function and their sexual relationships or satisfaction after surgery for prostate cancer. There is also almost no literature on how these changes affect dyadic adjustment. The majority of studies on couples reflect a one-time observation point (Garos, Kluck, & Aronoff, 2007; Langer, Rudd, & Syrjala, 2007; Navon & Morag, 2003; Neese et al., 2003; Soloway, Soloway, Kim, & Kava, 2005; Wootten et al., 2007). One study looked at the "prostate couple" pre-operatively and found discrepancies between patients' and partners' evaluation of their level of distress and of the man's erectile function (Soloway et al., 2005). Men were more distressed and regarded their own

erectile function as higher than did partners. A retrospective study asked couples in a focus group to recall the challenges to the maintenance of their sexual relationships during the post-operative period, but highlighted the need for increased communication within the couple, rather than the biopsychosocial aspects of the sexual recovery itself (Sanders, Pedro, Bantum, & Galbraith, 2006). Others have studied couples post-operatively and found that partners do not necessarily encourage men to seek help for sexual problems, assuming that sex will be over after prostate cancer treatment (Neese et al., 2003). Yet other research evaluated partner factors as predictors of men's sexual satisfaction (Garos, Kluck, & Aronoff, 2007) and concluded that partners' depression and depression about their sex lives had a negative effect on men's sexual satisfaction. Two studies attempted to get at couple issues by studying men's responses to questionnaires about quality of life, coping, mood, and marital satisfaction (Navon & Morag, 2003; Wootten et al., 2007).

Only one study of couples with prostate cancer has a longitudinal design. Couper and colleagues prospectively studied distress and dyadic relationship satisfaction of 103 men with prostate cancer and their partners (Couper et al., 2006b). They found that the female partners were more distressed at baseline and less distressed one year later than the men. On the other hand, unlike the men, female partners were markedly less satisfied with their couple relationship at the 1-year time point. Couper's findings are important because they show that couples can experience problems in the relationship with different timing, and that the lack of alignment in the experience can put them at risk for a poorer adjustment. Alignment does appear to be important; a study by Fagundes (2012) on intrusive thoughts in couples coping with prostate cancer reports that congruence in experience is associated with less negative affect within the couple (Fagundes, Berg, & Wiebe, 2012). Couper's study begins post-operatively and cannot,

therefore, address the impact of the change in the man's sexual function on the functioning of the couple.

Finally, currently available research on couples does not include factors that could have bearing on the change in couples' sexual function, sexual satisfaction, and dyadic satisfaction. Yet there are some factors that could be influential. During the past five or more years, men who are recovering erectile function after treatment have been advised to either take pro-erectile medications, to use vacuum devices, or both to promote blood flow and to prevent fibrosis in the penis. Recommendation of 'penile rehabilitation' has become widely disseminated in urologic practice as a part of the recovery experience (Mulhall & Morgentaler, 2007; Muller, Parker, Waters, Flanigan, & Mulhall, 2009; Teloken, Mesquita, Montorsi & Mulhall, 2009). In general, the effect of participation in penile rehabilitation is not included in the research on couples to date.

The cost of penile rehabilitation, as well as chronic use of aids to erections, can be high. Insurance coverage is very poor or non-existent. At least one study draws attention to the financial dilemma that men with erectile dysfunction face in the current system of insurance (Polinski & Kesselheim, 2011). Prostate cancer survivors are affected, by definition, because of their cancer treatment. Several studies attempted to identify whether cost plays a role in adherence to penile rehabilitation (Kimura et al., 2012; Lee, Cheetham, & Badani, 2009; Polito, d'Anzeo, Conti, & Muzzonigro, 2012; Teloken, Mesquita, Montorsi, & Mulhall, 2009). Their findings are equivocal; some suggest that cost is an issue, while others report that cost is not a barrier. In this study, both adherence to penile rehabilitation and income (a proxy to cost of rehabilitation) were considered as important covariates of couples' sexual recovery after surgery for prostate cancer.

It should be noted that extant research is largely motivated by an interest in helping the man recover optimally. Thus, looking at the partner factors is an element in this effort. The instrumental perspective on the partner places the partner at risk of being reduced to a tool in the armamentarium of aids to the man's recovery. This does not do justice to the experience of the partner in the couple's sexual recovery. The lack of recognition that the man's and partner's relationship is dynamic, and that the man and the partner have mutually influential roles in it, also hampers our understanding of the interactional sexual recovery of the couple (Lundgren, 2004). In this study, changes in sexual function, sexual satisfaction, and dyadic satisfaction were considered for both members of the couple.

The purpose of this study was to describe couples' recovery from before surgery to more than one year after surgery, based on functional changes at three time points of observation. Variables of interest, men's sexual function, men's sexual satisfaction, female partners' sexual function, and dyadic satisfaction were measured pre-operatively (T1), at three months after surgery (T2), and at approximately 18 months after surgery (T3). The relationship between the variables was explored. Age, length of relationship, income, education, comorbidities, the man's participation in penile rehabilitation, and the presence of sexual activity were also taken into account as potential important covariates.

Since couples experience sexual recovery in a way that proceeds from a pre-operative level of dyadic functioning to a new functioning based on coping with the sexual side-effect of surgery, these questions arose for the current research: How does the man's sexual satisfaction change after surgery? Does female sexual function and satisfaction change during the recovery period? Do couples retain sexual activity after prostatectomy? Does dyadic satisfaction (from

pre-treatment) change after prostate cancer treatment? What are the factors that affect dyadic satisfaction?

Method

Study Sample

Twenty-eight couples in which the man had prostate cancer participated in a previous study on the barriers to couples' sexual recovery after surgery for prostate cancer. Their survey data from the pre- and post-operative periods were available for this study. All couples were re-contacted as a part of the current study in order to obtain assessments for a third time-point.

Procedure

Participants were assessed with four validated measures at three time points: at baseline (T1), approximately three months after surgery (T2) and 6–28 months after surgery (T3). They filled out a demographic questionnaire at baseline, and answered questions about sexual activity and engagement in penile rehabilitation after surgery.

Measures

A battery of validated instruments was used to characterize (by way of patient and partner self-report) the man's and partner's sexual function, the man's sexual satisfaction, and the adjustment in the couple relationship. An example of data structure is shown in Table 4.1. Cronbach alphas from the original validation studies and from the current study are included in parentheses. Expanded Prostate Index Composite-Short Form (EPIC-SF) is a 13-item questionnaire assessing urinary, sexual, bowel and hormonal side-effects of prostate cancer treatment (Wei et al., 2000). Only sexual function assessment (five items) and urinary incontinence were used in this study. In each domain, participants responded to a 1-5-point Likert scale based on their experience in the last four weeks, with one reflecting low function

Table 4.1. Data Structure Used in the Analyses with Hypothetical Cases

Study ID	Patient	Timepoint	Dyadic Adjustment Scale Total Score	Male Sexual Function Total Score on Expanded Prostate Index Composite	Female Sexual Function Total Score on Female Sexual Function Index
1	1	1	116.00	83	
1	1	2	113.00	45	
1	1	3	119.00	54	
1	2	1	120.00		21
1	2	2	121.00		12
1	2	3	125.00		10
2	1	1	116.00	76	
2	1	2	126.00	40	
2	1	3	125.00	49	
2	2	1	104.00		28
2	2	2	91.00		22
2	2	3	114.00		17

and five reflecting high function. The questions in the sexual domain relate to the ability to have an erection, erection quality, and the extent to which erectile function has been a problem, denoted as 'bother.' Cut-off scores in the sexual function domains are 0-33 ('severe erectile dysfunction'), 34-45 ('moderate erectile dysfunction'), 46-60 ('mild/moderate' erectile dysfunction), (61-75 ('mild' erectile dysfunction), and a score above 75 ('no erectile dysfunction') (Wheat et al., 2009). Each domain has been validated. The sexual domain has a Cronbach $\alpha = 0.93$ (0.68). Urinary incontinence has a Cronbach $\alpha = 0.89$ (0.17).

The **Sexual Experience Questionnaire** (SEX-Q) (Mulhall et al., 2007) assesses satisfaction with erection, individual sexuality, and couple sexuality; it has 12 items and participants respond on a 5-point Likert scale. A higher number reflects a higher level of satisfaction. Cronbach α for the three domains are 0.88 (0.90); 0.79 (0.80); and 0.80 (0.90), respectively. The following ranges are used to describe satisfaction in each domain: 26–30

('satisfied'); 22–25 ('mild dissatisfaction'), 11–21 ('moderate dissatisfaction'), 1–10 ('severe dissatisfaction). The scores were adapted in this dataset to a 1– 100 scale to match the EPIC (multiplied by 3.33).

The **Female Sexual Function Index** (FSFI) (Rosen, 2000) is a 19-item assessment with six domains. A summary score assesses total sexual function (Total Cronbach α = 0.93 (0.97): desire (two items), arousal (four items), lubrication (four items), orgasm (four items), satisfaction (three items) and pain (three items). A summary score assesses total sexual function. Participants respond on a 1-5-point Likert scale based on their experience in the last four weeks, the number one reflecting low function and five reflecting high function. Questions related to intercourse have a 0 option for 'no intercourse'. All six domains of the FSFI have been validated and are reliable Cronbach α for the six domains is Desire = 0.92 (0.91), Arousal = 0.95 (0.97); Lubrication = 0.96 (0.97). Orgasm = 0.94 (0.97); Satisfaction = 0.89 (0.85), and Pain = 0.94 (0.99), respectively). Scores range from 1-6 with a maximum total function score of 36. Ranges are not defined.

The **Dyadic Adjustment Scale** (DAS) (Sharpley & Cross, 1982; Spanier, 1976) is a 32-item measure. Participants respond to a 1-5-point Likert scale, with a lower score reflecting a lower function. There are four domains: consensus, affect, satisfaction, and cohesion, but only the total score is reliable (Cronbach α = 0.96 (0.79) (Sharpley & Cross, 1982). A total score of 108 was considered to be average in both Sharpley's and Spanier's validation studies.

Demographic information was collected at baseline. **Clinical data** were abstracted from the patients' medical records. After surgery, data on compliance with penile rehabilitation recommendations, the use of erectogenic aids, and presence of sexual activity were collected.

Charlson Comorbidities Index (Charlson, Pompei, Ales & McKenzie, 1987) predicts the risk of death from comorbid conditions and is widely used in the research literature.

Data Analyses

General linear models allowing the errors associated with the repeated measurements on individuals to be correlated were fitted to each of four primary continuous dependent variables (DVs): (a) male sexual function (as measured by the Expanded Prostate Index Composite); (b) male sexual satisfaction (as measured by the Sexual Experience Questionnaire); (c) female sexual function (as measured by the Female Sexual Function Index); and (d) dyadic adjustment/satisfaction (as measured by the Dyadic Adjustment Scale). Predictor variables (IVs) were categorical and included time point, gender, and income. Income was measured in the Demographic Survey by a 9-range scale (e.g., $10,000-$19,999): it was categorized into a dichotomous variable with family income below or above $50,000, based on the mean range, which was $50,000-$59,999. Baseline assessments, i.e., age, education, men's comorbidities and post-operative participation in penile rehabilitation, as well as post-operative sexual activity, were considered to be covariates, with only one covariate tested in any given model due to the small sample size. Because urinary incontinence can be a handicap to sexual recovery, it was also considered as a covariate.

In this analysis, Level 1 represents evaluation of the change in average functional outcomes on all four dependent variables (male sexual function, female sexual function, male sexual satisfaction, and dyadic adjustment/satisfaction) at three time points. Level 2 represents a comparison of the sample average outcomes on the Dyadic Adjustment Scale for the men and the partners at the three time points. Level 3 represents the inclusion of covariates (baseline age, income, education, men's physical comorbidities, post-operative participation in penile

rehabilitation, and presence of sexual activity in the assessment of the average outcomes of all four dependent variables at the three time points.

The SPSS MIXED procedure, which enables the general linear models described above to be estimated (using a heterogeneous-compound symmetry covariance structure for the repeated measures on each individual, where the error variances are allowed to change over time) was used for these analyses (IBM SPSS Statistics 20). The University of Michigan Institutional Review Board approved the study.

Results

Description of the Sample

Table 4.2 represents participants' demographic characteristics at baseline. The reasons given by couples for dropping out during the post-operative phase included a choice of radiation treatment rather than surgery (2) absence for more than 5 months (1) and the man's return to work or the couple's return to retirement activities (5). The third wave of data collection was not anticipated by these couples and the reasons given for non-participation was death of the patient (1) and the couples' feeling that they were now at a distance from the surgery and did not wish to prioritize participation in the study (4). One couple returned to the study for the third time point (T3) although they did not participate during the post-operative phase.

The men's mean age was 62.2 (SD = 6.5) and their partners' mean age was 58.4 (SD = 7.4). The couples were married for 37 years on average. Seventy-one percent of the patients had high school and higher education; 58% of partners were similarly educated. The couples' mode yearly income was $90,000 and higher (range of $20,000-$90,000+). Twenty-six of the male participants were White, one was African American, and one was Asian. Twenty-six of the female participants were White, one was African American, and one was Hispanic. These

Table 4.2. Demographic Characteristics of Participants (N = 28 Patients and 28 Partners)

Characteristic	N	%
Ethnicity		
White		
Patient	26	93
Partner	26	93
African American		
Patient	1	4
Partner	1	4
Hispanic		
Patient	0	0
Partner	1	4
Chinese American		
Patient	1	4
Partner	0	0
Education beyond HS		
Patient	20	71
Partner	17	61
	Mean	**SD**
Age at baseline		
Patient	62.2	6.50
Partner	58.4	7.4
Length of relationship		
Patient	33.8	13.3
Partner	33.7	14.3
	Mode	**Range**
Income		
Patient and Partner	> $90,000	<$30,000-$90,000

characteristics reflect the population treated at this cancer treatment center. Most of the patients had low- (Gleason 6) or moderate- (Gleason 7) risk early stage prostate cancer. In general, these were fairly healthy men. At T3, they were 18 months past their surgeries, on average.

After surgery, of the 20 men who continued in the study, only a few men's pathology suggested a high risk of recurrence; four men had a Gleason score higher than 7 and a post-operative pathological stage T3. Eighteen had nerve-sparing surgery, which gave them the best chance of recovering erectile function and penile sensitivity. Two had partial nerve-sparing surgery. Two of the men with the higher risk disease had additional localized radiation therapy, which would have had a negative effect on their erectile function.

Table 4.3 summarizes the patients' clinical characteristics. Of the 20 couples that returned after surgery, 12 (60%) continued to be sexually active after surgery, while 8 (40%) reported minimal or no sexual activity. Fourteen men (70%) engaged in penile rehabilitation to some degree, four (20%) did not, and one (10%) did not respond to the question about penile rehabilitation.

Level 1 Analysis: Functional Outcomes at T1 (Baseline), T2 (Three Months After Surgery), and T3 (18 Months After Surgery)

Functional outcomes at the three time points are described in Table 4.4. The men's average baseline mean erectile function (as measured by the EPIC) was just one point above 'mild erectile dysfunction' range. Assessments at T2 demonstrated a statistically significant decrease (mean change = 30.86, $p < 0.001$ for T2 vs. T1 effect in general linear model; see Table 4.3) in sexual function to 'moderate erectile dysfunction'. By T3, there was a statistically significant increase in function (relative to T2) to 'mild to moderate erectile dysfunction' (mean change = 10.72, $p = 0.02$). Large standard deviations indicate great variability in the scores,

Table 4.3. Patients' Clinical Characteristics
(N = 28 at T1, N = 20 at T2)

Characteristic		
Pre-Operative PSA Mean (SD)	18 (6-28)	
	n	%
Pre-Operative Gleason Score		
6	11	39
7	13	46
8	2	7
9	2	7
Clinical Stage		
T1	22	79
T2	6	21
Post-Operative Gleason Score		
6	3	15
7	16	60
8	0	0
9	1	0.5
Pathological Stage		
T2	16	80
T3	4	20
T4	0	0
Nerve Sparing		
Bilateral	18	90
Unilateral	2	10
None	0	0
Comorbidity Score (median)	0	0
Prostate Cancer Treatment		
Surgery	28	100
Radiation	2	10

particularly at T3. Men's average scores regarding bladder control changed in a significant manner from nearly full continence at baseline to incontinence at T2 (on average). At T3, men on

average were still experiencing incontinence to a significant degree, although their bladder control appeared to be improving. Once again, there was great variability in scores. Men were mildly dissatisfied with baseline erection and individual sexuality (as measured by the SEX-Q). Satisfaction in both domains decreased significantly to 'moderate' dissatisfaction at T2 and remained in the same range at T3. Men were already 'moderately' dissatisfied at baseline with their couple sexual relationship, and their satisfaction declined significantly within that range at T2. Their dissatisfaction continued on the same trajectory at T3, but nearly reached the 'severe dissatisfaction' range. As the large standard deviations indicate, there was a great deal of variability in the scores, particularly at T2 and T3.

Female partners' sexual function (as measured by the FSFI) was moderately low on average at baseline and in general did not change over time. Most of the subscales of the FSFI did not show a statistically significant change between T1, T2, and T3, although there was a trend suggesting a decrease in function. Only sexual satisfaction, which was represented by a higher score at baseline than the other functional subscales, decreased significantly at T2 and continued to decline as time went on. Large variability in the scores was present for all subscales, particularly at T2 and T3.

Men and partners' Total Dyadic satisfaction (as measured by the DAS) did not show a statistically significant change, although graphic representation suggests that partners' dyadic satisfaction decreased markedly at T3 (Figure 4.1).

Level 2 Analysis: Patient and Partner Comparison

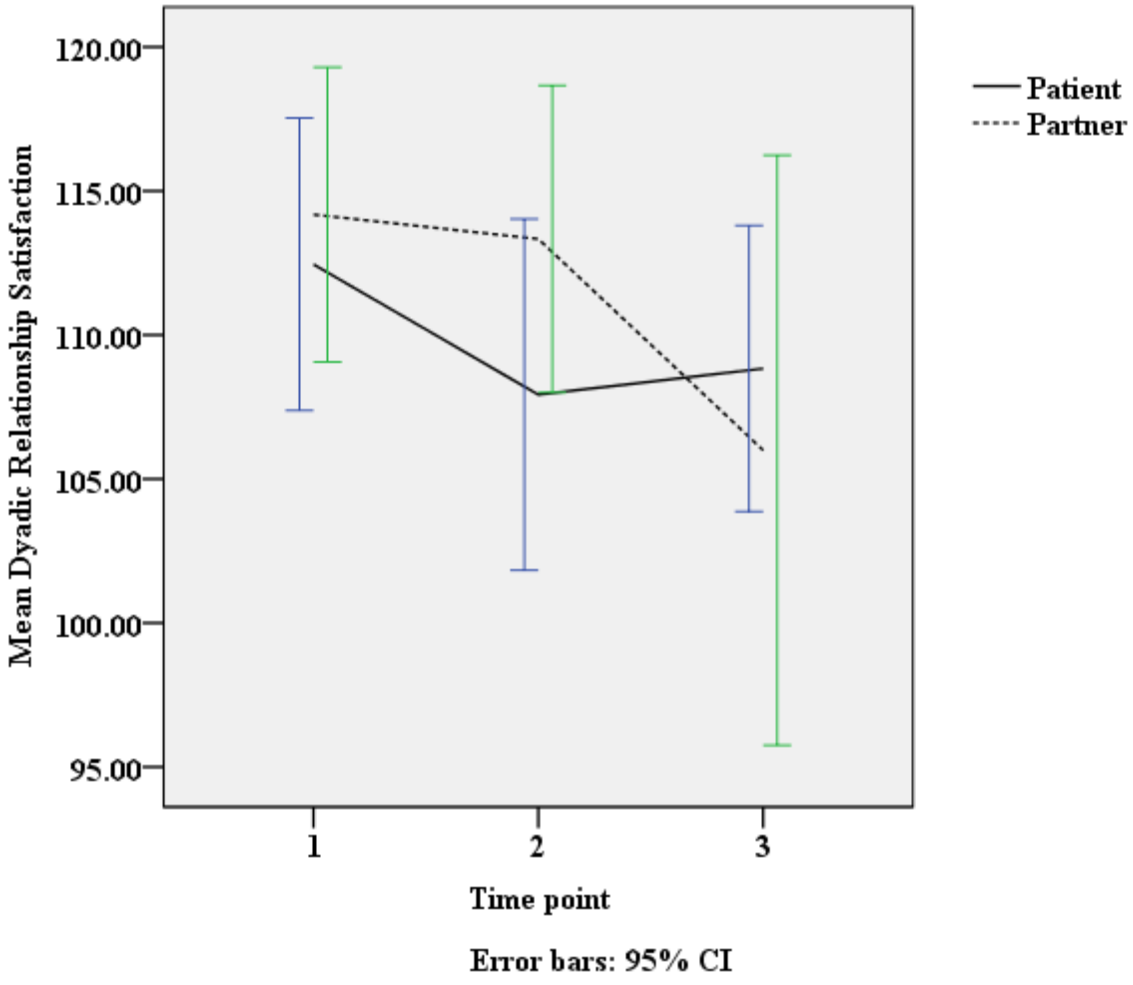
There were no statistically significant differences between the men's and partners' average scores on the Dyadic Adjustment Scale at any of the three time points. Graphical representation

Table 4.4 Men's and Partners Functional Scores at Three Time Points

Variable	Time point 1 n=28	Time point 2 n=20	Time point 3 n=16				
	Mean(SD)	Mean(SD)	Mean(SD)	F Statistic	*p* T2-T1	*p* T3-T2	*p* T3-T1
Patients							
EPIC sexual function	76.23(21.70)	45.37(24.90)	56.09(30.75)	25.693	<0.001	0.02	0.03
EPIC urinary incontinence	89.30(18.512)	74.55(26.89)	78.18(26.81)	8.934	0.001	0.44	0.02
SEX-Q erection	67.82(25.51)	40.62(24.85)	46.39(25.39)	14.425	0.01	0.37	0.01
SEX-Q individual	73.33(15.99)	52.38(20.27)	55.73(24.10)	17.599	<0.001	0.62	0.001
SEX-Q couple	61.67(26.59)	43.52(29.51)	39.74(34.72)	8.714	0.001	0.59	0.001
DAS total	112.45(11.45)	107.93(10.56)	108.83(7.81)	1.513	0.71	0.21	0.14
Partners							
FSFI desire	3.02(1.19)	2.94(1.21)	2.80(1.15)	0.214	0.96	0.60	0.55
FSFI arousal	3.95(1.79)	3.24(2.04)	2.90(1.94)	2.647	0.06	0.87	0.07
FSFI lubrication	4.06(2.07)	3.08(2.52)	2.86(2.44)	1.811	0.10	0.91	0.18
FSFI orgasm	3.90(2.05)	3.40(2.48)	3.09(2.49)	0.451	0.36	0.84	0.60
FSFI pain	3.70(2.53)	2.95(2.81)	3.04(2.99)	0.821	0.28	0.95	0.32
FSFI satisfaction	4.369(1.44)	3.54(1.71)	3.15(1.83)	5.328	0.01	0.75	0.01
FSFI total	23.46(8.36)	19.71(10.27)	17.84(11.11)	2.553	0.06	0.95	0.10
DAS total	114.18(11.54)	113.33(10.72)	106.00(16.95)	1.513	0.71	0.21	0.14

(Figure 4.1) suggests that men's satisfaction with the couple relationship plummeted after the surgery, but improved slightly at the third time point. Partners' satisfaction appears to have decreased at the third time point. The error bars (representing +/- 1 SE) in the figure illustrate the general statistical overlap in men's and partners' scores, particularly at T3. The standard error of the partners' average score at T3 suggests a wide range of dyadic satisfaction outcomes, and perhaps even a split sample.

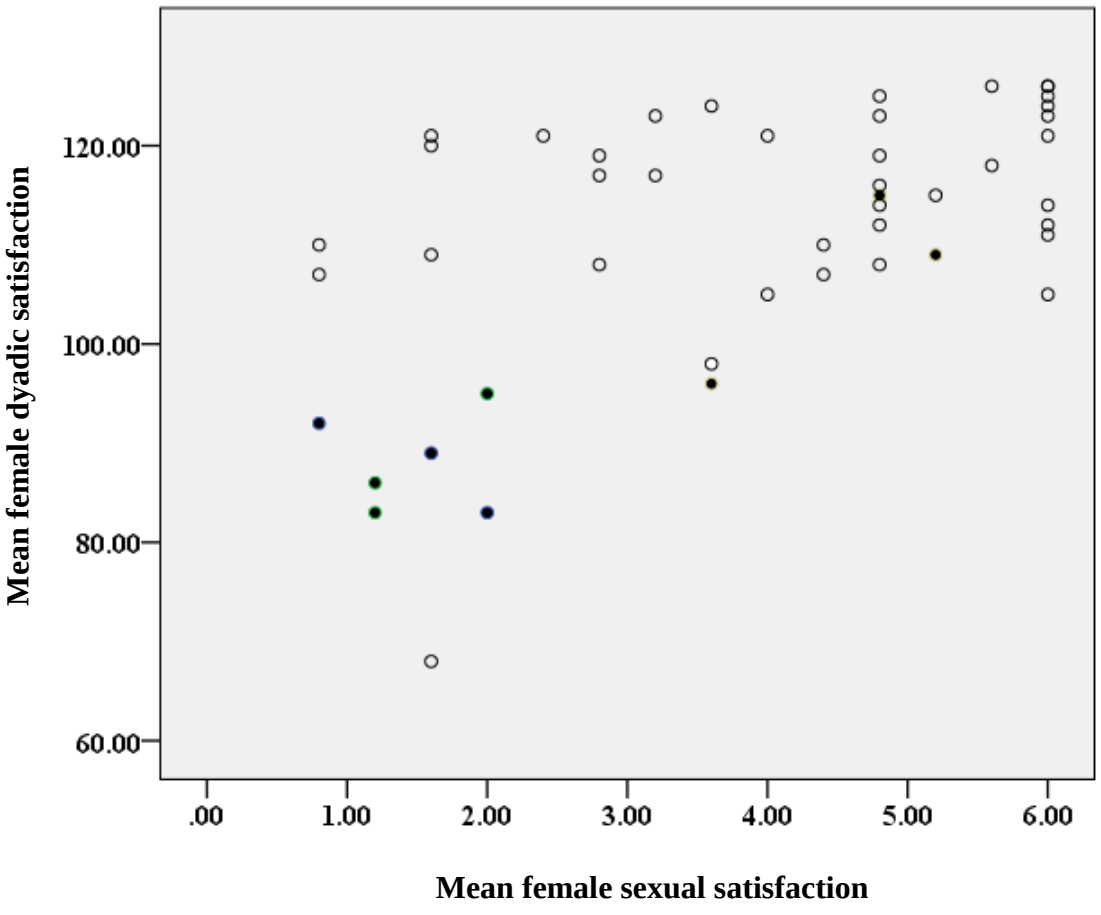
Figure 4.1 Dyadic Satisfaction at T1, T2 And T3 with Error Bars. For interpretation of the references to color in this and all other figures, the reader is referred to the electronic version of this dissertation.



Level 3 Analysis: Inclusion of Covariates

Controlling for age, income, education, penile rehabilitation, or sexual activity alone or in combination did not appear to change the statistical significance of the changes over time in any of the DVs of interest. Urinary incontinence as a covariate did not make a contribution. However, including female sexual satisfaction and income appeared to have an effect on the female relationship (dyadic) satisfaction that showed a trend toward significance, particularly between T2 and T3 (T1:2 p = 0.27, T2:3 p = 0.08, T1:3 p=0.18, respectively). Figure 4.2 demonstrates a split in the sample based on female sexual satisfaction and income, i.e., the

Figure 4.2 Female Dyadic Satisfaction Based on Female Sexual Satisfaction and Income



female partner's low sexual satisfaction and a couple's low income level are associated with a the female partner's lower dyadic satisfaction, while female partners' higher sexual satisfaction and high income level are associated with a female partner's greater satisfaction within the couple dyadic relationship.

Discussion

Although the small sample in this study requires that we view the findings with caution and not generalize to the population of prostate cancer survivors and their partners, the findings are intriguing and suggest the possibility of both confirmation and extension of the current state of knowledge about couples' sexual recovery after surgery for prostate cancer. Men's sexual function declined after surgery and began to improve 18 months later, as has been described in other research (Penson et al., 2005). However, while one might expect that men's sexual satisfaction might decline and correspondingly improve, the findings of this study do not affirmatively support that expectation. While men's satisfaction with their erection and individual sexuality began to rebound at 18 months after surgery, satisfaction with their couple sexual relationship, which was lower than satisfaction with erection and individual sexuality at baseline, did not improve; in fact, it appeared to continue to decline. The enormous variability in scores suggests that some men were experiencing their sexual relationships as improving, while others may have felt that their sexual relationship was seriously damaged by the loss of erectile function.

Female partners' sexual function appeared to decline after surgery and did not improve at 18 months after surgery. The statistically significant decrease in the partners' sexual satisfaction (which had been moderately high at baseline) between T1 and T2, and T1 and T3 seems to stand out because it is the only subscale in the FSFI that attends to the woman's psychological

response rather than to physiologic function. The small sample size does not allow for an inference of any specific meaning from this finding other than that it may be important in future studies to distinguish between female sexual function and sexual satisfaction. We can see in this study that there is difference in men's sexual function recovery and sexual satisfaction recovery. This distinction is likely equally useful when looking at female sexuality. Previous research suggests that female sexual function is the 'driver' of men's sexual recovery (Moskovitz, et al. 2010, Shindel et al., 2005). The findings of this study raise the possibility that women's feelings about sex, rather than physiologic sexual function, influence sexual recovery and overall sexual satisfaction.

Female partners' apparent decrease in dyadic satisfaction, based on their sexual satisfaction at 18 months after surgery (Figure 4.2) is reminiscent of Couper's study findings (Couper et al., 2006b). He and colleagues found that partners' satisfaction with their relationship declined at one year after prostate cancer treatment. As Figure 4.2 demonstrates, the decrease in both female sexual satisfaction and female dyadic satisfaction suggests that female sexual satisfaction may mediate dyadic satisfaction. A similar trend was not found for men, when looking at dyadic satisfaction based on the men's satisfaction with the couple sexual relationship. This finding is counter-intuitive in the light of previous research that tended to view female partners' low post-menopausal sexual viability as a negative factor in the couple sexual relationship and in the men's sexual recovery. The current findings suggest the possibility that partners try to stay engaged in the sexual recovery immediately after surgery, but that their ability to sustain that effort while not experiencing sexual satisfaction flags as time goes on. The role of the partner's sexuality and sexual satisfaction in the couple's sexual recovery is a subject that warrants further exploration.

The combined influence of couple income and female sexual satisfaction on the female partner's relationship (dyadic) satisfaction points to the possibility that overall economic or financial stress may affect the female partner's satisfaction with the relationship because of the couple's inability to attend to sexual recovery. This finding may be related to the research that has shown that cost can be a barrier to penile rehabilitation and, ultimately, to the sexual recovery of the couple (Lee, Cheetham, & Badani, 2009; Teloken, Mesquita, Montorsi, & Mulhall, 2009). Three couples in the sample reported financial worries; in two of those couples, the man was unemployed. The unemployed men reported feelings of guilt and marginalization. While one cannot draw conclusions from two participants' experiences, these men were feeling distressed in the two major roles that are socially constructed as the core of masculinity: sexual prowess and success in achievement. Both are eloquently described by Wall and Kristjanson (2005) who seek to revise what they call 'hegemonic masculinity' so as to provide men who are recovering sexual function and sexual relationships after prostatectomy with more flexible self-image options (Wall & Kristjanson, 2005). The complex nature of the relationship between individual and couple functional issues and external stressors should be further investigated in the context of couples' sexual recovery after surgery for prostate cancer.

Study Strengths and Limitations

The strength of this study is its longitudinal design, which started with a pre-operative assessment and went on to 18 months after surgery on average. The inclusion of men and partners as equal participants in the study of a sexual recovery of the couple after surgery for prostate cancer added a new dimension in that it did not view the partner as a variable in the man's recovery. Following patients' and partners' sexual function, satisfaction, and their dyadic relationship from before surgery to 18 months afterward provides an initial picture of the

challenges that couples experience as they attempt to recover their intimate lives. The findings triangulate the findings of the two qualitative studies of the dissertation which challenge the way in which the role of female partners' sexuality has been perceived in extant research on couples' sexual recovery after prostate cancer treatment.

There are several study limitations. The sample was small and non-diverse, both in terms of ethnicity and culture, and sexual orientation. The attrition of participants during T2 for reasons of different treatment choice, return to work and retirement activities, and lack of availability during the timeframe of the study, and during T3 for reasons of death and desire not to prioritize the research, resulted in missing data. The wide temporal range of the participants' assessments during T3 makes the 'average' time point less reliable and valid. In addition, while following patients for nearly 18 months was a significant contribution to the literature on sexual recovery after prostate cancer, erectile function continues to recover for six or more months on average after the end of the study, and the current study highlights what might be considered to be the 'trough' of the recovery trajectory rather than the ultimate end-point. Given the limitations, the findings of this study can be considered transferable, but not generalizable.

Tentative Implications for Social Work Practice

Men's loss of erectile function and its impact on the couple relationship need to be addressed along the whole trajectory of their experience of surgical treatment for prostate cancer. The importance of supporting couples and, in particular, partners during different phases of illness has been already described (Northouse, Mood, Schafenacker, et al., 2007) in the context of distress and appraisal of illness. This study's finding underscores the importance of attending to intimate relationships as well. Preparation for sexual changes can be anticipated and rehabilitation options discussed as a way of empowering couples to participate in their own

sexual recovery. After surgery, couples need support, and some need intervention as they navigate the path toward sexual recovery through extended periods of disappointment and uncertainty. The large variability in function after the surgery should be noted as, at least in part, the reason why it is difficult to predict for men and partners how each individual will recover. At the same time, imparting to couples information about rehabilitation activities can have an empowering effect during the prolonged waiting period.

Couple sexuality, and partners' concerns in particular, have not been addressed proactively in current usual care. Yet attention to sexual concerns and partners is necessary if the couple is to recover sexual intimacy. Social workers are attuned to the family context when working with patients with cancer. Addressing sexual concerns, however, is not one of the competencies typically attained in social work education (Zebrack, Walsh, Burg, Maramaldi, & Lim, 2008). The findings of this study strongly suggest that acquiring such competency would strengthen social workers' ability to empower men with prostate cancer and their partners as they work toward regaining meaningful, rich lives after definitive treatment for prostate cancer.

Implications for Research

This small pilot only begins to lift the veil from the struggles that couples experience as they cope with the sexual side-effects of surgery for prostate cancer. A large prospective study is needed that strives to learn about the changes not only in sexual function and dyadic adjustment, but also in the partner's experience and the couple's coping. In addition, a thorough investigation is necessary of the availability of insurance coverage vis-a-vis clinical recommendations for rehabilitation of sexual function and sexual intimacy. Patients and partners are set up to experience distress when their resources fall short at a time when they are encouraged by their survivorship care team to work on sexual recovery. A wholistic approach to research should

encourage not only the development and testing of interventions for the physiologic, psychological, and couple level issues: it should assess those practical aspects of the recovery that can inform insurance companies and policy makers about the full extent of the needs of patients who are recovering their intimate lives after surgery for prostate cancer.

Conclusion

Although men's erectile function improves with time, men do not reach sufficient function not to need aids to erections and couples cannot return to familiar sexual interactions. Both men and partners experience dissatisfaction with their sexual relationship. Female partners' sexual dissatisfaction, in combination with the stress of low income, can affect negatively couples' satisfaction with their relationship.

CHAPTER V

INTEGRATION OF FINDINGS

The purpose of the dissertation was to develop an empirically based model of couples' sexual recovery after surgery for prostate cancer. The extant research literature has described the significant problems that men and partners encounter as a result of erectile dysfunction, a side-effect of the surgery, and their difficulty coping emotionally and in their couple relationships (Bokhour, Clark, Inui, Silliman, & Talcott, 2001; Bokhour, Powel, & Clark, 2007; Couper, Bloch, Love, Duchesne, et al., 2006; Couper, Bloch, Love, Macvean, et al., 2006; Hedestig, Sandman, Tomic, & Widmark, 2005; Sanda et al., 2008; Tanner, Galbraith, & Hays, 2011; Wootten et al., 2007). Although there have been attempts to describe the effect of surgery for prostate cancer on sexuality (Bober & Sanches-Varela, 2012; Tierney, 2008; Wittmann, Foley, & Balon, 2011), there is no coherent description of the overall experience of the impact of erectile dysfunction on couples, and no understanding about how the couples think about the recovery or what actions they take to cope with the physiologic change in practical terms, emotionally, and in the relationships. The partner's response to prostate cancer has been studied to some degree, but the partner's role in the sexual recovery has been viewed primarily as a factor in the man's sexual recovery, only somewhat in terms of the partner's own authentic experience (Moskovic et al., 2010; Shindel, Quayle, Yan, Husain, & Naughton, 2005; Soloway, Soloway, Kim, & Kava, 2005). The few studies that describe partners' responses have viewed partners as helplessly

adjusting to the sexual dysfunction and giving up sex either in the context of gratitude for cancer survival or with deep grief, even trauma (Bruun, Pedersen, Osther, & Wagner, 2011; Tanner, Galbraith, & Hays, 2011; Thomas et al., 2012). Finally, the research literature addresses neither the process of recovery nor the meaningful end-point at which couples can say that they have recovered their sexual intimacy.

This dissertation combined qualitative and quantitative methodologies to begin to answer the questions raised by the gaps in the research: what does the recovery look like; how do couples anticipate and then cope with erectile dysfunction; what is the role of the partner, and how do couples define return to sexual intimacy; is the process of grief and mourning a relevant variable in the recovery? How does men's and partners' sexual function, sexual satisfaction, and dyadic satisfaction change over time? Starting with a biopsychosocial theory of sexuality (WHO, 2002), the theory of ambiguous loss with a grief and mourning response (Boss, 1999; Parkes, 1971), and a definition of recovery adapted from the field of substance abuse (http://www.samhsa.gov/, 2011), the three research studies provide individual contributions to the research literature on couples' coping with prostate cancer. Together, the tree studies' findings coalesce into a rich, comprehensive description of couples' sexual recovery after surgery for prostate cancer which helps conceptualize a model of the recovery.

The purpose of Chapter I was to review the literature on couples' coping with prostate cancer and to position the dissertation research in such a way that it could begin to fill an identified gap in knowledge. Relevant concepts were defined and a preliminary model of couples' sexual recovery, based on a biopsychosocial theory of sexuality and grief theory, was proposed. The significance of the dissertation research was stated.

In Chapter II, the first dissertation study focused on couples' common experiences of anticipating and living with the sexual side-effects of the surgery for prostate cancer. A substantial sample of 20 couples described in semi-structured interviews their thoughts and feelings about the anticipated sexual consequences of surgery for prostate cancer and their lived experience of the work of sexual recovery after the surgery.

During the pre-operative period, while their first concern was the eradication of cancer, couples were aware of the side-effects and the need to cope with them afterwards. Their reactions ranged from sadness about anticipated sexual losses to a preference not to anticipate and cope as the experience unfolded. The participants confirmed the findings of several previous studies which had demonstrated that patients had over optimistic, even unrealistic expectations of the recovery of erectile function despite pre-operative education about the consequences of surgically induced damage to the nerves that govern erections (Symon et al., 2006; Wittmann et al., 2011). In this study, it was shown that partners were aligned with the men in their expectations; men and partners mutually reinforced each other**.** Men and partners' mutual influence has been noted in other research (Ko et al., 2005).

Unlike in previous studies, this study uncovered possible explanations for these expectations: couples' firm faith in the resilience of their long-term relationships with each other and success in overcoming previous challenges, as well as their high confidence in the skill of the surgeon. For some couples, this meant a hope that, if the man's erectile function were to recover, they would not have to use erectile aids during the recovery period. In this way, couples underestimated the dramatic influence of nerve damage that takes place even in the most skillfully performed prostatectomy. Psychologically, it is also possible to infer that the high expectations represent a defense against loss which is present in the early stages of grief,

particularly if the grief is ambiguous because the outcome is uncertain and cannot be predicted for the individual (Boss, 1999). After surgery, couples' description of their efforts to cope gave a foreshadowing of the kinds of strengths and vulnerabilities that bode well or poorly for the recovery of sexual intimacy.

It must be stressed that the recovery is arduous from a physiologic, psychological, and relationship point of view. Couples described the recovery as "work" and listed a number of challenges that they had to overcome: dislike of unspontaneous sex and the use of sexual aids, men's loss of sexual confidence and confidence in themselves as men, the partners' uncertainty about how to be sexually helpful, and the awkwardness of sexual relating in the new circumstances. Couples that appeared to be coping well engaged in ongoing sexual activity, communicated reasonably well, and accepted lower sexual function and erectile aids. Female partners in those couples were engaged sexually regardless of menopausal status. This finding conflicts with previous research which regards post-menopausal women's sexual function as a potential hindrance to men's recovery of erections (Moskovic, et al., 2010; Shindel, et al., 2005). Couples that seemed poised for a more difficult recovery had one or more of the following challenges: pre-existing or new relationship problems, pre-existing sexual difficulties, inability to overcome dislike of unspontaneous sex and dislike of aids to sexual function, persistent urinary incontinence, financial worries, and partners who had a low interest in sex, regardless of menopause. In at least two cases, a need for additional treatment put a pall on sexual recovery despite a satisfactory couple relationship because additional treatment reduced the man's sexual sensitivity. It is therefore important to recognize that sexual.

The influence of urinary incontinence, of additional treatment and other clinical conditions such as comorbidities (not significantly present in this sample, but likely true of aging

couples) should not be underestimated, as it colors the more specifically sexual issues by introducing stress and distraction from the sexual recovery.

The role of grief and mourning was identified as the process that begins after diagnosis and continues after surgery as couples cope with their sexual readjustment. The ability to grieve and mourn varied in the couples who participated in this study. For some couples, grief was a difficult, but tolerable aspect of the experience, a sorrow that was shared and accepted. For those couples, sexual losses became a challenge, but their ability to accept their feelings and their changed sexual relating led to greater emotional intimacy and a resumption of a meaningful sexual relationship. While they continued to be highly aware of their new sexuality and needed to reassure each other, these couples began to emerge with a sense of accomplishment in the second year of the recovery. One can conclude that these were the 'resilient' or 'thriving' couples. The research literature on post-cancer thriving and resilience describes factors such as an ability to come to terms with loss with an optimistic outlook and a newly constructed meaning, an ability to reframe and normalize what is negative, and an ability to continue to be active on one's own behalf as critical to successful adjustment (Gannon, Guerro-Blanco, Patel, & Abel, 2010; Parry & Chesler, 2005). The presence or availability of a supportive significant relationship has also been associated with the ability to thrive in cancer survivorship (Ruini, Vescovelli, & Albieri, 2012). The couples who were able to thrive demonstrated flexibility in their sexual expression and the ability to do so was meaningful to them, which agrees with Reese's model of post-cancer coping with sexual changes (Reese, 2011; Reese, Keefe, Somers, & Abernethy, 2010).

Several couples found the sexual loss or changes in the sexual relationship sufficiently overwhelming that they did not move through grief, but remained deeply affected. These couples

did not recover their sexual relationships and continued to mourn intensely. Several couples who experienced relationship difficulties found sexual recovery harder to attain. Their grief encompassed both the sexual changes and the relationships. From these findings, it is possible to conceptualize grief and mourning as a mediating process through which couples move with greater or lesser success toward a new sexual paradigm. It is possible that these couples were experiencing 'complicated mourning' (Rando, 1993), a condition that prevents normal grief from proceeding. This aspect of the grief experience needs further investigation.

Couples defined the end-point of sexual recovery in various ways, but the most compelling definition that did not focus on erectile function per se was one in which both the man and the partner could return to unselfconscious sex. Men expressed gratitude for the support they received from their partners. Partners, while at times frustrated, loyally reassured the men and tried to be helpful in any way they thought was needed, including being sexually available as men attempted to resume sexual activity. The role of the partner, an important aspect of the recovery, was examined in depth in the second study on the partners' role in the couple's sexual recovery.

Chapter III describes the findings of the second study. The candid discussion of the partner's role in the couple's sexual recovery was able to proceed because men and partners were interviewed separately. Ten men and nine partners participated. For the most part, men and partners agreed on many aspects of the role such as emotional support, help with appointments, and availability for sexual activity. They also agreed on seeing partners' own sexual interest as particularly important to the success of the process of recovery, presumably by giving men confidence that the partners were not offering sexual interest purely as a part of rehabilitation. This was true of partners who were post-menopausal and of the partner who was gay and a

prostate cancer survivor himself as well. Clinically, sex therapists know that women with low post-menopausal desire can continue to enjoy sex because their capacity for pleasure and for orgasms remains intact for most. Sexual interactions no longer rely on a hormonal surge. Instead, they become intentional, and women may need sexual aids such as lubricants and vibrators. Not all men and women are fully aware of this. As characterized by Basson (2004) in her description of female sexuality, intentionality is actually a part of female sexual expression even before menopause, because women are exquisitely attuned to environmental distractions and the quality of their couple relationship; as a result, they come to sexual interactions based on a decision rather than physiologic desire (Basson et al., 2004). After prostate cancer, this mode of sexual expression also becomes relevant to men who are distracted by worries about performance because they are unable to achieve a spontaneous erection. In the sample of the 'partner' study, intentional, communicative, engaged pre-operative couple functioning that entailed pleasurable sexuality augured well for the couple's sexual recovery.

In this study, partners spoke candidly about their sexual needs and needs for support, which had been put on hold for most. Men were unaware of the partners' needs. Neglect and self-neglect of partners' needs is an issue that can become a problem in the long run and contribute to partners' distress.

As was noted in the first study, the recognition of the ability of post-menopausal partners to enjoy sexual pleasure in the context of couple relationships is particularly important because the research literature in prostate cancer is replete with doubts about the viability of female sexuality after menopause. Yet in this study, female interest in sex regardless of menopause was one of the critical mediators of the effectiveness of the role of the partner in the couple's sexual recovery, as perceived by both men and partners. Given the recognition of the significance of

the partner's role, understanding the partner's needs becomes a necessary aspect of the evaluation of the couple's ability to work toward renewing sexual intimacy. To this point, the research literature has not been oriented toward addressing partners' sexual needs or the need for men to know about and have empathy for them. This research discovered that partners tend to be naturally protective in the attempt to provide unstinting support to men who struggle with the loss of sexual function, but they have unmet needs which can quickly transform into a burden if not recognized and addressed. It is therefore in the best interest for the research paradigm to recognize partners' post-menopausal sexual viability and to adopt a stance of mutuality when learning couples' sexual recovery after prostatectomy.

The survey findings of this mixed methods study were described in Chapter IV. They focused on change in functional outcomes: sexual function, sexual satisfaction, and dyadic satisfaction. They were not intended to make an inference about the population of surgically treated men with prostate cancer and their partners. Rather, they corroborated what the interviews so eloquently uncovered: even as men began to recover erectile function in the second year after surgery, they continued to be dissatisfied with their ability to perform, and their feelings about their couple sexuality suffered the most. The partners were also experiencing sexual dissatisfaction which did not rebound in the second year. The surveys revealed that it was female sexual satisfaction that governed most significantly how they appraised their couple relationship. Couper and colleagues (2006b) speak to the temporal misalignment in the men's and female partners' relationship satisfaction as time proceeds from prostate cancer treatment (Couper, Bloch, Love, Duchesne, et al., 2006b). At the end of the first year after treatment, partners became dissatisfied with the relationship. We now have a potential explanation why this might happen. If partners are willing to forego sexual satisfaction for some time, they may not be

willing to forego it forever without a major adjustment in expectations. If the adjustment fails, partners may experience intensely the chronic nature of the loss of familiar sexuality in the relationship. Supporting their 'patient' partners may become a burden, and finally, relationship dissatisfaction may ensue.

The impact of income, when added to female sexual satisfaction in the dyadic relationship, is important, but the meaning of this combination of effects is not fully obvious. It is difficult to draw specific conclusions from this finding. The only research that addresses the financial aspects of sexual recovery after surgery of prostate cancer is the two studies that suggest that the cost of aids to erections is a barrier to sexual recovery (Lee, Cheetham & Badani, 2009; Teloken, Mesquita, Montorsi & Mulhall, 2009). This is a much under-appreciated aspect of the sexual recovery: insurance coverage is either minimal or non-existent, and couples often do not realize it when they plan treatment for prostate cancer. This is a familiar concern in clinical practice. However, it is not clear that the current findings represent these concerns or whether they may be related to other aspects of financial concerns.

Building a Theoretical Model of Couples' Sexual Recovery After Surgery for Prostate Cancer

The goal of this exploratory research was the development of a theoretical model of couples' sexual recovery after surgery for prostate cancer that could be tested further in confirmatory research. The findings reported in the mixed methods study described in Chapters II, III and IV suggest a conceptualization based on couples' own perception of their experience, as demonstrated in the interviews, and on the surveys that documented change in function and reinforced the interview narratives. In this model, grief and mourning mediate couples' sexual recovery after surgery for prostate cancer. Pre-existing couple relationship, surgery outcome,

couple coping, clinical variables such as urinary incontinence and comorbidities, as well as income moderate the sexual recovery of the couple and dyadic satisfaction. The role of the partner, mediated by the partner's interest in sex, regardless of menopause, moderates couple coping. Couple coping affects and is affected by the grief process (Figure 5.1). The variables in this model can be operationalized, and the model can be tested in a hypothesis-driven quantitative study with a large and diverse sample. If confirmed, this model can serve as a basis for the development and testing of interventions aimed at helping couples recover their intimate lives.

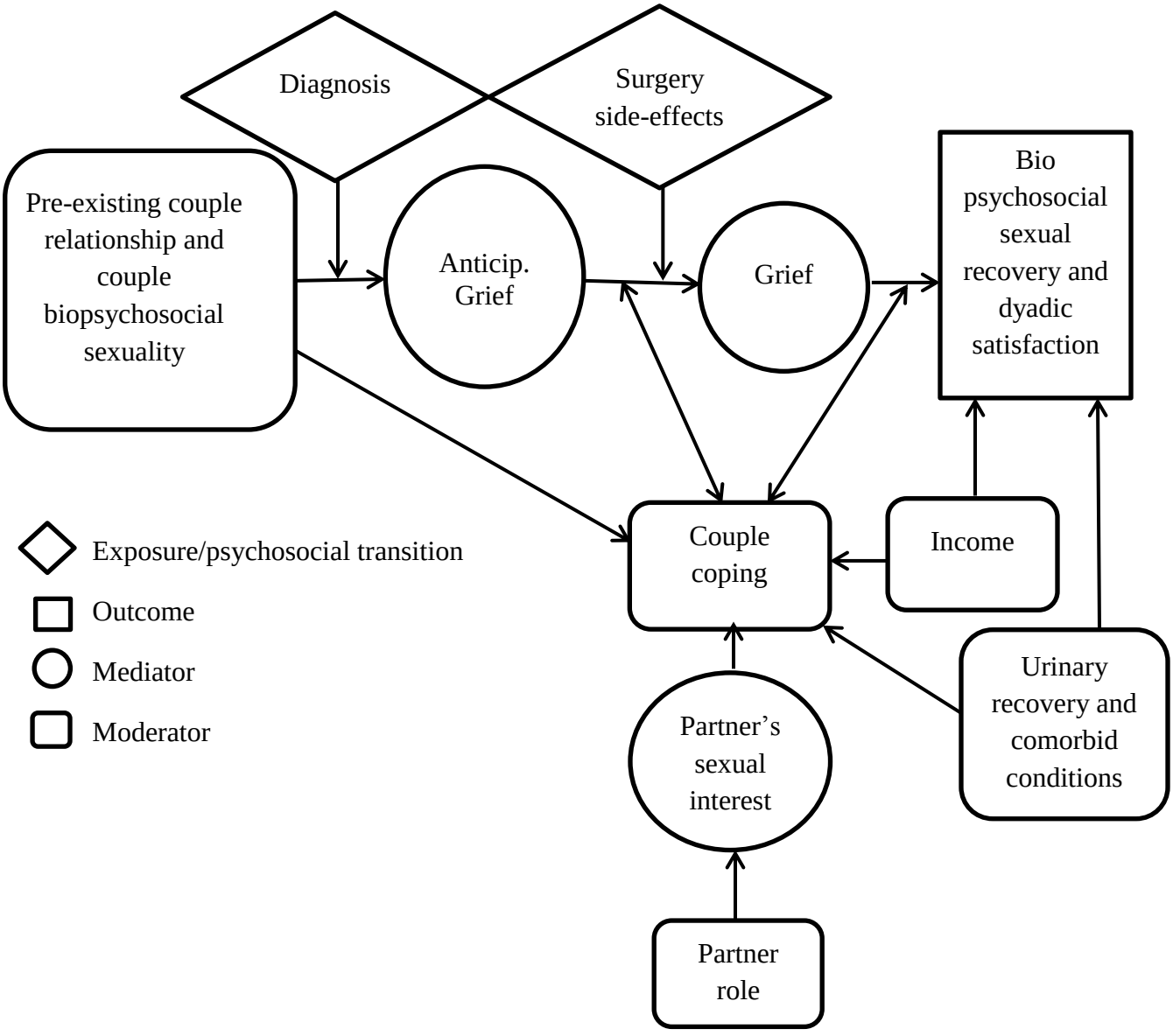
In developing this conceptual model, it is important to recognize that sexual loss begins to happen to couples prior to surgery for prostate cancer. Both men and partners came to prostate cancer with those losses to some degree, as was demonstrated in the study sample and in research on sexuality and aging (Lindau et al., 2007). Cancer treatment has a tendency to make the already occurring trend more precipitous, bringing with it more intense feelings and a greater need for creative adaptation. It is not surprising that some of the participants conflated the loss of erectile function with aging. Although some may consider this to be a form of denial, it can also be seen as adaptive coping with the inevitable decline that is experienced in so many areas of functioning during the process of aging. It is important to retain this perspective when designing research and interventions for couples who are coping with the sexual side-effects of prostate cancer surgery.

Strengths of the Dissertation Research

This mixed methods study followed men and partners longitudinally from before the surgery to 18 months after surgery on average. Based on interviews at three time points and data from outcome surveys, the author was able to construct a model of couples' sexual recovery after

surgery for prostate cancer that can be operationalized and tested further quantitatively with a larger, diverse sample. The sample was large enough to permit theoretical saturation of the data

Figure 5.1 Conceptual Model of Couples' Sexual Recovery after Surgery for Prostate Cancer



based on semi-structured interviews. The survey data provided preliminary findings about the trajectory of couples' sexual function, sexual satisfaction, and dyadic satisfaction. The study

findings confirmed some previous research in terms of the challenges of the recovery for the man, the partner, and the couple. The findings extended the extant research by identifying grief and mourning as a process through which couples recover more or less successfully. The findings also highlighted with greater depth the understanding of the role of the partner's sexuality in the couple's sexual recovery. As the research moves forward, the recognition of the couple as the most appropriate unit of observation has been confirmed, and the need to view the partner as not just an instrument in the man's sexual recovery, but as a legitimate stakeholder in her or his own right has been clarified.

The significance of this research extends beyond couples' sexual recovery after prostate cancer. The model, if confirmed, can be adapted to other cancer groups as well as to patients and partners who cope with other chronic illnesses. Grief and mourning as a process in sexual recovery are likely to be universally present and couples' pre-existing relationship factors as well as income are likely to have a similar influence. It is the moderating effect of the illness, its treatment, and the partner role that may need to be modified.

Limitations of the Dissertation Research

As an exploratory study, this research is limited to transferability of the findings to the population of prostate cancer patients and their partners. Although the findings are quite compelling, it is not possible to draw an inference at a population level. The quantitative findings are particularly limited by the small size of the initial sample and subsequent attrition. The sample was very homogeneous in terms of sexual orientation, ethnicity, race, income, and education. The sample composition is difficult to overcome, given the make-up of the community within which the research is conducted. This limitation calls for a larger,

confirmatory study to be conducted with a multi-site sample if possible. Oversampling for ethnic and sexual minorities may be necessary.

The survey measures were limited in what they could ascertain. Future research should include a definition and measure of couples' coping during the recovery period that would give insight to the way in which members of the couple support each other. This research has empirically described behaviors and attitudes that are important aspects of the definition. However, a 'couple' coping definition needs to include the mutual influence of the members of the couple.

Finally, men continue to recover erectile function for two years and longer (Rabbani et al., 2010). This study followed couples through the most difficult period of sexual recovery. A longer study follow-up would have given a clearer sense of the couples' ultimate coping and adaptation.

Implications for Social Work Practice

Men who plan surgery for prostate cancer and their partners share a trajectory which often has an excellent outcome in terms of cancer control, but together enter uncharted territory as they experience recovery from the sexual side-effects of the surgery. Social workers typically help patients navigate the psychosocial experience of cancer. In the process, they learn about the biology of the cancer and its treatment as a way of supporting patients' self-determination in decision-making, treatment adherence, emotional coping of the individual and the family, and resource management. In prostate cancer, social workers, in order to be effective, will have the role of recognizing the challenges of the patients' biopsychosocial sexual recovery even before the patient and partner recognize them. Currently, social workers are not prepared in their graduate programs to address sexuality, and sexual health assessment is not one of the typically

expected social work competencies (Zebrack, Walsh, Burg, Maramaldi, & Lim, 2008). Social workers should seek training that would provide them with sufficient initial awareness of sexuality issues in cancer to be able to be helpful to their patients with prostate cancer and their partners.

Early preparation for the side-effects and rehabilitation activities enables patients and partners to conceptualize a period of recovery which may be challenging but will have its rewards. Men and partners can be taught that sexual recovery is a couple experience which includes physiologic rehabilitation, emotional coping, and changes in sexual intimacy that have to be approached with an open mind and an attunement to a process rather than an outcome. Promoting pleasure and flexible sexuality can take pressure off on-going couple intimacy while nerves that govern erections, damaged by surgery, slowly recover in the course of two years. After surgery, social workers can support couples in the work of sexual recovery by opening access to relevant resources, facilitating the grief process, and recommending help from a qualified sexuality counselor or therapist where indicated. Awareness that couples can experience challenges and barriers, such as pre-existing couple difficulties, financial problems, and uncertainty about how to proceed, is necessary so that the social worker can screen couples for potential problems with sexual recovery. Attention to grief work can help couples cope with resistance to the more awkward aspects of the sexual recovery and free them to take advantage of helpful resources.

Although the role of the caregiver is increasingly recognized as critical to the patient's good outcome, in this case, the role of the partner in the sexual recovery is two-fold and can result in double distress for the partner. The partner's post-menopausal status may need to be discussed to ascertain the partner's sexual interest and viability. Partners, if interested, may need

education about how to maintain healthy sexuality after menopause. Supporting partners and validating their own individual needs can be a positive experience for the couple, as the partner's dissatisfaction can be influential and prognostic for the couple's sexual recovery,

Future Research

There are several research steps that should be undertaken, based on the development of a conceptual model of couples' sexual recovery after surgery for prostate cancer. The model should be confirmed and validated with a larger, more diverse cohort of prostate cancer survivors and partners. It would be preferable to use a community sample rather than one derived from university settings, as the use of a community sample would make the inferences based on the model more valid.

A screening measure that will help identify couples who desire to work on sexual recovery and may need assistance, as well as couples at risk for poor sexual recovery, can be developed based on these findings: Most of the couples in this study indicated that sexual recovery was important to them; yet the road to recovery of sexual intimacy was by no means clear to them. Couples who function well overall may simply need to be educated about the biopsychosocial aspects of sexual recovery and about the grief process. They can be alerted to potential pitfalls along the way. Potential barriers such as relationship problems, complicated grief, already problematic sexual difficulties related to aging, and financial concerns can be identified with a screening measure and couples can be supported in order to overcome them. Primary, oncology, and urology providers, as well as social workers who work with prostate cancer survivors, can use a screening measure to help direct patients and partners toward information or qualified professionals who can help them maintain or improve quality of life

after treatment for prostate cancer. A screening measure developed from this research can be easily used in other cancer or chronic illness settings.

Further research is needed to evaluate partners' needs. While this research began to uncover partners' sexual and support needs, their poorly defined role needs to be further investigated so that couples can be helped to have realistic expectations not only of the return of erectile function, but of each other's participation in the sexual recovery. The legitimacy of the partners' concerns and needs will be supported if they continue to be included in the research on couples who are recovering sexual intimacy after prostate cancer treatment. It can lead to a shift in patients' and providers' perspective on the recovery from the patient to the couple, thus recognizing the need for mutuality if a couple's sexual recovery is to succeed.

The impact of the financial stress related to the cost of penile rehabilitation and sexual aids should also be further investigated, particularly in the context of the cost of penile rehabilitation and erectile aids. A survey of patients' experience with insurance coverage and personal financial outlay would help define the financial burden, as well as the extent to which cost can become a barrier to couples' sexual recovery.

The development of a measure of sexual loss would be most useful in evaluating couples' responses to sexual changes after cancer treatment. Wilmoth (2001), in an effort to quantify sexual loss due to breast cancer treatment which in many cases included mastectomy, pioneered the recognition that sexual loss is a significant aspect of breast cancer survivorship that should be addressed (Wilmoth & Tingle, 2001). Building on her research, a measure of sexual loss that could be used across cancers would help researchers to identify and understand the impact of cancer treatment on couples' sexual relationships.

Finally, and most importantly, interventions that support couples' recovery of the biopsychosocial aspects of sexual intimacy, with attunement to the grief and mourning process, should be developed and tested so that support for couples' recovery of sexual intimacy after surgery for prostate cancer can become an accepted and available aspect of comprehensive care for prostate cancer survivors. Psycho-education about the recovery that is offered pre-operatively begins the process of supporting couples even as they anticipate surgery. Interventions that address sexual function of both members of the couple, facilitation of the grief process, and help to broaden couples' sexual repertoire and sexual communication will address the biopsychosocial aspects of the sexual recovery. Timing of interventions, as well as dose at different time points, should be ascertained in order to use resources optimally throughout the adjustment period after prostate cancer treatment.

APPENDICES

APPENDIX I

SEMI-STRUCTURED INTERVIEW GUIDES

Couple Semi-Structured Interview – Pre-Op

1. As you are getting ready for surgery, can you describe your thoughts about it and any concerns?

2. Are you aware that you will be experiencing side-effects that affect urinary control and the ability to have erections? What are your thoughts about those side-effects?

3. What do you expect will happen to you sexually?

4. Can you imagine yourself with a flaccid penis? What would it be like?"

5. Do you think that this affects just the man or both of you as a couple?

6. Are you both on the "same page" with respect to interest and willingness to do the sexual and emotional work which might help recovery?

7. How do you communicate as a couple about sexual interactions?
   Prompts
   i. In words, by touch, by sound?
   ii. Has your way of communicating worked for you

8. Have you thought about how you will cope emotionally with the sexual changes and what would be helpful in coping?

9. If intercourse were not possible after surgery, how do you expect that it would it affect you?

10. You have been told that there are things that can be done to keep the tissues of the penis healthy. It is called 'penile rehabilitation'. What is your reaction to it?

11. Do you think you will be willing to do it after surgery?

12. You also learned about the way in which you can produce erections while you are waiting for spontaneous erections to recover, e.g., the use of vacuum pumps, injections. or suppositories. Although you cannot yet decide fully about their use at this time, in principle, are these aids to erections something you will want to learn more about?

13. There are sometimes some costs involved in doing penile rehabilitation. Can you walk me through how you might think about that?

14. Are you aware of what insurance might cover?

15. Working on new sexuality after prostate cancer involves some experimentation, trying new ways of stimulating for pleasure, perhaps new positions for sexual activity. How do you think you might work with that idea?

16. Usually men and partners experience some feelings in reaction to the sexual changes. Some men and partners have described feelings of grief (sadness, frustration, anger, worry). Those are normal feelings. What do you think of that idea?
    Prompts:
    i. Are those feelings something you can imagine feeling?
    ii. If so, can you express them to each other, share them?

17. Sometimes people seek help and see a sex therapist, especially when unsure about how to re-connect sexually after the surgery? How does that strike you?

18. Would it make any difference to you if seeing a sex therapist required an extra visit or a visit to another site such as a Sexual Health Center?

19. Would you be willing to pay for it if insurance did not cover?

20. Do you foresee anything that would make working on your recovery difficult?
    Prompts:
    i. Emotional
    ii. Grief
    iii. Depression
    iv. Anxiety
    v. Communication
    vi. Knowledge about what to do
    vii. Experimentation
    viii. Protective buffering
    ix. Lack of efficacy
    x. Invasiveness
    xi. Lack of spontaneity
    xii. Urinary incontinence
    xiii. Cost
    xiv. Embarrassment or inconvenience at seeing sex therapist

21. Are there any other stressors that are affecting you? Can you tell me how?

22. What do you imagine will be the final outcome sexually?

Couple Semi-Structured Interview 3 Months Post-Surgery

1. Can you tell me about your experience of recovering your sexual relationship since the surgery?

2. Where are you from the point of view of bladder control?
   Prompt:
   Have urinary problems interfered with your efforts to get your sex life back?

3. What kind of information have you received to help you in your sexual recovery?

4. How is the experiment going – are you able to try new things sexually?

   Prompt
   What have you tried?

5. What kinds of techniques do you use to please each other?
   Prompts
   i. Has that been satisfactory?
   ii. If not, what is still missing?

6. Have you been able to have intercourse? If yes, tell me about how you achieve erections and how satisfied both of you are with them. If not, tell me what has made it difficult?

7. How does your sexuality compare to the way you were before the surgery?
   Prompt:
   If there is a difference, tell me what has changed and how you feel about it?

8. How are you doing emotionally with all the changes?
   Prompts:
   i. OK
   ii. Grief
   iii. Depression
   iv. Anxiety
   v. Apathy

9. If sex is less satisfactory and/or less frequent, what do you see as the reasons for not getting you back on track in a way that would work for both of you?
   Prompts: (use only when couple exhausted own ideas)
   i. Lack of information
   ii. Lack of efficacy/inability to achieve erections
   iii. Lack of spontaneity
   iv. Excess invasiveness
   v. Side-effects of treatment
   vi. Embarrassment
   vii. Urinary incontinence
   viii. Excess emotional work
   ix. Discouragement after failure
   x. Cost
   xi. Unawareness of options

xii. Need for experimentation
xiii. Anxiety and/or depression
xiv. Partner sexual concerns
xv. Poor communication between partners
xvi. Avoidance of communication about sexual problems
xvii. Lack of motivation
xviii. External stressors

10. Have you sought any help regarding sexual concerns?
    Prompts:
    i. Where did you seek help?
    ii. If so, was it helpful?
    iii. How did you cover the cost?

11. Are you open to meeting with a couples' counselor for sexual issues? If not, why not? If yes, why yes?

12. When you look back on your experience, is there information or guidance that would have been important to you before surgery that you did not receive?

13. From what we talked about with both of you, can you envision any barriers that might make sexual recovery difficult?

The Role of the Partner Semi-Structured Interview – Patient

So far in our study, most couples have told us that sexual recovery after prostate cancer surgery is a 'couple' experience, in other words, it affects the partner, not just the patient. Today, I'd like to ask you some questions about the role that a partner has, in your experience, in the man's and couple's sexual recovery.

1. Can you walk me through the overall sexual recovery experience as it has been for you and your partner?
    Prompts:
    i. It would be helpful if I could have a sense of what happened to your erections after surgery.
    ii. Loss of ejaculation
    iii. How was the experience of penile rehabilitation for you? Did you do it?
    iv. Did urine leakage have a role in your sexual recovery?
    v. Post-menopausal partner's lack of interest
    vi. How often do you make love?

2. Has the way you and your partner make love changed? Can you talk about what has changed?

    Prompts:

    i. Less frequency
    ii. Spontaneity
    iii. Arranging for love making
    iv. Who initiates
    v. Use of aids his/hers
    vi. Repertoire – changed, expanded, diminished
    vii. Have you and your partner talked about the changes and how you feel about them?

3. Some people would say that you have experienced some losses in your sexual relationship with your partner. When we experience losses, we usually grieve them. Do you think that you and your partner have experienced any such feelings?

    Prompts:

    i. Anger
    ii. Sadness
    iii. Frustration
    iv. Hopelessness
    v. Despair
    vi. Uncertainty about the future of your sexual relationship
    vii. Has your partner expressed anything like that?

4. Can you give me your impression of how you saw your partner participate in the sexual recovery?

    Prompts:

    i. Sexual interest
    ii. Scheduling appointments with your doctor/PT
    iii. Your compliance with rehab activities
    iv. Making sure you had time to be sexually intimate
    v. Your rest
    vi. Your moods/emotional support
    vii. Manage your expectations
    viii. Your frustration with recovery/calming influence
    ix. Taking on your roles in finances, house responsibilities, elderly parents support

5. What do you think went on for your partner sexually during that period? As far as you could tell, did she have interest in sexual activity for herself?

    Prompts:

    i. Desire

ii. Involvement in sexual activity
iii. Learning new repertoire
iv. Orgasm
v. Satisfaction
vi. Use of aids to sexual functioning
vii. Words, sounds, facial expression, body movements

6. How do you and your partner feel about your sexual connection with your partner, compared to before the surgery? Do you talk about that?

7. If you were to look back, what would you say your partner's contribution to your sexual recovery as a couple has been? How would you summarize it? How do you feel about her contribution?

8. Do you think your partner got anything out of having that role? What do you think that 'something' is?

9. Can you describe any hardship that your partner may have experienced as a result of her role in your sexual recovery personally and as a couple?

10. Can you think of any kind of support that partners need during this period of sexual recovery?

Role of the Partner Semi-Structured Interview – Partner

So far in our study, most couples have told us that sexual recovery after prostate cancer surgery is a 'couple' experience, in other words, it affects the partner, not just the patient. Today, I'd like to ask you some questions about the role that a partner has, in your experience, in the man's and couple's sexual recovery.

1. Can you walk me through the overall sexual recovery experience as it has been for you and your partner?
   Prompts:
   i. Is sexual recovery important to you? To your partner?
   ii. What does sexual recovery meant to you?
   iii. It would be helpful if I could have a sense of what happened to your partner's erections after surgery.
   iv. Where do you stand with regard to menopause- desire, pleasure, aids
   v. How was the experience of penile rehabilitation for your partner and for you? Did he do it; was it uncomfortable?

vi. Do you, as a couple, have any sexual challenges related to urinary incontinence or to anything else?
vii. Have you and your partner re-engaged sexually?

2. Can you tell me about the way your lovemaking changed after your husband's loss of erections?

    Prompts:

    i. How is a sexual encounter initiated – who initiates?
    ii. Using aids to sexual function his/hers
    iii. Changes in sexual repertoire
    iv. Talking during sex
    v. Frequency

3. How have you and your partner reacted to the change emotionally? One could say that you have experienced sexual loss. When people experience a loss, they grieve what they used to have. Has that happened to you in this context?

    Prompts:

    i. Loss of spontaneity
    ii. Loss of familiar sexuality
    iii. Loss of sensation with a smaller penis or a penis that has a new angle
    iv. Loss of confidence
    v. Feelings of sadness
    vi. Anger
    vii. Guilt about one's own pleasure
    viii. Hopelessness
    ix. Optimism
    x. We're in it together

4. Did you and your partner share the feelings about the losses?

5. If you were to look back, what would you say your major contribution to your partner's and to your sexual recovery as a couple has been? How would you summarize it?

    Prompts:

    i. Making appointments with Dr./PT
    ii. Encouraging his compliance with rehab. activities
    iii. Making sure you had time to be sexually intimate
    iv. His rest
    v. His moods/emotional support
    vi. His frustration with recovery/calming influence
    vii. Being realistic/managing expectations
    viii. Taking over roles such as house responsibilities, elderly parents support

6. What went on for you sexually during that period?

Prompts:

i. Did you have interest in sexual activity for yourself?
ii. Did you communicate to your partner about wanting your own sexual needs during this time?
iii. Did you experience sexual pleasure during this time?
iv. If so, how did you communicate your own sexual pleasure? (words, sounds, body movements, facial expression)

7. Is there a way you could describe what it is like to be a sexual partner to a man who is worried about his erection?

8. How do you feel about your sexual connection with your partner now, compared to before the surgery?

9. How do you think your partner feels about your contribution?

Prompts:

i. Sexually and otherwise connection now as compared to before surgery
ii. Appreciates your contribution?

10. If you were to weigh the "benefits" and the "toll on you" that your role has taken, what would you say?

11. What kind of help/support do you think partners need during the couples' sexual recovery after prostate cancer?

Prompts:

i. Other partners
ii. Education about partner role
iii. Lack of pressure from medical providers
iv. Education about post-menopausal sexuality
v. Make the man understand that having sex is NOT a part of penile rehabilitation

APPENDIX II

MEASURES

Charlson Comorbidity Method

Assigned weights for diseases	Conditions
1*	Myocardial infarct Congestive heart failure Peripheral vascular disease Cerebrovascular disease Dementia Chronic pulmonary disease Connective tissue disease Ulcer disease Mild liver disease Diabetes
2	Hemiplegia Moderate or severe renal disease Diabetes with end organ damage Any tumor Leukemia Lymphoma
3	Moderate or severe liver damage
6	Metastatic solid tumor AIDS

* Assigned weights for each condition that a patient possesses. The composite Charlson Comorbidity Index score equals composite score. Example: "chronic pulmonary" (1) and lymphoma (2) equals a total score (3).

Dyadic Adjustment Scale – Full Scale – sample questions

Most people have disagreements in their relationships. Please indicate the approximate extent of agreement or disagreement between you and your partner for each item on the following list. Check the box under one answer for each item.

	Always Agree	Almost Always Agree	Occasionally Disagree	Frequently Disagree	Almost Always Disagree	Always Disagree

Dyadic Adjustment Scale (Continued)

1. Handling family finances:						
2. Matters of recreation:						
3. Religious matters:						
4. Demonstrations of affection:						
5. Friends:						
6. Sex relations:						

Female Sexual Function Index (FSFI)

Q1: Over the past 4 weeks, how **often** did you feel sexual desire or interest?

5 = Almost always or always
4 = Most times (more than half the time)
3 = Sometimes (about half the time)
2 = A few times (less than half the time)
1 = Almost never or never

Q2: Over the past 4 weeks, how would you rate your **level** (degree) of sexual desire or interest?

5 = Very high
4 = High
3 = Moderate
2 = Low
1 = Very low or none at all

Q3: Over the past 4 weeks, how **often** did you feel sexually aroused ("turned on") during sexual activity or intercourse?

0 = No sexual activity
5 = Almost always or always
4 = Most times (more than half the time)
3 = Sometimes (about half the time)
2 = A few times (less than half the time)
1 = Almost never or never

Q4: Over the past 4 weeks, how would you rate your **level** of sexual arousal ("turn on") during sexual activity or intercourse?

0 = No sexual activity
5 = Very high
4 = High
3 = Moderate
2 = Low
1 = Very low or none at all

Q5: Over the past 4 weeks, how **confident** were you about becoming sexually aroused during sexual activity or intercourse?

0 = No sexual activity
5 = Very high confidence
4 = High confidence
3 = Moderate confidence
2 = Low confidence
1 = Very low or no confidence

Q6: Over the past 4 weeks, how **often** have you been satisfied with your arousal (excitement) during sexual activity or intercourse?

0 = No sexual activity
5 = Almost always or always
4 = Most times (more than half the time)
3 = Sometimes (about half the time)
2 = A few times (less than half the time)
1 = Almost never or never

Q7: Over the past 4 weeks, how **often** did you become lubricated ("wet") during sexual activity or intercourse?

0 = No sexual activity
5 = Almost always or always
4 = Most times (more than half the time)
3 = Sometimes (about half the time)
2 = A few times (less than half the time)
1 = Almost never or never

Q8: Over the past 4 weeks, how **difficult** was it to become lubricated ("wet") during sexual activity or intercourse?

0 = No sexual activity
1 = Extremely difficult or impossible
2 = Very difficult
3 = Difficult
4 = Slightly difficult
5 = Not difficult

Q9: Over the past 4 weeks, how often did you **maintain** your lubrication ("wetness") until completion of sexual activity or intercourse?

0 = No sexual activity
5 = Almost always or always
4 = Most times (more than half the time)
3 = Sometimes (about half the time)
2 = A few times (less than half the time)
1 = Almost never or never

Q10: Over the past 4 weeks, how **difficult** was it to maintain your lubrication ("wetness") until completion of sexual activity or intercourse?

0 = No sexual activity
1 = Extremely difficult or impossible
2 = Very difficult
3 = Difficult
4 = Slightly difficult
5 = Not difficult

Q11: Over the past 4 weeks, when you had sexual stimulation or intercourse, how **often** did you reach orgasm (climax)?

0 = No sexual activity
5 = Almost always or always
4 = Most times (more than half the time)
3 = Sometimes (about half the time)
2 = A few times (less than half the time)
1 = Almost never or never

Q12: Over the past 4 weeks, when you had sexual stimulation or intercourse, how **difficult** was it for you to reach orgasm (climax)?

0 = No sexual activity
1 = Extremely difficult or impossible
2 = Very difficult
3 = Difficult
4 = Slightly difficult
5 = Not difficult

Q13: Over the past 4 weeks, how **satisfied** were you with your ability to reach orgasm (climax) during sexual activity or intercourse?

0 = No sexual activity
5 = Very satisfied
4 = Moderately satisfied

3 = About equally satisfied and dissatisfied
2 = Moderately dissatisfied
1 = Very dissatisfied

Q14: Over the past 4 weeks, how **satisfied** have you been with the amount of emotional closeness during sexual activity between you and your partner?

0 = No sexual activity
5 = Very satisfied
4 = Moderately satisfied
3 = About equally satisfied and dissatisfied
2 = Moderately dissatisfied
1 = Very dissatisfied

Q15: Over the past 4 weeks, how satisfied have you been with your sexual relationship with your partner?
5 = Very satisfied
4 = Moderately satisfied
3 = About equally satisfied and dissatisfied
2 = Moderately dissatisfied
1 = Very dissatisfied

Q16: Over the past 4 weeks, how **satisfied** have you been with your overall sexual life?

5 = Very satisfied
4 = Moderately satisfied
3 = About equally satisfied and dissatisfied
2 = Moderately dissatisfied
1 = Very dissatisfied

Q17: Over the past 4 weeks, how **often** did you experience discomfort or pain during vaginal penetration?

0 = Did not attempt intercourse
1 = Almost always or always
2 = Most times (more than half the time)
3 = Sometimes (about half the time)
4 = A few times (less than half the time)
5 = Almost never or never

Q18: Over the past 4 weeks, how would you rate your **level** (degree) of discomfort or pain during or following vaginal penetration?

0 = Did not attempt intercourse
1 = Very high
2 = High

3 = Moderate
4 = Low
5 = Very low or none at all

Sexual Experience Questionnaire (sex-Q)

Instructions:

For each of the following questions, place an "X" in the one box that best describes your answer.

Over the past 4 weeks,

1. How often were you able to maintain an erection for as long as you wanted to?

Never or Almost Never	Rarely	Sometimes	Usually	Almost or Almost Always
□	□	□	□	□

2. During sexual intercourse, how often were you able to penetrate your partner?

Never or Almost Never	Rarely	Sometimes	Usually	Almost or Almost Always
□	□	□	□	□

3. How much have you worried about whether you could get an erection?

Not at All Worried	A Little Worried	Somewhat Worried	Very Worried	Extremely Worried
□	□	□	□	□

4. How confident were you that you could get an erection when you wanted to?

Not at all Confident	A Little Confident	Somewhat Confident	Confident	Very Confident
□	□	□	□	□

5. How satisfied were you with the hardness of your erections?

Very Dissatisfied	Dissatisfied	Equally Satisfied and Dissatisfied	Satisfied	Very Satisfied
□	□	□	□	□

6. How satisfied were you with the duration of your erections?

Very	Dissatisfied	Equally Satisfied	Satisfied	Very Satisfied

Dissatisfied		and Dissatisfied		
□	□	□	□	□

7. How satisfied were you with the level of sexual desire?

Very Dissatisfied	Dissatisfied	Equally Satisfied and Dissatisfied	Satisfied	Very Satisfied
□	□	□	□	□

8. How satisfied were you with your overall sexual activity?

Very Dissatisfied	Dissatisfied	Equally Satisfied and Dissatisfied	Satisfied	Very Satisfied
□	□	□	□	□

9. How much pleasure did you get from sexual activity?

No Pleasure	Little Pleasure	Some Pleasure	Much Pleasure	Great Pleasure
□	□	□	□	□

10. How confident were you that you could satisfy your partner during sexual activity?

Not at all Confident	A Little Confident	Somewhat Confident	Confident	Very Confident
□	□	□	□	□

11. How often did you achieve mutual satisfaction with your partner?

Never or Almost Never	Rarely	Sometimes	Usually	Almost or Almost Always
□	□	□	□	□

12. How satisfied were you with your ability to control the timing of your ejaculations?

Very Dissatisfied	Dissatisfied	Equally Satisfied and Dissatisfied	Satisfied	Very Satisfied
□	□	□	□	□

Expanded Prostate Index Composite-Short Form – Sample Questions

1. Over the **past 4 weeks**, how often have you leaked urine? Circle one number.
   More than once a day.....1
   About once a day.....2
   More than once a week..... 3

About once a week..... 4
Rarely or never.....5

2. Which of the following best describes your urinary control **during the last 4 weeks**? Circle one number

No urinary control whatsoever..... 1
Frequent dribbling..... 2
Occasional dribbling..... 3
Total control..... 4

3. How many pads or adult diapers per day did you usually use to control leakage **during the last 4 weeks**? Circle one number

None 0
1 pad per day..... 1
2 pads per day..... 2
3 or more pads per day..... 3

4. How big a problem, if any, has each of the following been for you **during the last 4 weeks**? Circle one number on each line.

	No Prob.	Very Small Probl.	Small Prob.	Moderate Prob.	Big Prob.
Dripping or leaking urine ….....	0	1	2	3	4
Pain or burning on urination.....	0	1	2	3	4
Bleeding with urination.....	0	1	2	3	4
Weak urine stream	0	1	2	3	4
or incomplete emptying.....	0	1	2	3	4
Need to urinate frequently during the day.....	0	1	2	3	4

5. Overall, how big a problem has your urinary function been for you **during the last 4 weeks**? Circle one number

No problem..... 1
Very small problem..... 2
Small problem..... 3
Moderate problem..... 4
Big problem..... 5

6. How would you rate each of the following **during the last 4 weeks**? Circle one number on each line

	Very Poor to None	Poor	Fair	Good	Very Good
Your ability to have an erection?	1	2	3	4	5
Your ability to reach orgasm (climax)?	1	2	3	4	5

7. How would you describe the usual QUALITY of your erections **during the last 4 weeks**? Circle one number

None at all.....1
Not firm enough for any sexual activity..... 2
Firm enough for masturbation and foreplay only..... 3
Firm enough for intercourse..... 4

8. How would you describe the FREQUENCY of your erections **during the last 4 weeks**? Circle one number

I NEVER had an erection when I wanted one..... 1
I had an erection LESS THAN HALF the time I wanted one.....2
I had an erection ABOUT HALF the time I wanted one 3
I had an erection MORE THAN HALF the time I wanted one.....4
I had an erection WHENEVER I wanted one..... 5

9. Overall, how would you rate your ability to function sexually **during the last 4 weeks**? Circle one number

Very poor.....1
Poor..... 2
Fair..... 3
Good..... 4
Very good..... 5

10. Overall, how big a problem has your sexual function or lack of sexual function been for you **during the last 4 weeks**? Circle one number

No problem..... 1
Very small problem..... 2
Small problem..... 3
Moderate problem..... 4
Big problem..... 5

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