

**Penile Length Shortening Post-Radical Prostatectomy:  
A Qualitative Study on the Perceptions and Responses of Men**

by

**Wellam Yu Ko**

A Thesis submitted to the Faculty of Graduate Studies of  
The University of Manitoba  
in partial fulfilment of the requirements of the degree of

**Master of Nursing**

Faculty of Nursing  
University of Manitoba  
Winnipeg, Manitoba, Canada

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**FACULTY OF GRADUATE STUDIES**

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To my parents, with love and gratitude.

### Abstract

**Background.** Prostate cancer (PC) is the most common type of male specific cancer in North American men. Many men choose radical prostatectomy (RP) in order to remove the cancer. Although penile length shortening (PLS) occurs in a reported 68% to 71% of men undergoing RP, little is known about it. In an electronic search conducted during the month of October 2007, only 9 medical articles with no nursing publications were retrieved under the keywords: penis, size, penile length, prostate cancer, and radical prostatectomy between 1980 and 2007.

**Purpose statement.** The goal of this research program is to generate knowledge that will provide an account of patients' perceptions and responses that allow them to live with PLS after RP.

**Design.** Semi-structured interviews in a grounded theory approach were used to discover the basic social processes regarding men's perceptions of a shortened penis and overall sense of self.

**Subjects.** Six men who underwent RP and consequently noticed PLS were recruited from a local PC support group for semi-structured interviews lasting between 40-60 minutes.

**Results.** Based on subjects' own definitions of masculinity, no significant changes in the constructs of masculinity and overall self-image perception were reported. Two models explaining the process by which men become cancer survivors and maintain their masculinities intact are proposed herein.

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I would like to express my fervent gratitude to each of the men who took the time to participate in this research project. This study would not have been possible without each of you. I treasure the valued contributions of the participants in this study.

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## Chapter I

### Statement of the Problem

Prostate Cancer (PC) is the most common type of male specific cancer in American and Canadian men, with an estimated 186,320 (American Cancer Society, 2008) and 24,700 (Canadian Cancer Society, 2008) new cases being diagnosed in 2008, respectively. Although the incidence of PC is highest in western countries, new evidence suggests it is rising globally (Bosetti, Malvezzi, Chatenoud, Negri, Levi, & La Vecchia, 2005; Sim & Cheng, 2005), with Parkin, Bray and Devesa (2001) predicting that the disease will be the most prevalent male cancer within the next few years. Given the rising trend and the potential iatrogenic and social consequences of treatment (i.e.: urinary incontinence, bowel dysfunction, erectile dysfunction[ED], chronic fatigue, etc.), Steginga and partners (2001) hint that PC represents a major public health concern. Nonetheless, men expect and are expected to endure quietly through the process of adjusting to the changes brought forth by PC (Chapple & Ziebland, 2002).

Typically, men diagnosed with localized prostate cancer have two options for potentially curative treatment: radiation therapy (RT) or radical prostatectomy (RP). Patients and their health care teams will often take into consideration factors such as the stage of the cancer, age and lifestyle preferences when choosing the type of treatment to follow. Early stage, non-metastasized prostatic cancer in men under the age of 70 will usually undergo RP, whereas men with later stages of prostate cancer and/or over the age of 70 may undergo either or a combination of treatments ranging from watchful waiting (WW), hormone ablation therapy (HAT) and/or RT.

Many men choose RP in order to remove the cancer. Erectile dysfunction and urinary incontinence are widely known side effects of surgical intervention for prostate cancer. However,

penile length shortening (PLS) is often not associated with RP even though it has been reported to occur in 68% to 71% of men who undergo the procedure (Munding, Wessells, & Dalkin, 2001; Savoie, Kim, & Soloway, 2003).

The size of the penis is a common concern among males. Figurines, paintings and phallic art attest to the fact that preoccupation with the penis and its size has accompanied humans since prehistoric times. The penis is perceived as a symbol of masculinity, strength, endurance, ability, courage, intelligence, knowledge, dominance over other men, possession of women and a symbol of loving and being loved (Wylie & Eardley, 2007). However, the treatment of cancer can produce various physical and psychological changes that threaten patients' concept of sexuality and body image (Bertero, 2001; Cohen, Kahn, & Steeves, 1998; Penson et al., 2003; Schag, Ganz, Wing, Sim, & Lee, 1994; Wilmoth, 2001). Thus, the shortening of penile length after RP can have negative effects on the psychological well-being of prostate cancer survivors.

In an electronic search conducted during the month of October 2007 using electronic search engines such as CINAHL, Pub Med, EBSCO Host, and Psych Info; and utilizing the following keywords: penis, size, small penis, penile length, prostate cancer, and radical prostatectomy; only 9 relevant medical articles were retrieved (Briganti et al., 2007; Ciancio & Kim, 2000; Dalkin & Christopher, 2008; Fraiman, Lepor, & McCullough, 1999; Gontero et al., 2007; Köhler et al., 2007; Munding et al., 2001; Perugia Liberti, Vicini, Colistro, & Gentile, 2005; Savoie et al., 2003), with no nursing publications in this topic between the period of 1980 to 2007. Clearly, there is a very wide knowledge gap with regard to this side effect.

Although there is a large body of literature on the perceptions of living with the consequences of prostate cancer (Clark, Bokhour, Inui, Silliman, & Talcott, 2003a; Korfage, Hak, de Koning, & Essink-bot, 2006; Kunkel, Bakker, Myers, Oyesanmi, & Gomella, 2000;

Rondorf-Klym & Colling, 2003; Milne, Spiers, & Moore, 2008), this would be the first study that focuses on the lived experience of PLS after RP. The findings of this study would complement many studies that look into body image perception after treatment for prostate cancer. Furthermore, results of this study have the potential to be used as a platform for developing an integral set of interventions that assist men to adjust to surviving with prostate cancer.

In summary, there is abundant literature regarding the lived experiences after RP focused on primarily on urinary and sexual issues. Whilst penile length is not thought to decrease with aging (Schneider, Sperling, Lummen, Syllwasschy, & Rubben, 2001), many men experience a noticeable decrease in penile length shortly after RP. The effects of a decrease in penile length after RP and/or during adulthood have not been previously investigated. The present study lends itself to be the first to focus in PLS after RP.

#### Purpose Statement and Definitions

The goal of this exploratory research program is to generate knowledge that will provide an account of patients' perceptions and responses encountered with PLS after RP. Studies on the loss of penile length in men following surgical treatment for prostate cancer have found that such decrease ranges from 0.5cm to 4.0cm (Munding et al., 2001), and 0.5cm to 5.0cm (Savoie et al., 2003). For the purposes of this study, penile length shortening will be defined as the subject's perceived loss of penile length after undergoing RP, irrespective of actual length changes. Therefore, measurements of penile length before and/or after RP will not be necessary.

There is a large body of qualitative designed nursing literature on the side effects of prostate cancer treatment. However, as mentioned earlier, none deals with PLS post-RP. A

qualitative approach to this study will give us an understanding of the meanings of experiencing a decrease in penile length by prostate cancer survivors.

### Research Questions

The main purpose of this research project is to explore what are men's perceptions regarding the decrease in penis size after radical prostatectomy. There are four areas of inquiry within this overarching question:

- a) *Self image*. Currently, there are no published studies describing the effects of penile size changes in men's concept of identity or self image.
- b) *Importance*. Knowing about the importance attributed to the size of the penis before and after RP will let us know how much penile length and/or girth means to men.
- c) *Satisfaction*. Inquiring about the level of satisfaction regarding penile dimensions will allow us to better understand the level of acceptance of overall treatment outcomes.
- d) *Coping*. How men manage to accept and live with a smaller penis will illuminate some of the methods or resources men utilize to deal with overall consequences of RP.

## Chapter II

### Literature Review

#### *Life after Radical Prostatectomy*

Current nursing literature on prostate cancer focuses on the lived experience of its treatment. Most of the qualitative studies regarding patients who had RP center on the glaring sexual (with some emphasis on the perceptions of masculinity) and urinary side effects of surgical treatment for prostate cancer. Amounting evidence suggests quality of life decreases after prostate surgery, and concepts such as loss of control, anger and decreased self-esteem are positively correlated to the severity of losses in urinary continence and sexual performance (Clark et al., 2003a; Clark et al., 2003b; Dalkin & Cristopher, 2008; Davison, So, & Goldenberg, 2007; Kirschner-Hermanns & Jakse, 2002; Milne et al., 2008; Rondorf-Klym & Colling, 2003).

Sexual performance is hindered by the occurrence of ED in most men after RP. Several studies shine light on the long lasting effects of ED after prostate removal. In a five year study conducted by Penson and colleagues (2008), only 24% and 28% of the men who had undergone RP were able to achieve erections firm enough for intercourse at the 24<sup>th</sup> and 60<sup>th</sup> month after surgery, respectively, many of whom (over 60% of those under the age of 60; less than 46% for those aged over 60) had to use sildenafil citrate to procure erections.

Men who experience sexual performance issues are more likely to feel anxiety about physical intimacy, uncomfortable awareness of the loss of sexual interest, a change in their relationship with women, have doubts about their ability to satisfy their spouses and themselves, and a diminished sense of masculine self-esteem (Clark et al., 2003a; Clark et al., 2003b; Davison et al., 2007). In spite of the emotional burden that these issues may bring to men with PC, men seem to endure anonymously with the effects of cancer. In two separate studies by

Bailey and colleagues (2004) and Harrison and associates (1995), men with cancer were found to be quiescent about their illness related concerns, were unlikely to disclose their emotions, and when they did, it was done so exclusively to their spouses and rarely to their friends or physicians.

Urinary incontinence is an issue that affects at least 50% of all men who undergo RP (Rondorf-Klym & Colling, 2003; Smither, Guralnick, Davies, & See, 2007; Talcott et al., 1997). Although the incidence of incontinence has been reported to decrease with time (Penson et al., 2008; Smither et al., 2007), its occurrence affects negatively on quality of life (Moore & Gray, 2004; Moore & Jensen, 2000). The wearing of incontinence pads, malodorous garments and skin irritation are only some of the consequences that affect men to varying degrees. Conversely, embarrassment seems to be a universal response in men who suffer from urinary incontinence (Burt, Caelli, Moore, & Anderson, 2005; Maliski, Heilemann, & McCorkle, 2001; Palmer, Fogarty, Sommerfield, & Powell, 2003; Palmer, 2004), which they hide from the knowledge of others by limiting outings and social interactions. Unfortunately, these measures increase social isolation on those who suffer from it.

### *Masculinity and Health*

Social norms mold men into behaving in specific ways that make them distinctive from women. Courtenay (2000) argued that men enact masculine roles in order to exercise power and maintain status within one's social class and culture. This type of masculinity is known as hegemonic masculinity, where men engage in activities that emphasize leadership and authority in relation to the gender order as a whole. Hegemonic masculinity is a dominant form of masculinity that seeks to lower the standing of femininities and other masculinities by shaping the interactions amongst men, and between men and women (Courtenay, 2000). In order to fit

into the hegemonic category of masculinity, men display characteristics such as stoicism, sexual prowess and invulnerability, and seek to embrace ideals that are associated with being successful, capable, reliable, and in control.

Nevertheless, such behavior is linked to negative health consequences. Men are at an increased risk of engaging in health adverse practices such as alcohol abuse, tobacco use, dangerous occupations, or violence (Connell, 2000; Payne, 2001). In a qualitative study conducted by Hale, Grogan, and Willott (2007), men with PC were found to believe that they, by virtue of being male, were bestowed with health benefits that made them more resistant to disease and illness. Additionally, there are ample observations on how masculine ideals of strength, self-reliance, and physical prowess are seen as reasons for delaying medical consultation (Courtenay, 2000; Hale et al., 2007; O'Brien, Hunt, & Hart, 2005). Thus, masculine ideals can also be considered as a hindrance to admitting the need for medical assistance.

Concepts of reproduction and sexuality are central to men's self-identity (Forrest, 2001). Yet, in order to maintain their status and reduce exposure to being singled out as being deficient in these areas, men often conceal their vulnerabilities and are less inclined in entrusting with others about their health problems (Courtenay, 1998; Hale et al., 2007). In the event men seek medical advice, hegemonic masculinity lays out the expectation that men should deal with an illness regardless of the effects of treatment and to deny the expression of emotional experiences from these effects.

The interplay of masculinities between the prostate patient and the male physician is an interesting one. In a study conducted by Oliffe and Thorne (2007), men in an initial medical consultation setting were found to be able to pause dominant ideals on how men compete with other men by changing their usual way of interacting and communicating into a "businesslike

transaction” mode that did not harm either masculinities. However, often after the diagnosis of PC, the patient-urologist relationship is altered, and unknowingly subjugates the help-seeking patient under an expert physician masculinity (Courtenay, 2000; Oliffe & Thorne, 2007).

Although survey studies have reported that many patients prefer taking greater responsibility when making decisions about prostate cancer treatment (Davison & Degner, 1997; Davison, Degner, & Morgan, 1995; Davison, Gleave, Goldenberg, Degner, Hoffart, & Berkowitz, 2002; Davison, Parker, & Goldenberg, 2004), men often concede authority, knowledge, and access to physicians, disclosing information that expose their vulnerabilities to entities considered as being better situated to make decisions for them (Oliffe & Thorne, 2007).

### *The Penis, Phallus and History*

Sociologically speaking, the penis is seen as more than just a body part. It represents an idea, “a conceptual but flesh-and-blood gauge of man’s place in the world” (Friedman, 2003, p. 6). In ancient Greece, the aesthetic ideal of the proportionately formed male physique was fused with the moral and political ideal of the good male citizen. Representations of the male body had a tendency to display young men with “small and taut” genitals, reflecting an emphasis on sexual and physical control (Keuls, 1993). Greek society viewed large genitals as symbols of carnal excessiveness and immorality that threatened their projection of rational and self-controlled individuals. On the contrary, Roman society admired the penis of large proportions. To them, the phallus was perceived as a symbol of potency: always desired and respected, and at times, feared (Friedman, 2003). Roman reverence of the phallus is portrayed in the famous fresco of Priapus in the House of Vettii, a bordello in Pompeii. In the depiction, Priapus is seen weighting his tumescent penis against a sack of coins; plainly, his phallus is worth its weight in gold (Stephens, 2007). It is in this context that Lehman (1998) reminded us of the distinction between *penes* and

*phalli*. The penis is seen as the physical representation of the phallus. However, the penis on its own does not carry any of the significance derived from the phallus. The phallus, on the other hand, is likened to the erect penis and all of the symbolic attributes associated with it. Therefore, the phallus represents the ideological essence of male distinctiveness. Remarkably, in spite of the different values attributed to the penis and the phallus, one cannot be represented without the other (Stephens, 2007). Symbolism, then, is the true value of the phallus. In other words, the phallus is seen as the rightful proprietor of the symbolic characteristics attributed to the penis.

Throughout history, the female body has received a great deal of attention in science, religion and philosophy whereas the male body has received relatively little illustration in these areas. Not surprisingly, even less emphasis has been placed on the defining aspect of the male body: the penis. Comments on the relationship between penis and phallus refer to it as an ironic one. Stephens (2007) contend that the penis as an anatomical feature is represented everywhere “through the proliferation of phallic imagery and privilege” (p.87); yet, its physical existence is kept guarded, almost invisible. Society has often denied the appearance and description of the naked penis, often criticizing those who portray it in art and literature as part of a healthy human body. The phallic connotation of power embodied by the penis is seen as the reason why the naked male body has been under-represented when compared to the female body. Lehman (1998) argued that phallic mystique perpetuates the political advantage of the male body; and, by hiding the penis, the mechanisms of male dominance remain safely guarded. However, when the penis is shown, its appearance is scripted in an attempt to exaggerate its phallic attributes, as in the pornographic construct; or to limit its variations by presenting an average representation as in the medical construct (Lehman, 1998). In so doing, the range of

variation in actual penises is often neglected, misleading the public into believing that there are only a few sets of standards for what a penis should be.

In western societies, there has been an increased tolerance for the media's representation of the penis, even though it follows the above mentioned scripts. Today, most North American and Western European audiences can unrestrictedly hear the word "penis", but cannot see its appearance in non-pay-per-view programming. Pervasively, Hollywood films have been known to ridicule the small penis and exalt the greater phallus (Lehman, 1998; Stephens, 2007). Ironically, the media's influence has led some men to attempt to enhance their masculinity through practices previously considered feminine such as cosmetic surgery to enhance one's masculine looks (Haiken, 2000), or to undergo [still] risky phalloplasties (Vardi, Harshai, Gil, & Gruenwald, 2008). As Haiken (2000) commented: "...conceptions of manhood and masculinity provide less armor against the onslaught of market-driven culture than we might like to think" (p. 389).

#### *Distinctions between Phallus and Masculinity*

We can conclude from the above discussion that phallus and masculinity are different concepts that seem to be interrelated. Both have different characteristics that are undeniable, which make them unique. In the following argument, the author will attempt to further differentiate and assign specific ideas to each of the terms, in order to provide an understanding of the results of this study.

The phallus should be thought of as a non-bodily scheme that conceptualizes the attributes of being male. A description of the phallus may include ideas such as virility, fertility, and potency, which are characteristics specific to the individual. Although obvious, these concepts are not directly visible, and their existence does not have to be proven to the social

group. Phallic characteristics are non-transmutable, cannot be learnt or taught, much less acquired; but, they can be identified, distinguished, and exist empirically in the individual as an awareness of their presence. Because of the abstract nature of the phallus, Stephens (2007) suggested that the phallic ideal is neither a perpetual one, nor that it exists in an essentialist, unchanging state in relationship with the male body. Rather, the reappraisal of the phallus is possible under circumstances where it faces a threat or a change in the individual's priorities. Hence, the concept of phallus is malleable.

Masculinity, on the other hand, refers to the socially accepted rules, expectations and indoctrination that men are to abide by and exhibit. These are learnt, ingrained and enforced by the group. As a characteristic of social behavior, masculinity serves as an avenue for the expression of the phallus, often in the form of bravado and/or machismo.

#### *Relationship between Penis, Phallus, Masculinity*

Although the present literature review does not attempt to offer the reader with a definitive explanation of the concepts of penis, phallus and masculinity, it is hoped that it will provide a general idea of their value in the discussion section of this thesis. It is to this purpose that we now turn to explore the relationship between the three concepts.

In spite of the fundamental differences between penis (physical), phallus (ideological) and masculinity (behavior), each needs of the others in order to justify its own existence. For example, in order to express (most likely to *impress*) the grandeur of one's phallus, a man needs to advertise his phallic nature to the persons around him by using socially accepted avenues of such advertisement. The rules of masculinity will dictate how a man will publicize the phallic characteristics under his possession. Bragging about one's history of satisfied women, or the size of one's penis (as the embodiment of the phallus) are common tactics used to this end.

However, under certain circumstances, men engage in behaviors of masculinity without the presence of the normally accepted characteristics of phallus or penis. In several studies, men demonstrated that their own perception of maleness (how they perceive themselves as men in relation to other men) remained unchanged in spite of ED (Chapple and Ziebland, 2002; Fergus, Gray, & Fitch, 2002a; Oliffe, 2005; Stansbury, Mathewson-Chapman, & Grant, 2003). The authors of these studies explain that men change their own values regarding masculinity to accommodate for alterations in the body (i.e.: ED), while maintaining the socially expected roles of masculinity. That is, men who are unable to use their penises for coitus remain masculine simply because they no longer hold erectile function as a fundamental characteristic of manliness. Men's new evaluation of masculinity is justified, expressed and confirmed to the social group through behaviors such as stoicism, dominance and leadership.

#### *Concepts of Penis Size and Perceptions*

Popular media frequently highlights the connection between penis size and masculinity. Pornographic material is often portrayed by men with larger than average genitals, reinforcing the belief that a small penis size is undesirable. The prevalence of such message is exemplified in advertisements in newspapers such as the *Los Angeles Times* with captions such as "Size Matters" (Beverly Hills Surgical, 2005), and "Bigger is Better" (Total Life Enhancement, 2005). All of which may deceive men into believing that their penises are inadequately small. This is exemplified by Montague's (2007) findings suggesting that even men with erectile dysfunction who received penile implants to attain erections expressed dissatisfaction with their penile length during prosthetic erection.

The perceptions about penis size may be closely related to other aspects of male identity. In a large internet survey consisting of 52,031 heterosexual men and women, Lever, Frederick

and Peplau (2006) found that men who reported a larger than average penis also rated their overall appearance most favorably. However, the perception that a larger penis leads to a positive evaluation of one's body is contested by Morrison, Bearden, Ellis, and Harriman (2005). In a study examining genital perceptions among Canadian post-secondary students, Morrison and colleagues (2005) discovered that sexually experienced men negatively correlated perceptions of genitalia with body image and sexual anxiety, while positively correlating sexual esteem. Undoubtedly, further qualitative research exploring the significance penile size has on men is needed.

Evidence suggests that the concern with penis size affects men more than women. In a survey conducted by Francken and partners (2002), women were found to rate penile length as being "unimportant" and "totally unimportant" in 55% and 22% of the respondents, respectively. While, Lee (1996) found in a sample of 128 single male college students that, self-perception about penis size had a skewed distribution towards a small penis, even though these men felt they had adequate body hair distribution and physique. These findings support a more recent study performed in 2003, where 123 men visiting a military hospital in Korea had their penises measured and surveyed for perceptions of penile size, finding that there was a tendency for men to underestimate the dimensions of their own penis (Son, Lee, Huh, Kim, & Paick, 2003).

Interestingly, the phenomenon of underestimating one's penile size is not geographically confined. Mondaini et al. (2002) found that, of 67 men (ages between 16 to 55, median age 27) who sought a consultation at an Italian andrology clinic complaining about having a short penis, none was found to have an abnormally short penis. All of the men reported having intact erectile function, and upon assessment, none had penile deformities. The report also suggests that the subjects had an early preoccupation with the size of their penis. Sixty percent of them traced the

origins of their concerns to childhood, when they noticed their friends had more developed genitalia. Surprisingly, 85% of the men believed that the “standard” size of the penis was larger than what it truly was. However, with proper education, the majority of the subjects (70%) were believed to have been reassured that the size of their own penises were within normal range and were no longer known to seek enlargement treatments (Mondaini et al., 2002).

In a similar study, Shamloul (2005) documented the complaints of 92 Egyptian patients (ages between 19 to 52, with a mean age of 25) who were dissatisfied with what they believed to be a short penis. None of them suffered from ED or any other type of penile anomaly and all measured within normal penile length parameters. By conducting brief interviews with the men, Shamloul (2005) found that the subjects had been confronted either by their peers during childhood, and/or erotic materials during adolescence about what an adequate penis size should be. Nevertheless, the study demonstrated that with information and education about what a normal penile size is, none of the returning patients expressed concern about penile length or were interested in further surgical interventions to enhance penile dimensions (Shamloul, 2005).

In spite of all of the literature suggesting that men place great importance in the size of their penises, most of the evidence is based on studies conducted with subjects of relatively young age, mainly men in their second decade of life. The current review of the literature did not find information regarding the importance of penis size in middle aged men or older. The present study is the first to explore the meanings of penile size in PC survivors, all of whom are over the age of 50.

### *Normal Penile Length*

There are several studies that have investigated what the normal penile length is. Although the methods of measuring penile length have been varied, we can derive some commonalities from the published results. Flaccid penile length seems to correlate poorly with erect penile length, while stretched penile length is considered to be a good predictor of the erect penis (Wessells, Lue, & McAninch, 1996). Except for two of the reviewed studies (Şengezer, Öztürk, & Deveci, 2002; Son, Lee, Huh, Kim, & Paick 2003), the values for penile length are somewhat consistent, with an average value of 9.0-10.0cm for the penis in its flaccid state, the stretched genital is usually 3.0-4.0cm longer, while the typical erect penis measures 13.0-16.0cm (see table 2.1).

Both, Şengezer et al., (2002) and Son et al., (2003) reported shorter than average flaccid and stretched penile lengths. In spite of shorter non-erect lengths, Şengezer et al., (2002) measurements on the erect penis are not very different from Wessells and colleagues' (1996), whose flaccid and stretched measurements fall within the average range, while their average erect length is on the shorter side of the spectrum. An explanation to these differing results may reflect some of the variability inherent in the populations under study and the methods of measurement used. Except for the measurements conducted by Şengezer et al., (2002) (Turkey) and Son et al., (2003) (Korea), all current data on penile dimensions are based on studies conducted in either Western Europe and/or the United States. Although trends can be made from the mentioned studies, these are not necessarily representative of different geographical locations or cultures.

Table 2.1

Review of selected studies on the measure of penile length.

Study	n	Mean age and/or age range	Mean flaccid length	Mean stretched length	Mean erect length
Wessells et al., (1996)	80	54 21-82	8.85	12.45	12.89
Smith et al., (1998)	194	-	-	-	15.71
Bogaert & Hershberger, (1999)	Homosexual 813 Heterosexual 3417	- -	10.4 9.8	- -	16.4 15.6
Ponchiatti et al., (2001)	3,300	17-19	9.0	12.5	-
Savoie et al., (2003)	124	59.1 42-76	Pre-RP 9.3 Post-RP 8.1	Pre-RP 13.5 Post-RP 12.4	- -
Schneider et al. (2001)	111 32	18-19 40-68	8.6 9.2	- -	14.48 14.18
Şengezer et al., (2002)	200	20-22	6.8	8.98	12.73
Shah, & Christopher, (2002)	104	54 17-84	-	13	-
Son et al., (2003)	123	21.7 19-27	6.9	9.6	-

Note: all length values are in centimeters.

### *Etiology of Penile Shortening*

The found literature on the topic focuses exclusively on the physiological aspect of PLS, suggesting a range of possible explanations for the phenomenon. However, the true etiology of PLS is not known. What is known about PLS is that the greatest loss of length peaks during the first year following surgery. Fraiman et al., (1999) noted that the most notable shortening occurred during the first four to eight months after RP, coinciding with Munding and colleagues' (2001) findings of most length loss during the first three to four months after surgery. In contrast, Gontero et al., (2007) found that the greatest loss of length peaks at the time of catheter removal (usually during the first few weeks after surgery) and continues to diminish in length, albeit to a lesser rate, for at least 12 months after surgery. Additionally, Fraiman and associates (1999) noted that men with erectile dysfunction after RP will also report a decrease in penile length, suggesting that intraoperative injury may also conduce to morphometric changes of the penis.

Several possible explanations exist regarding PLS. Munding and associates (2001) suggested that either one or a combination of two of the following factors may play a role in the decrease of penile length: a) the resection of the urethra within the prostate, shortening the total length of the urethra; and, b) that prepubic lesions, may shorten the suspensory ligaments of the penis decreasing penile length. Another theory involves the formation of fibrotic tissue in the penis after RP. Ciancio and Kim (2000) found that 41% of the patients who were referred to them for erectile dysfunction after RP also developed fibrotic changes causing the penis to physically change, leading to the perception of a shortened penis.

There are conflicting results on the type of prostatectomy and their effect on penile length. Bilateral nerve sparing radical retropubic prostatectomies (a technique where the pudendal nerves that run posteriorly along the prostate are carefully separated from the prostate

and left intact) were not found to prevent penile length loss when compared to non-nerve sparing open prostatectomy (a procedure where the pudendal nerves are severed) by Perugia et al., 2005 and Savoie et al., 2003. Conversely, Briganti and associates (2007) noted that the former correlates positively with a decreased incidence of PLS. Clearly, the effects that each technique has on PLS needs to be studied further.

Changes at the histological level that may decrease penile length have also been pointed out. Klein and colleagues (1997) explained that apoptosis of penile erectile tissue after cavernous neurotomy in the rat model caused neural damage that may lead to a decrease in penile size after RP. Also, Moreland (1998) found that human penile smooth muscle cell culture tissues underwent changes when exposed to hypoxic conditions, suggesting that circulatory deficiencies resulting from a radical prostatectomy may also affect penile length. Although the specific significance of these changes on the length of the penis are not known, they keep the door open for possible explanations at a cellular level. Clearly, the question of what causes the penis to reduce in length remains unanswered.

#### *Interventions to Prevent Penile Shortening*

Interventions to prevent PLS have been devised. However, these are in their early stages of development and further research on their effectiveness is required. These include: a) use of hyperthermia as a prophylactic to penile fibrosis, and b) use of vacuum erection devices (VED).

- a) *Hyperthermia*. In a randomized controlled trial involving 40 men who had undergone RP, Perugia and associates (2005) demonstrated that fewer men in the hyperthermia treatment group (who received microwave frequencies aimed at the penis to attain an increase in temperature) suffered from PLS than those in the control group. The authors of the study

believe that the effects of hyperthermia effectively prevent or reduce the occurrence of fibrotic tissue after RP.

- b) *Vacuum erection devices*. Vacuum erection devices have not been found to be effective in increasing penile length in healthy men (Aghamir, Hosseini, & Alizadeh, 2006); nonetheless they increase arterial blood flow to the penis (Bosshardt, Farwerk, Sikora, Sohn, & Jakse, 1995). In an attempt to demonstrate if the use of VEDs would prevent PLS by increasing the flow of oxygenated blood to the penis, Dalkin and Christopher (2008) recruited 42 men after nerve-sparing RP whom were required to use a VED daily. In the study, almost all (97%) of the compliant men were found to have maintained penile length 90 days after their first use of a VED. In another study, Köhler and colleagues (2007) studied the effectiveness of using VEDs at different times post operatively. Subjects who started VED use in the first month were found to have better rates of penile length maintenance, compared to the group that started using VEDs on the sixth month post-RP. In spite of the positive results of using VEDs shortly after RP, caution should be taken when interpreting these results. Both studies warn the generalization is limited due to the small sample size used, and that subjects in both studies underwent nerve-sparing surgeries, which in itself may decrease the incidence of PLS (Briganti et al., 2007).

Although surgical interventions for implanting penile prosthetics in men who suffer from erectile dysfunction after RP are available (Lane, Abouassaly, Angermeier, & Montague, 2007), they do not increase penile length or girth (Deveci, Martin, Parker, & Mulhall, 2007). On the other hand, surgical interventions for increasing penile length and girth, known as phalloplasties are available for men (Panfilov, 2006; Vardi et al., 2008), but the indications on their appropriateness after RP remain unstudied.

## Summary

The penis has been attributed great power and prestige throughout history. In spite of its importance, the penis has received little attention in the sciences, arts, and literature. This lack of attention and study has created many misconceptions about its characteristics and significance. Currently, media descriptions assume that the size of the penis is related a man's masculinity, with ample examples of men desiring a penis of greater dimensions to express their "male worthiness". However, often after RP, the penis suffers from a reduction in size that may seem to attempt against perceptions of masculinity on those who suffer from PLS. Although interventions to prevent penile length decrease have been employed and tested, patients' perceptions regarding penile length reduction remain unknown. This study attempts to shine light on the perceptions of men who experience PLS.

## Chapter III

### Design and Methods

#### *Design*

The design of the current study is based on the grounded theory approach and was carried out by conducting semi-structured interviews. As with grounded theory studies, the author did not ascribe to any theoretical model or framework of analysis in order to be free from any preconceived logic regarding the phenomenon under study. Such theoretical freeing allowed the researcher to attain the ideological fluidity required to develop a theoretically comprehensive explanation of the perceptions and responses men experience due to the perceived shortening of their penis after RP.

Grounded theory research is an approach designed for exploring social processes and social structures by focusing on the development and evolution of social experiences (Polit & Beck, 2004). Given that men's perceptions on the adequateness of penis size is highly affected by social norms (Lee & Reiter, 2002), grounded theory seems to be the best fitting research method for exploring the phenomena of PLS. The real value of grounded theory, however, is its ability to generate comprehensive explanations of phenomena that are grounded in reality. This characteristic was appropriate to explore men's experiences with PLS post-RP.

Due to the lack of any previous work on the perception of PLS post-RP, the current study was designed as a substantive theory type of grounded theory research. Substantive theory research is based on the information gathered on a specific, substantive area of interest such as post-partum depression (Polit & Beck, 2004). Usually, this type of research serves as the basis for more comprehensive studies that combine the results of several other related studies based on

the substantive theory model that result in the formal grounded theory approach (Polit & Beck, 2004).

### *Sampling*

A convenience sample of six subjects from the Manitoba Prostate Cancer Support Group (MPCSG) was recruited for this study. Because men continue to lose penile length up to a year post-RP (Gontero et al., 2007), subjects recruited were men who have undergone a RP at least one year before the interview and have since noted a decrease in penile length. There was no initial set number of subjects to be recruited, as recruitment in qualitative studies usually stop by the Nth subject where data saturation (described as the point at which no new information is attained) is achieved (Polit & Beck, 2004). In this case, saturation was reached by the fifth subject, and a sixth was interviewed with the intention of finding new themes.

The MPCSG is a not-for-profit group of volunteers that provide information and support to men diagnosed with PC, their families, and friends for the city of Winnipeg, Manitoba. Group meetings are characterized by sharing personal experiences with PC by members, emotional support for those who are experiencing it, and information sessions on a variety of topics related to PC. The MPCSG provides a forum where members feel safe to disclose issues related to PC that may be considered extremely personal. Thus, it is this author's belief that subjects recruited from the MPCSG, being used to sharing personal effects of PC, were less hesitant to disclose information regarding perceptions on penile size. Additionally, many of the subjects recruited from the MPCSG could be considered as "information rich" cases, providing the greatest insight into the research question (Devers & Frankel, 2000).

Access to subjects depended greatly on gatekeepers' referrals. The term "gatekeeper" refers to the individuals in charge or with access to specific groups of people the researcher

wishes to study (Devers & Frankel, 2000). Planning and later recruitment was conducted in collaboration with the gatekeepers at the MPCSG. For this study, identified gatekeepers were the support group leaders at the MPCSG.

Recruitment of subjects from the MPCSG was aimed at increasing the sense of confidentiality for those taking part in the study. The recruiting process was conducted in two ways. The first method was initiated by the support group's leader announcement of an ongoing study, who asked for group members to consider participating and to approach the interviewer after the meeting was over. The announcement contained no indication that the current study looked into PLS post-RP. This was done to ensure that none of the men seen approaching the researcher by fellow attendees were associated with having a shortened penis. Men who approached the interviewer after the meeting were asked for permission to be phoned at home, at a time of their choosing for disclosure of the purpose of the study and assessment. Of those who met the inclusion criteria and agreed to participate were met in person by the interviewer to obtain consent and proceeded with the interview. Volunteers became subjects upon agreement to participate and signing the respective documents of agreement (see Appendix 1).

The second method involved the publication of an advertisement appearing in the MPCSG's newsletter. The advert was reviewed and approved by the MPCSG's Executive Committee for publication (see Appendix 2). Again, the advertisement contained no information regarding PLS so as to protect the men who had originally approached the researcher from any association with PLS. Men who contacted the researcher either by phone or by electronic mail were explained the purpose of the study and assessed on the phone for the inclusion criteria. All of the men who met the inclusion criteria agreed to participate and were later met in person by

the researcher to fully explain the procedure and the purpose of the study. All of the men agreed to the terms and conditions by signing the respective consent forms.

By the end of each interview, all subjects were asked two questions regarding: a) further participation in the study, and b) receiving the results from the study.

- a) *Further participation.* Subjects were asked whether they would like to be contacted later on for evaluating preliminary results with the researcher, who would use the opportunity to measure the fitness of data gathered.
- b) *To receive the results.* Participants who wished to receive a copy of the results from the study will be mailed a copy of the published results of the investigation.

In either case, subjects did not answer yes or no to the interviewer. Instead, the interviewer gave participants a form (see Appendix 3) to complete and left the room. Subjects completed the forms and handed in the completed documents in a sealed envelope to the interviewer. Envelopes were opened upon data saturation.

#### *Remuneration*

Participants received gift certificates from a coffee vending franchise as they handed in their envelopes, in gratitude for the time spent. Parking fees were paid for the subjects who were interviewed at the University of Manitoba.

#### *Inclusion and exclusion criteria*

English speaking men who reported perceiving PLS post-RP irrespective of the actual loss in length were recruited for the study. All subjects had undergone RP at least 12 months prior to the interview. Men who were undergoing any other form of treatment for increasing PSA scores after RP were also recruited for the study, as long as they too perceived a loss in penile length.

### *Setting and Data Collection*

This author was the sole interviewer of the study. All subjects were offered a choice of venue for the interviews, which were conducted at participants' homes, at a university interview room, and at a subject's office. Subjects completed a demographic information questionnaire before commencing the interview (see Appendix 4). The generation of data was accomplished by carrying out semi-structured interviews. Although unstructured interviews are noted to provide greater depth and detail than semi-structured interviews (Polit & Beck, 2004), it was this author's concern that the former may have allowed interviews to wander off topic. A topic guide containing a list of main areas of interest and/or questions was used to help direct and maintain focus during each interview (see Appendix 5). Interviews focused initially on the areas of interest mentioned under the Research Questions section of this proposal. However, this author acknowledges that changes in focus occurred with subsequent interviews as more data was accumulated and understood, all of which is consistent with the grounded theory approach (see Appendix 6).

During interviews, the interviewer encouraged subjects to express themselves in their own words, allowing subjects to provide as much detail as they wish, and to offer illustrations and explanations. Probes or follow-up questions such as "Please explain what you mean by that", "When that happened, how did you feel?" were used to elicit more information from subjects.

All interviews were audio-tape recorded. Confidentiality was secured by the use of numbers instead of subjects' real names on all documents. Interviewees were addressed as "You" or "Sir". Furthermore, the interviewer encouraged subjects to address any other person by their relationship to the subject (i.e.: "My wife", "My brother", etc.). Recorded interviews were transcribed verbatim and coded for analysis.

Tapes have been incinerated after full transcription. Additionally, analytic memos, notes, and quotes presented in this thesis do not contain any type of information such as names or workplaces that may give away a subject's identity. Memos were only used to document the researcher's ideas about how some themes are interrelated.

### *Research Questions*

The main overarching question in this study was: What are the perceptions of men regarding the decrease in penis size after radical prostatectomy? There are four main areas to be explored under this overarching question, which are: a) self image, b) satisfaction, c) importance, and d) coping.

- a) *Self image*. Unveiling how men see themselves after undergoing RP allow us to discover the extent of the impact prostate cancer treatment has in men. Although previous work on image perception post cancer treatment has been done in PC patients, none dealt with the more intimate aspects of penile length changes (Di Lorenzo, Autorino, Perdoni, & De Placido, 2005; Ng, Kristjanson, & Medigovich, 2006; Weber & Sherwill-Navarro, 2005). Questions asked include: What do you think about your current body image? What are the differences in body image before and after surgery? How do you perceive your own masculinity in relation to the size of your penis? How do you perceive yourself with respect to other men?
- b) *Importance*. Questions probed the value assigned to the size of the penis before and after RP. The literature suggests that penis size is important to adolescent men (Lee & Reiter, 2002). However, this author has not been able to find literature related to the perceptions of penile size in older men. Questions asked under this heading included: How important

was/is penile length to you before/after surgery? How important do you think penile length is to your spouse/partner?

- c) *Satisfaction*. Inquiring about satisfaction allowed the researcher to explore the level of approval and contentment men experience with their penis size and overall PC treatment outcomes. Questions included: Are you satisfied with how your penis functions? How satisfied were/are you with the length of your penis before/after RP? How satisfied do you think your spouse/partner is with the length of your penis? What would improve your satisfaction with your penis?
- d) *Coping*. Query on the methods used to manage the perceived loss of length gave us a better understanding of the mechanisms that are used to deal with penile shortening and, thus, be extremely useful in planning nursing interventions. The interviewer asked: What are the strategies used to deal with the perception of a smaller penis? How are you dealing with the changes that prostate cancer brought you?

#### *Data analysis*

Analysis of the data was conducted exclusively by the author of this thesis. Initial coding was carried out in consultation with the author's Thesis Supervisor. This step was taken in an attempt to ensure that coding process was carried out appropriately. Analysis followed Glaser and Strauss' (1973) description of substantive theory, within the grounded theory method. This is a method concerned with the generation of categories, properties and hypotheses rather than testing them, and lends itself to topics where there has been little or no previous knowledge generated (Polit & Beck, 2004).

The processes of data collection, coding, and analysis occurred simultaneously (Speziale & Carpenter, 2007). However, coding continued long after the last interview was conducted and can be described as occurring in three levels:

- a) Level I coding was conducted along with data collection. This type of coding is distinguished by the process of scrutinizing the data line by line and identifying the processes in the data by writing code words in the wide margins of the transcribed data.
- b) Level II coding is also known as categorizing. This step required the researcher to constantly compare the data and its assigned codes so that it can be clustered into categories according to obvious fit (Speziale & Carpenter, 2007).
- c) In Level III coding, theoretical constructs were derived by identifying the central themes that emerged from the data.

A selective sampling of the literature was carried out once emergent categories were identified. Stern (1980) suggested that literature search before the study begins is unnecessary and that it may lead to prejudgments that result in a premature closure of ideas. Literature sampled was based on the categories that emerged from the data.

As the main concepts or variables became apparent, the author constantly compared them with the data to determine their importance and the conditions in which they occur. The data gathered from the six participants in this study provided ample information to derive at the conclusions presented in this thesis. Categories were reduced into groups that represented the core variables which also symbolize basic social processes. In other words, core categories that emerged from the reduction of categories resulted in themes of broader scope.

Theoretical coding ensued after the identification of a core category, where the researcher selectively coded all the data related to the core variable. This allowed the author to focus on the data examination process in a theoretical rather than in a descriptive manner (Speziale & Carpenter, 2007). The abstraction of the data was fitted into different analytical schemes. That is, categories and themes were put into different theoretical structures that allowed for the visualization of how the process of living with the perception of PLS occurs in men with PC (see Appendices 7, 8 and 9). The use of memos ensured that the author's ideas regarding analysis were recorded helped develop the characteristics of categories that integrate them, creating a theory (Backman & Kyngäs, 1999).

#### *Issues of rigor*

The purpose of the grounded theory approach is to create a theory that results from the data. Consequently, the elements of rigor must demonstrate that the resulting theory is supported by the data. To achieve this, the author has recorded the process that took him to arrive at the findings, which helped in understanding the connection between the data and the results.

Glaser (1978) suggested that there are two essential factors when evaluating grounded theory: a) it must have fit, and b) it must work.

- a) *Fit* refers to the connection the categories have to the data. That is, the data should simply “fall” under the categories that represent them and must not be forced into them. Such connection between data and categories was be validated by the continuous comparative process of all data to the codes, categories, and theories that emerge from the study.
- b) *Work* means that the theory must be able to explain a phenomenon, predict, and interpret actions related to the phenomenon. However, Backman and Kyngäs (1999)

warn that the newly discovered grounded theory may need to be tested before it can be used for predicting. The author of the study is aware that it may take him more than his thesis work to make reliable predictions.

To further confirm the appropriateness of the results, the subjects of this study were met by the principal investigator to review the preliminary results obtained from the data before presenting final results. This allowed the author to confirm that the findings represent the data obtained.

### *Ethics*

There was a risk of eliciting negative experiences during interviews; however, none of the participants required a detailed debriefing or closure session after the interviews. This proposal adhered to the ethical principles of respect for human dignity, respect for free and informed consent, respect for vulnerable persons, respect for privacy and confidentiality, respect for justice and inclusiveness, balancing harms and benefits, minimizing harm, and maximizing benefit, as outlines in the Tri-Council policy statement on ethical conduct for research involving humans (1998). This study was approved by the Education and Nursing Research Ethics Board, at the University of Manitoba and the MPCSG (see Appendices 10 & 11).

## Chapter IV

### Sensitizing Frameworks

Once the basic social processes were established from data analysis, and after exhausting different ways of interpreting the data, the author employed two distinct theoretical frameworks to further guide the investigation. This allowed the investigator to gain greater sensitivity to specific concepts that may influence the phenomena of interest, while remaining focused on the methodology ascribed in grounded theory. The frameworks used in this study are based on the contemporary modern humanist positions and the postmodern positions on masculinity. Although both positions attempt to describe the process by which men become “men”, they have fundamental differences that add to the complexity of understanding what it means to be masculine.

#### *Distinctions between sex and gender*

Before commencing the discussion on the views of masculinity, one must first understand the differences between sex and gender. Sex refers to the basic, physical attributes of being either male or female, which are manifested through the body, nature and biology. Sex is seen as stable, rigid, and unchangeable throughout the life of the individual. It has traditionally been thought of as the bedrock on which gender identity and behavior are formed. Gender, on the other hand, relates to social learning, where individuals start as a true tabula rasa on which gendered lessons acquired match the expectations consistent with the born sex. Therefore, gender does not have to be permanent or stable; it is, in fact, assumed changeable (Phillips, 2006).

#### *Contemporary modern theories on masculinity*

The modern analysis of masculinity holds that traditional theories of development are hazardous to male physical and mental health, as well as dangerous to others. This school of

thought centers on the examination of traditional male norms and evaluates masculinity as a troubling psychological construct (Bergman, 1995; Brooks & Silverstein, 1995; Lazur & Majors, 1995; Pleck, 1995; Phillips, 2006; Pollack, 1995, 1998; Real, 1997). Within this view, the mind is seen as an independent entity from the body. Correspondingly, the individual is detached from the collective, but connected through socialization. In such a framework, masculine norms that emphasize competition, status toughness, emotional stoicism, and other male problems such as aggression, violence, homophobia, misogyny and neglect of health are the direct result of the male socialization process (Levant & Pollack, 1995).

Biological sex is at the center of modern theories on masculinity. They hold that the anatomical manifestation of sexual characteristics exerts a certain degree of maleness that is unmovable and predictive. Based on the body, men are socialized with “male” specific lessons about what men should be like. The individual’s mind, on the other hand, exerts its influence on the body by giving the person the ability to counter the effects of gender socialization. For example, Pollack (1995) assumed that men are innately wired to display a masculine potential, which he calls “core gender identity as male” (p.60). This masculine potential is one that is naturally capable to experience love, sadness, and empathic responsiveness; but is socialized to abhor its own natural emotive tendencies. The denial of its own emotions finds its roots in the long established constructions of masculinity, which hold that men must be in possession of their own autonomy, and that men should not be feebly in need of help from others. Unfortunately, the price paid for masculine autonomy is one that leads to a path of human disconnection (Bergman, 1995). In other words, although men have the intrinsic potential of being emotively expressive, they are molded into rigid social schemas of what it means to be male, and define themselves as masculine by learning how not to be feminine (Phillips, 2006). Under this framework of

differentiation, men constantly compare and evaluate their masculine worthiness; thus, perpetuating a cycle of comparison and competition with other men around traditional standards of masculinity. The salient feature is the constant process of becoming a “better than” individual, rather than being in relationships (Phillips, 2006).

*Postmodern assumptions about masculinity*

One of the greatest postmodern criticisms of the traditional view of masculinity is that it valorizes the male in the male/female dyad as the desired ideal. This preference implies that, biologically, males are hardwired to be “better” and must strive for constant improvement through risk taking, competitiveness and domination, which limits social change (Phillips, 2006). Postmodernist thinkers challenge the conventional concepts of “man”, “woman”, “masculinity” and “femininity” that have long been used as categorizing filters that set people and social relations into distinct pockets (Allen, 1996; Allen, Allman, & Powers, 1991; Collier, 1998; Drevdahl, Phillips, & Taylor, 2006; Phillips, 2006). Preset individual subjectivities derived as a consequence of being born as either male or female are no longer valid statements in postmodernism and the effort here is to reconcile gender as an individual’s social option.

Postmodern views seek to confront traditional concepts of “man” and “masculinity” by disrupting the traditional expectations of sex by virtue of being born as either a male or female. This is done by blurring the boundaries between body and the mind, sex and gender, and between the individual and society. This way, sex, gender, individual, mind and body are seen as concepts that interact with each other within a social medium. This allows for a different appreciation of the male sexed body, one that is the product of cultural discourse and made to symbolize or transmit masculine gender and identity in a different way (Phillips, 2006).

At the heart of the postmodern discourse lays the notion that the human body is attached to social schemas based on race, gender, and other kinds of bodies. Thus, moving analysis from the biological and socialization discourse, towards analysis of the social as productive of masculine subjectivity. The transmission of one's gender identity under the postmodernist construct consists on behaving in specific ways that produce the effect of an internal gender essence. Such behaviors performed are consistent within a regulatory frame that is culturally sustained over time (Phillips, 2006). Under this framework, humans understand that the anatomical body is a virtual truth that needs to be expressed by performing behaviors that represent it (Gatens, 1996). Butler (1997) suggested that these behaviors attempt to legitimize a fabrication, which is sustained via corporeal signs and other discursive means. Therefore, the becoming of a "man" does not necessarily have to start with a normal male body, but is a continuous process of repetition that reinforces the individual's chosen identity, all of which occurs within a social milieu that clues individuals on how to be masculine.

#### *Implications for data analysis*

Both, the modern and the postmodern views on masculinity provide a sensible understanding of how the concept of masculinity is formed. Although both agree that the social realm affects how males become "men", the former sustains that being of the male sex predisposes men to a certain degree of masculinity, while the latter suggests that having a male body has little influence on how a man identifies himself as, or how his masculinity should be expressed. In light of these differences, the author reminds the reader that he does not intend to debate the extent to which the body has an effect on masculinity, but to understand the possible changes that a shortened penis (and to a limited degree, the effects of ED) may have on subjects' concept of masculinity.

## **Chapter V**

### Findings

#### *Introduction*

This chapter will report and describe the data gathered from the interviews carried out on men who perceive PLS as a consequence of RP. An account of the subjects' characteristics will be provided, and a presentation of the themes will be conducted in an effort to lay the groundwork for the discussion of findings, in Chapter V. The themes presented in this study are in fact, stages that men go through after diagnosis of prostatic cancer.

#### *Description of the Sample*

A total of 11 men demonstrated interest in partaking in this study. Nine men responded to the request for subjects at an initial MPCSG meeting presentation, and two contacted the author by phone in response to the advert published in the support group's newsletter. A second recruitment presentation was attempted, resulting in no interested men. Of the men who contacted this author, one noted no PLS since RP, two had PLS which lasted for a few months but regained their original length back, one had received an orchiectomy and had not undergone a RP, and one man requested to be dropped off the study after an appointment for interview was established as he claimed having issues with memory loss. The remaining six men were recruited for semi-structured interviews held during the months of June and July of 2008. All of the men lived in Winnipeg, Manitoba. The mean age of participants was 64.7 and ranged from 58 to 77. Five of the men were married living with their spouses, while one was divorced and lived alone. Subject education level varied, most of them attained some form of post-secondary education (four), whereas, one was university graduate, and one was a high school graduate. Four of the men in the sample were retired, while two of them were employed full time. Ethnic background

was fairly homogeneous, with five Caucasians and one Ukrainian. The years in which men had prostatectomy ranged from 1992 to 2007, with four undergoing the procedure between 2006-2007. Four of the six men received additional therapy for rising PSA after RP. Of the four, two received radiation treatments alone, one received hormonal ablation exclusively, and one underwent both radiation and hormone ablation therapies (see table 4.1). Although five of the six participants described experiencing occasional urinary stress incontinence, nocturia, and urinary urgency, none of the men in the current sample reported such symptoms as being troublesome or causing bother. There was a range in the perceived amount of penile length loss reported by subjects. One man felt that his lost length was minimal attributing it to a “psychological” factor, while two participants experienced such extreme length loss that they could not urinate into a standing urinal. They attributed this to a slow stream and a retracted penis that made it difficult to aim their stream, choosing instead to void sitting on a toilet. Except for the period of time when men were undergoing radiation therapy and shortly thereafter, none of the men reported having bowel symptoms (bowel urgency and/or incontinence) at the time of interview.

Table 4.1

## Demographic Information

**Age**

Mean 64.7

Range 58-77

**Marital Status**

Married/Common Law 5

Divorced/Separated 1

**Highest Level of Education**

High school	1
Community/Technical College	3
University	1
Other (postsecondary):	1

**Employment Status**

Full-time	2
Retired	4

**Ethnic Background**

Caucasian	5
Other: Ukrainian	1

**Date of Radical Prostatectomy**

- a) May, 1992
- b) Nov., 1997
- c) Sept., 2006
- d) Oct., 2006
- e) Jan., 2007
- f) Jan., 2007

**Additional Treatments for Prostate Cancer**

- a) Hormone Therapy: undated. Radiation Therapy: 1999
- b) Hormone Therapy: 2002 and 2008
- c) Radiation Therapy: 2008
- d) Radiation Therapy: 2008

*Theme: Resigning*

Whilst several themes emerged from this study, the central theme, “resignation”, permeates throughout the data collected. Resignation was not found to be readily identified or distinctively pointed out by the subjects. Its occurrence had a subtle and non-descript form, often taking an ethereal structure that men did not seem to be able to distance themselves from. Subjects in this study conveyed feeling resigned to the effects of diagnosis and treatment of cancer. Although men did not state categorically that they were in a state of resignation, it was

evident that they were aware of their inability to revert to a pre-cancerous lifestyle; and thus, adapted themselves to living with the diagnosis of PC.

Resignation was not seen by the subjects as a state of “giving up” or “losing the will to fight”. On the contrary, it was observed as a condition of accepting one’s fate, which led to notions of “living with”, “carrying on”, “striving for normalcy” and “doing the best” given the circumstances in which men were in. In order to deal with resignation, men employed a strategy that required them to “focus on the bigger picture” that provided them with the stimulus to strive for other important goals in life.

#### *Theme: Adapting*

Adapting to the consequences of PC treatment has several characteristics. Except for men’s definitions of masculinity, all of the characteristics are themes on their own right that work together to provide men with the means to make sense of the life changing events sustained after diagnosis of cancer. In other words, adaptation is a phase in the subjects’ experience of cancer that is made up by a cluster of themes that are essential to live with prostate disease. Some of them, as in the case of subjects’ definitions of masculinity and the unchanged evaluations of their own masculinity, seem to have been established prior to their diagnosis of cancer. Whereas themes such as the constant pursuit of seeing the bigger picture, the lack of importance of PLS, and the view of ED as a minor setback, seem to be proper reactions to the diagnosis and later treatment of PC.

#### *Sub-Theme: Focusing on the Bigger Picture*

All of the men recognized that “focusing on the bigger picture” became an important tool in their arsenal that allowed them to co-exist with the diagnosis of PC. Each time the men were faced with a challenging condition related to prostate cancer and its treatment, they would

attempt to evaluate the situation by considering past experiences, current state of affairs, and hypothesizing how potential outcomes would affect them. Descriptions of the bigger picture often included family, stage of career, life goals, achievements, and comparing one's current state with other, less fortunate individuals. Evaluations of the bigger picture allowed men to see where they have come from, where they were at, and where they wanted to be. By focusing on the bigger picture, men recognized that there was a change in their priorities that included shifting their goals to cater for the needs of others. Subjects often reiterated the importance of family relations and, in the event of death, made sure that their surviving loved ones would be cared for, or at least, that they were left with the greatest monetary resources possible.

The diagnosis of cancer brought men to face their own mortality. In response, most men felt that there was a lot more to life than what they had come to know and the diagnosis of cancer was a catalyst for them to appraise life in a different way. In a sense, all of the men noted a change in the way how they saw life in general. Examples given by the subjects varied, but overall responses included a constant evaluation of what is important in life, increased appreciation for positive events, greater value in pursuing relationships, and the acknowledgement that life could be a lot "worse". When asked about how the diagnosis of cancer affected a man's view to life in general, one subject responded:

"I'm not sure that a lot of the basic values have changed... but uh... I much more value the relationships that I have with people... uh, you know and sort of being able to spend time with people and just talking, and that type of thing. You know, that's much more important to me now than was previously... A lot of detail that maybe I used to concern myself with previously, uh... you know, I just sort of let that go... and that's hard for me, because I'm one of these... I do analytical research and I'm concerned about detail and that type of thing... But some of it I have to tell you, I just don't have time for, I would much rather be doing other things than worrying about the detail... that's probably the biggest change...

...When you are confronted with this disease and specially, talking in terms of your own mortality, there are very, very simple things that suddenly you value... because, you know... how much longer you're going to keep your, regular life going?"

The same man also added:

“...there is also some frustration... you know, the kind of things that you see people fussing over and worrying about... you sometimes want to reach over and shake them a little bit and say: “listen stupid, it’s not that important”, you know? But that’s all part of that mortality thing...”

Although the diagnosis and treatment for PC can cause great distress to individuals and those around them, the imperative of the “greater view” shined through in how they evaluated negative events. This did not mean that the men in this study simply turned negative events into positive ones, but reasoned that in light of the diagnosis and treatment of cancer (or any other unwanted occurrence), men were able to see the positive consequences from the diagnosis that ameliorated its impact. This allowed men to justify the decisions and actions taken after diagnosis. The following is an example of how one man accepted the “negative” news of diagnosis and treatment side effects into a constructive event:

“...you become thankful, that things turned out as well as they did... thankful that you discovered it early enough...”

Another man narrated how he saw life with PC:

“You know, it’s a hiccup in my life... sure I don’t like it, uh... but... you know... I’m still alive today... I still feel good today... I know in my mind... I’ve done all the things that I can possibly do... (clears throat)... to protect my family... uh... financially and uh, made sure that the right keys are in place...”

While subjects’ views about life changed, they also perceived a transformation in how they viewed spousal relationships due to PC. It could be said that men’s sense of self expanded and in many times included, at least figuratively, their spouses. Subjects believed that significant others prioritized relationships and they reciprocated by making an effort in spending time together and appreciating each other’s company. Communication between subjects and spouses/partners also changed, becoming more sincere. As one man explained:

“...I think we sort of value each other more... Just being around type of thing... there is a little more discussion that goes on now, there is a little bit more... you know, hanging out together, being together sort of thing... ...the quality of [communication] has improved I would say... maybe we talk a bit deeper about things and what not...”

### *Definitions of Masculinity*

In order to understand the current thesis, this author saw the need frame the findings of this study on the subjects' own conceptions of masculinity. Although some men view masculinity as the possession physical prowess, subjects in this study tended to view masculinity as the ability to fulfill male gender roles. The emphasis is on how men feel and behave rather than how masculinity is displayed. It is obvious, from their accounts, that being “macho” does not necessarily translate into being masculine. One subject described masculinity as:

“... the way a man carries himself, [has] the responsibility and expectations to provide and protect his family. A man is expected to do certain things that give a sense of stability and make sure that the needs of the family are met.”

Another subject said that a masculine man was:

“... just being a man... [displays] the basic qualities that a man would see... I'm not saying do the physical or being an athlete... I guess it's how he carries himself as a person... you don't have to really be manly to be strutting all of your stuff all the time...”

Physical appearance and prowess are also seen as traits of masculinity, though not as defining characteristics:

“ ...I wouldn't use terminology like, lots of muscles, terribly athletic, you know... I would describe [masculinity] in terms of someone who looks after things... men have responsibilities and, so you look after your responsibilities...”

Men in this study did not believe that the size of the penis affected their own perception of maleness, suggesting that penis and masculinity are separate entities. When a man was asked to describe how masculine or manly felt in relation to the size of his penis, he answered:

“I'm not sure there's much relationship... um... I don't see a lot of relationship there.”

*Sub-Theme: Unaltered masculinity*

Given their definition of masculinity, none of the men saw any changes in the way they perceived themselves as masculine beings after noticing PLS post-RP. It can be assumed that one of the factors determining how masculine men feel is that their self perception about being heterosexual men has not changed. One man compared how masculine he feels in relation to other men:

“... I feel about normal... I’d say I match up with most men, I’m not very athletic, but I can do a lot of things that other people do, and get along... I don’t feel unmanly or not a man...”

Men compared themselves equally to other men in terms of their own perception of masculinity:

“I think I’m pretty masculine... (laughter)... I mean, I’ve never been a terribly muscled guy, or whatever... I think I’m just as masculine as the next guy...”

However, some men saw masculinity as an umbrella term that included the ability to perform sexually with the opposite sex. This created some ambiguity for men when differentiating masculinity (expected behaviors) from how manly they feel (in terms of their own sex and gender). However, they appear to distinguish between masculinity and manliness with further interrogation. The following excerpt describes how one man tries to explain his views on ED and its effects on masculinity and manliness:

Interviewer: How would you define masculinity?

Subject: In what perception? In which way?

Interviewer: In the way that...

Subject: Do I feel less manly? Yes... is it enough that it bothers me? No... um... that’s about it.

Interviewer: How is it that you feel that you are less manly nowadays?

Subject: Well... just to the point where I’m no longer able to have erections and service a woman.

There seems to be some impact ED has on the perception of masculinity for some men. This has to do with the fact that men saw themselves as being unable to perform an expected “masculine” role in procuring coitus, but this did not mean that men saw themselves as unmanly. One of the men compared how masculinity was affected by PLS and ED:

“... I don’t think the size of my penis bothers me that much, whether I’m manly or not. I guess what bothers you is that you’re unable to perform with a woman.”

Men felt that they projected the same level of masculinity as they did prior to prostate surgery. Furthermore, they believed that others perceived no difference in the subjects’ masculinity. However, some men in this study may have felt that their masculinity could be threatened if others knew of their ED. Some men may intentionally protect their masculinities by keeping RP induced ED from the knowledge of others. As one man explained:

“I don’t see any difference as long as they didn’t know I had a prostatectomy... uh... I don’t see that has changed how they would view me... I don’t see a difference there at all, like you know... you are not performing with women, but as far as how other men view me... whether they would see me as [less] masculine, I don’t think they would know”.

Sitting down to void due to the side effects of prostatectomy was seen as a normal occurrence to both gentlemen afflicted by it. The men did not correlate urinating in a sitting position with neither unmanliness nor thought it affected masculinity; however, there is a sense of inconvenience associated with it. When a man who underwent urethral dilation due to urinary symptoms secondary to RT (and consequently noted a return of up to 50% of his original penile length) was asked to explain how he felt having to sit on the toilet to urinate, he said:

“Well, I just kind of thought it was sort of normal to have to do that... I suppose if I had to continue to do that, then of course I would just have to live with it... you know... but being able to get back to normal... [there is] some sense of normality you know.... That was good that I was able to do that.”

Another man placed more emphasis on his overall physique, the display of a well toned body was more important than his penis when projecting his masculinity to others:

“I feel that if I’m physically fit, uh... I feel good about that... that’s not my manliness, but I’m proud of my physique and I try to keep in shape, and I work out and use weights and treadmills and stuff. I just feel that, that is more important to me than the size of my penis. In fact, uh... now my penis doesn’t... doesn’t matter, you know?”

One man believed that the shape of the body could lead to a perception of a threatened masculinity under the influence of androgen suppression therapy. Side effects such as gynecomastia, hot flushes and weight gain were seen by this individual as characteristics that do not fit with masculinity. In spite of the undesirable side effects, this man reasoned that in the event of undergoing HAT, he would simply have to adapt to its effects:

“Well, I have to tell you that hormone therapy is a possibility for me, sort of on the horizon... ..They start talking about suppressing the testosterone, so, you may experience swelling of the breasts, your chest and you start going through night sweats and things of that nature... just like a woman who is going through a change in life... ..But in terms of masculinity... if you end up with your testosterone being inhibited, you know, your breasts are swollen... I don’t know how you cannot feel like you’re losing your masculinity to some extent... I guess you find a way to deal with that.”

Although these are just a few examples of how men perceive their own masculinity, they illustrate a common theme. The subjects in this study see the qualities that characterize them as men remain unchanged and do not feel that neither masculinities nor their perception of manliness are threatened by the side-effects of RP.

#### *Sub-Theme: Unimportance of PLS*

None of the men in this study had any complaints related to an inadequate penis size prior to RP, judging that the length and girth of their penises were of satisfactory dimensions to their partners and themselves. When a man was asked about how important penile length or size was to him before surgery, he replied:

“I thought I was pretty normal, you know? And uh... my wife and I had a good sex life, so... I never really gave it a lot of thought... if it was too small or too big...”

Another man said:

“Well, of course any male would like to think that his is a good... (laughter) is a sufficient size... I had great sex before, and I felt I was an average [size]...”

Overall, there was a sense of acceptance of one’s penile length and size prior to surgery:

“I accepted what God gave me and I didn’t have a problem with that. I would think that I probably considered myself average, or on the smaller side but I was probably more on the bigger side and... it didn’t really fizz on me either way.”

Following RP, none of the men were concerned with what they believed to be a shorter penis; some of whom cited the fact that due to ED, the penis became an appendage that was no longer used as originally intended, rendering its length and/or size irrelevant. Some men also noted a renunciation in their intention to maintain sexual intercourse as well. As one man said:

“...the size... doesn’t mean much if you’re not trying to get blood into it to get an erection... it’s just there to empty the bladder. As far as using it for sexual purposes... I just lost interest in that.”

Another man added:

“...it’s funny with guys, you know, you go into the shower and look into the guy beside you and he’s like a horse... (laughter)... you know, you start staring at this other guy... (laughter)... and then you look at yourself and say: “Holy smokes, Charlie down there doesn’t look that healthy!”... (laughter)... But you know what? I haven’t taken a tape measure to it, but it seems that it shrunk, okay?... uh... I really don’t pay any more attention to the situation. I’m more interested in having an erection, that’s for my wife and I... but if it has to be, it has to be... that’s fine.”

None of the subjects believed that PLS was an issue for their spouses or partners. As a matter of fact, all of them stated that ED had a greater bearing on their spouses than PLS. All of the married men saw such impact as being acknowledged and accepted by their significant others, which further justified their own perception that the shortening of their penis was unimportant:

“We have discussed sex, of course... there is uh... accept[ance] of what has happened to me and the size of it now... I don't think she's thinking much about it per se... sex in her eyes has diminished and she's accepted that... we just feel that the penis is not used for intercourse anymore... so the size doesn't really matter to me or to my partner, I think.”

Another subject explained:

“It's probably less of an issue for her than it is an issue for me. You know... part of it she just doesn't care about... she's just concerned about... you know... am I going to be okay? ...am I going to get better? ...that sort of thing.”

All of the men in this study attributed a different meaning to their lives upon diagnosis of cancer. Men reasoned that concentrating on a few fundamental tasks became more important to them after undergoing treatment for cancer. It is obvious that men spent a lot of energy in surviving cancer, and in establishing and maintaining a routine. Subjects identified PLS as an issue that did not deserve nor was given much importance to be dealt with. When a man was asked about what had become a priority, or more important issues than the size of the penis, he answered:

“Well, I sort of zeroed in on trying to get myself cancer free... you know... uh... being alive and being able to function sort of normally otherwise... that's much more of a priority to me than the size of my penis... I'm more concerned about the bigger picture stuff than just that particular issue.”

There was a sense that the shortening of the penis represented only one item in a package of accepted side effects associated with treatment for prostate cancer. Such an acceptance is the result of resignation to the unpreventable consequences of treatment. Men shifted their priorities and focused their attention on other matters. The following excerpts document such an acceptance:

“You know, [the penis] shrank considerably. And I have to say I wasn't somehow, terribly surprised. Uh... nobody told me that it would [shrink], I have to say that... nobody advised that at all. But I have to say that I wasn't surprised that it did happen. I'm not sure why, it didn't surprise me. Um... up until recently, as well, I have some problems... because of shrinkage, and because of what turned out to be a bit of scar tissue, you know post surgery. I had trouble sort of standing and peeing normally... if

you combine the small penis with the fact that I didn't have a very sort of normal stream... I simply could not stand and pee... I had to sit... But, for the most part, I have to say... I have much, more important things to worry about than the size of my penis."

Another man stated:

"Well, I would have to say that, it does look shorter and it obviously is shorter, it feels shorter. I guess when they attach the urethra, after the operation it does shorten the length of your penis. Although, uh... what... what can you say? It's part of the operation, I guess..."

The lack of physical discomfort associated with a shortening of the penis is one of the reasons why men did not see PLS an issue that needed to be dealt with in terms of medical interventions. Except for ED, men did not have any complaints about penile performance. When a man was asked how satisfied he was with the way his penis worked, he said:

"I'd say very satisfied simply because there is no incontinence... that was my big concern... it seems to work really well, it passes the fluid, the urine easily, no pain, no dripping... I am very happy with the way that's turned out."

Although the length of the penis was not an issue for all of the subjects, one of them explained that the return of some of its original length was desired along with the return of erectile function:

"... even if you have an erection, [but] were so short that you couldn't perform the act properly... that would be a concern. Sure. But, otherwise if I could get an erection, and I was on the shorter side, that would be okay too."

*Sub-Theme: Erectile dysfunction as a speed bump*

All of the men stated that the return of erectile function was seen as the single event that would improve satisfaction with penile function. But they also understood that ED was a consequence of treating PC. Age too was noted to play a role in the perception that the importance of sexual intercourse diminishes as couples get older. In light of this, all of the subjects acknowledged that sexual intimacy as they had known it was lost, but recognized that the experience is not a paralyzing one. One man described living with ED as follows:

“... as you get older, sex doesn’t mean as much, although it is important... there is no argue[ment] with that and it makes one feel good after having sexual intercourse. But after the surgery, well... that was gone and as time moved on, surprisingly, I kind of accepted it... it’s not easy, but I just accepted it... I guess my desire [for sex] too lessened and lessened I guess from the surgery... or not having sex and not being able to get an erection... well, it kind of fades away, the interest.”

To men, erections are seen as an avenue of personal enjoyment. Men grieve the loss of such pleasure, knowing that there are no substitutes to replace it:

“Well, it’s probably one of the greatest pleasures in life, but when you can’t do it... it’s quite a big loss.”

These men reasoned that, although unfortunate, ED was an undeniable element in their lives and that, a way of living with it is to acknowledge that there are more important things in life than the loss of erectile function.

“...I guess a guy always dreams or thinks about having sex again, but, you know, as time goes on... I have been involved in other things... It’s not as important as it was like five years ago...

...But as far as my relationship with my wife, uh... I feel we’re just as close, for sure. In the relationship you know you don’t get the feelings of the sexual satisfaction of having intercourse, but that’s something you just live with.”

Erectile dysfunction was trivialized by these men, who saw greater threat in not treating PC. They also sought solace by reasoning that the experience of ED affected more men than publicly acknowledged:

“... erectile firmness would be one problem, but other than that it’s not a big thing to worry about... because that’s all you’ve lost, and I guess there’s been men around that probably lost erectile hardness maybe younger...”

When it comes to maintaining intimacy, men acknowledged that ED was an issue that decreased intimate encounters, however, they compensated by increasing demonstrations of affection. When a man was asked how he and his spouse lived with ED, he said:

“Well, I think we’re basically coping okay... you know... like I say, there are other things to worry about. Uh... you know... kind of uh, miss the intimacy... you know...”

associated with, uh, sexual activity... but you try to compensate a little bit just by hugging, cuddling..."

The majority of men (4/6) had tried using medications to attain erections. However, all of them eventually stopped utilizing those citing headaches, a feeling of unnaturalness, or were simply not satisfied with the type of erection achieved under them. Men acknowledged their inability to have erectile function, and justified their condition by shifting their priorities to other endeavors:

"So I have not been able to have a normal erection. Over the past while, I have tried Cialis®... and there was another... another one of those types of medication that I tried... but you know... I have not been able to have a normal erection... that's unfortunate... but I can live with it, provided that the big picture items can get taken care of..."

It seems that men tend to view ED from a perspective of resignation, taking into consideration other aspects of life that help strengthen the perception that the inconveniences derived from the treatment for PC are acceptable and, eventually normalized. Erectile dysfunction is therefore, seen as an incident that "slows down" men's views on sexual satisfaction, and they move on by re-evaluating life in a broader sense.

*Theme: Looking at the Future*

The diagnosis and treatment for PC can alter the lifestyle many men had long strived for. As cancer of the prostate mainly afflicts men close or in their retirement years, to be diagnosed with PC may mean that men have to suddenly change many long term goals. One man felt resentment towards PC for altering the plans he had already made with regards to retirement. When asked about how he felt with respect to the perceived challenges he will face in the future, he explained:

"I tell you what I feel: mostly resentful... at the disease... I'm supposed to be approaching my so called golden years, right? My plan was to retire at age 60, less than 2 years away... ..and so my wife and I should be at a point where even if we continue working, we should be able to enjoy life, do the things we want to do, and that sort of

things. So, I feel very resentful that this gets in the way... and I suppose at some point I'll get over that?"

Some men felt a sense of an impending negative outcome due to the progression of PC. Radiation therapy and/or androgen suppression therapy after RP are equated with an increase in cancer aggressiveness by subjects. Because cancer of the prostate is mostly asymptomatic in these men, there is a sense of incongruence between how men feel physically and how the advancement of PC required more aggressive treatment. Men explained that they did not have any physical symptoms that would clue them into believing that they needed further treatments. It is worth mentioning that men did not try to deny or ignore the progression of the disease due to a lack of symptoms. A man who had just received RT after RP explained how he saw his situation as follows:

"... it doesn't seem like things may end up especially rosy... you know, things may not work out in the end... especially because of the aggressiveness of the tumor that I had, and the age of onset of the disease... it would seem as though the hormone therapy path may be on the horizon. I certainly hope that's not the case, I feel pretty good, I don't feel sick..."

"...I'm sitting here talking to you and I don't feel like I have cancer, I don't feel like I'm sick. But yet, a lot of the information that I'm receiving is pretty, pretty bleak. You certainly hope that things turn out... ..we don't really try to worry about these things until you have to."

At the same time, men also felt cautiously hopeful that things may turn to their favor:

"You always live with the hope of improvement and you will always tend to see... perceive that things will get better... but not necessarily do they get better..."

Men also perceived that the uncertainties of the disease provided them with the incentive to be proactive to enjoy from personal relationships and to plan ahead, in the case of an eventual passing:

"Well, you want to make sure that you're with your family quite a bit... you don't know what to expect... whether your health is going to get worse or whether it's going to

stabilize and get better... so you tend to be conscious of your wife and your family... and uh... you keep on living... keep on rolling... but uh... it's at the back of your mind... I mean... I think anybody with any kind of ailment is concerned about the financial and everything else... make sure things are in proper places... it wouldn't matter whether you were healthy at a certain age, but I think you have to go into that type of thing..."

*Sub-Theme: Living from PSA to PSA*

The men in this study felt that their futures were dictated by their PSA results. A common denominator in the interviews was the "sense of living from PSA to PSA". Men waited anxiously to learn about their PSA tests soon after providing blood samples. Upon being notified about desirable results, men felt relieved until the next PSA test date approached. As a category of how these men saw their future, the uncertainty of the progression of PSA results forced men to make short term plans around their PSA tests. One man said:

"I'm uh, 61 years old... Am I going to get to mortality? Uh... I'm not sure... I guess really, you know, everything depends upon my test, on December 25<sup>th</sup>, my PSA, you know, maybe I'll need a second rerun... see how I'm coping at that stage in my life... ...I'll see when I cross that bridge..."

*Sub-Theme: Incongruence between PSA and physical symptoms*

Men did not notice any differences in how they felt physically with the fluctuations of PSA values. Potentially, men who do not feel physically restrained by rises in PSA may choose not to follow treatment, as they may believe that they are exposing themselves to the consequences of further treatment side effects in spite of having no physical reasons for it. This caused some ambivalence in how one man felt about his PSA scores. The following excerpt is an example of how this man felt with regards to PSA testing:

Subject: I have my doubts about the PSA readings, I don't know why. But I don't know if this... and yet they tell me, and I listen (laughter), to what this... I would normally object to even, uh... hormonal treatments, if I felt that... but I'm not sure what that PSA is really telling me.

Interviewer: Is there any specific reason why you don't connect with your PSA values?  
or the importance of PSA values?

Subject: Because I haven't noticed any changes, really...

Interviewer: Physical changes?

Subject: Any physical changes, whether it's 10, or 11, or 20, or 25... that's why.

The same man later added:

"...I doubt the PSA has such great effect on your changes... PSA may go up, but you don't see a reason for it... so there is something going on, but you can't understand it... I still don't understand it... ..I can go along and do my curling and my golfing and whatever... it's just that my reading is higher..."

### Other Findings

#### *Choosing Radical Prostatectomy*

Most men in this study felt that they could have been better informed about other types of PC treatment before undergoing prostate surgery. They identified the little time to interact with physicians as a barrier to properly investigate the options available to them and their consequences. While none of the men expressed decisional regret after undergoing RP, they believed that greater knowledge on RP and RT would have been beneficial at the time of decision making. The following excerpt documents the feelings of subjects:

"...I know these guys are so busy, these doctors, you know, they just don't have the time... and even you don't know what to ask... as you know, I also work as a consultant for a corporation, and if you ask me about buying an asset, you take the trust of the recommendation that I'm making to you. You may know a little bit about the issue, but it's just a general idea... but you really trust the person you are talking to, that he or she knows exactly what, and what questions to ask that you don't... is it a good investment? Or is it a good surgeon?  
... [radical prostatectomy] wasn't really explained to me... you know, they explained that I was going to have my prostate removed, hopefully there is no cancer, blah blah blah, but there's pros and cons to it, ok?"

One extreme example of lack of information was provided by another subject who was asked about his reaction when he was diagnosed with PC:

“Well, it was a bit of a surprise, but I didn’t take it extremely serious, because my doctor ordered an operation, which I didn’t even know about... and uh... because of the high PSA, my PSA was 26 at the time, and he ordered an operation at the hospital, and uh... it just happens that my friend works there and she said: “You’re scheduled for an operation”. So, there was a little bit of a surprise...”

The following excerpt from the same interview depicts the reasons for the same man to undergo RP:

Interviewer: How did you feel after learning you had prostate cancer?

Subject: There was a little bit of anxiety, but you really don’t know what’s going on, so you’re not overly scared at that point

Interviewer: Were you trying to look for information related to your diagnosis?

Subject: I probably did read in the books and that’s about it.

Interviewer: So, how did you come to agreeing or how did you come to decide to have surgery, to have your prostate taken out?

Subject: I had the biopsies, and then it did show that I had pros... uh, cancer, so there was just... uh... I just didn’t have to make a decision; I just went ahead with it.

Interviewer: Right, right... And what were the main contributing factors that had you go for surgery? Because there are other treatment options...

Subject: I really didn’t know about the options, and I also heard that surgery was the best way to go.

The diagnosis of cancer can be a shocking experience for many men, preventing them from being able to digest the large amounts of information that they are suddenly given. In spite of this, one subject believed that a man had to take a leading role in his own treatment, suggesting that the patient should be fully aware of the different options available, their consequences, and lastly being able to make a decision according to one’s priorities:

“... You know, you have to look after your own health. You can’t rely on even a doctor saying: “This is what you should do”... or maybe get a second opinion from a urologist... you have to be comfortable with your own choice, and have to be knowledgeable about the disease, the side effects, and make a decision, like I say with your spouse and uh... it does boil down to your decision in the end...”

### *Return to Normalcy, Seeking Routine*

Striving for normalcy was something that men valued, acknowledging that they were no longer able to fully perform the activities they enjoyed before PC, but would like to maintain their current level of activity for as long as they could:

“...I’m just happy to be around, and you know... for the most part I’m maintaining my regular, my normal life... that’s pretty important... at some point I may not be able to do that, just sort of keeps things going normally...”

After treatment for PC, men tried to maintain control by striving to achieve precancerous levels of function. Returning to normalcy and setting a routine was a way of recovering from the experience of PC treatment. This was seen by some men as being difficult to achieve, as their physical condition did not allow them to undertake many of the activities they once took for granted. The sudden inability to perform or endure physical tasks as the time before treatment can lead to frustration in some men. However, acknowledgement of their physical limitations grounded men’s insight on realistic goals, allowing them to achieve these goals.

“One of the things I had to do, even though I was trying to maintain routine, it took me about eight weeks to recover from surgery... ..The biggest thing is scaling back on what I do... and it’s a little bit frustrating, at times... but, you know... uh... it’s slowly coming back... ..I can’t quite do, physically, the things that I could do previously, so I have to take it easy, or just come off the loop, you know... and so I take time off work, I’m taking Mondays off... so I’m just trying to scale back a little bit... ..But like I say, things are improving, I kind of don’t think they’ll go back to normal, like they were... probably... but they’re improving.”

### *Helping Others*

Some men felt that they needed to reach out to other men who may benefit from information and/or support from those who have experienced PC. Although a community support group has been actively working to bring helpful information to those diagnosed with cancer of the prostate, men felt as though their activities within the support group are somewhat

limited. While all of the men in this study were recruited from the same community support group, some believed that the presence of women during meetings was an obstacle to openly discuss about certain issues that these men encountered with PC. The following narration is an example of the reluctance men feel about disclosing personal experiences at the meetings:

“...an orgasm... but most of the time it’s just dry... um... which is probably one of the things that, when I go to the meetings, when there are women there, you don’t really want to talk about...”

Not knowing how women may react to some of the topics that men would like to share was an issue for some of the subjects. It was suggested that small group sharing of experiences amongst men would increase comfort levels to improve communication between members. Nonetheless, there is explicit agreement that even men may not fully discuss issues within a smaller group of men:

“...it would be nice is, say, for 15 minutes there’s no women in there, just so that it could be a little bit more open... but even then, some of the guys can sort of back down, you know? Like there was one guy, very early, when I started going to those meetings, and repeats what he’s said is that everybody get together and, uh... go for coffee and sit around and talk... I can handle that pretty well too... but uh... when there are women around... you never know how it’s going to come across with them.”

There is a sense that discussing about very personal issues related to prostate disease makes them feel vulnerable and risk being embarrassed. In spite of this, one man suggested that he would be willing to offer his time and meet with other men who may need information and/or emotional support related to cancer:

“...but there are a lot of personal things, a lot of intimate things, you know... uh, maybe you want to say something, but you don’t want to be embarrassed, okay? You know, maybe talk about penis, or about intercourse... Maybe one man... I don’t care, but to the other person that’s very intimate... so... I’m willing to, if I can help another person on a one to one relationship... it’s that in a group sometimes, it can be overwhelming...”

*Erectile Dysfunction as a Hindrance to Intimate Relationships for Single Men*

Erectile dysfunction may affect single men differently than men with steady partners. Single men with ED may have difficulties in pursuing long term intimate relations with women as concepts of sexual satisfaction and companionship may be different from those already committed in long term relationships. The only bachelor in this study disclosed being engaged prior to diagnosis of PC, but terminated the relationship believing that ED was one reason for the breakup, as his partner prioritized sexual activity in the union. He explains:

“I guess her love life wasn’t very good through life... although we had gotten along in lots of ways, not being able to have sex really bothered her... and I don’t think I blame her. I don’t think it’s the length that is a concern to a partner... I think it’s the ability to produce an erection that affects a partner... and I can understand it pretty well. My sister said I should go look for a woman who hates sex... I don’t know if that would work either...”

Being diagnosed with cancer can also be a strain in pursuing long term relationships. The uncertainty about remaining physically healthy for a prolonged period of time meant that prospective partners risked losing their partners prematurely and/or spending time and energies looking after an ill person during old age:

“I guess when I was talking to my fiancée about that kind of stuff... ..she wanted me to guarantee her that I was going to be around for 10 years...”

The same man also endures the lack of physical closeness with the opposite sex. Sexual workers were seen by this individual as a way of obtaining the distinct pleasure of heterosexual physical closeness, and recognized that ED may have an impact on how he interacts with them. However, the legal consequences of soliciting from prostitution services deterred him from doing so. As he put it:

“It’s [ED] a strain on relationships... it’s something you have to accept, that’s all... there is one thing to do it with a woman... but you think... even well, go out and get a prostitute in this day and age you’re so scared of being nabbed and thrown to jail, or

having your name spread all over the place... I guess I myself wouldn't have a problem in seeing prostitution legal... which is another way but... that [ED] has an effect on it too."

The same man disclosed feeling uneasy around potential sexual partners since the onset of ED. The inability to achieve erections was seen by the subject as a disincentive in pursuing romantic relationships. Constant avoidance of topics related to sexual performance in casual conversations was also noted. To him, the fear of embarrassment and disappointment was obvious:

"...there's very few women that you would've got to the wet hole... we were discussing how everything works and I think you probably... uh... try as hard as possible not to talk about that anyways... right? Uh... it probably comes down to the point where you would... you are on your way to the bed, and you'd finally say you can't because you can't get it hard... you know... I guess... I believe it would end the relationship... or further strain the relationship."

#### Summary of Findings According to Original Areas of Exploration

The purpose of this exploratory study was to understand and describe the experiences of the PC patient when faced with the onset of PLS after RP. The following summary of research findings are presented under the headings of the four original areas of exploration (as described in Chapter III). Interplay of the items presented in this summary will be discussed in the following chapter.

#### *Self image*

None of the men in this study thought they noticed any significant changes in their perceptions of self after RP. Because ED is an intimate performance issue that is not displayed publicly, men felt secure in keeping this side effect from the knowledge of others. This allowed men to believe that there was a continuation in how they were being perceived by others after the removal of the prostate.

Although perceived penile length decreased in all participants, this did not affect in any way their perceptions of self either. None of the men considered themselves as being disfigured or maimed due to the onset of PLS; however, they felt the need to conceal the shortening from others as a way to project an image of being fully capable individuals.

### *Importance*

None of the interviewees felt that penile length was of great importance either before or after RP. In retrospect, all of the men were satisfied with the dimensions of their penises before surgery of the prostate, believing that their organs were appropriate for the satisfaction of their spouses. After surgery, all of the men assumed that penile length lacked importance due to the inability to use them for intercourse. The penis, in a sense, became obsolete for the satisfaction of their spouses.

### *Satisfaction*

Except for the loss of erectile function, none of the men were dissatisfied with how their penises worked. Urinary function was associated with the penis for some men, and in that respect, all of the men expressed relief that they did not suffer greatly from incontinence. Men assumed satisfaction of penile function as having little or no importance, given that erections were no longer achievable.

### *Living with PLS*

Men saw PLS as a consequence of RP that did not affect them in negative ways. For the men who reportedly were unable to void using urinals, penile shortening was viewed as an inconvenience more so than a bother. Surviving prostate cancer required more attention than ED and PLS combined, accepting the consequences of treatment were part of living with cancer.

## Chapter VI

### Discussion

### Introduction

The findings of this study contribute to knowledge about the experiences of men who undergo surgical treatment for prostatic cancer. The major purpose of this research project was to investigate the effects of perceiving a shortened penis due to radical prostatectomy. To this end, the study had an exploratory, descriptive nature designed around the grounded theory approach to qualitative studies. The main goal of the design was to generate substantive theories or models that explain, from the subjects' perspectives, the processes occurring due to the perceptions of a shortened penis secondary to RP. This chapter will provide a discussion of the findings obtained in this study and a presentation of the models derived from the data. Suggestions based on the findings will also be made on what should be done in the provision of care for men with prostate disease and future directions of research in this area will be proposed.

#### *Changes in male genitalia and masculinity*

The findings of this study suggest that changes in the male genitalia after undergoing surgical treatment for prostatic cancer do not diminish men's perception of masculinity nor have an effect on overall body image perception. As a matter of fact, none of the men saw differences in how masculine they felt before and after RP, nor as being less masculine or different from other men. These results are in line with findings encountered by DeFrank and associates (2007), who looked at body image dissatisfaction in cancer survivors. In their study, men treated for prostatic cancer reported less body image dissatisfaction than men with other types of cancer such as colorectal, bladder and melanomas, suggesting that treatment side effects affecting physical appearance have a greater bearing on issues related to body image perception (DeFrank,

Bahn Mehta, Stein, & Baker, 2007). A divergent view is brought to us by focus group studies conducted by Bokhour and colleagues (2001), and Clark and associates (2003a, 2003b), who reported that men experienced damaging changes to interpersonal relationships and their overall sense of self image due to the consequences from treatment of early prostate cancer. Clark et al., (2003b) explained that decreases in sexual intimacy, marital affection and masculine self-esteem were associated with symptoms such as frequent diarrhea, urinary and bowel urgency, and incontinence. The differences proposed in this study may be explained by the minimal urinary and bowel dysfunctions resulting from cancer treatment of the current sample.

The fact that PLS was seen as a side effect unrelated to identity, sexual performance, and masculinity gives reason to believe that the size of the penis might not be as important as it is commonly assumed, at least to PC survivors. In a similar way, DeFrank et al., (2007) found that sexual dysfunction in PC was not associated with body image for men. However, to say that the physical aspect of ED did not affect men's perception of masculinity either is to ignore the data completely. Although the respondents perceived ED as having no major impact to how masculine they perceived themselves, they felt restricted in their capacity to fulfill an expected masculine role during sexual intercourse. This was not seen by the men as a threat to their masculinities, but simply as the inability to participate fully in the range of activities performed by other men. This contrasts with the findings of a number of studies that have found that men sense a decrease in their own perception of masculinity after undergoing treatments for PC (Bokhour, Clark, Inui, Silliman, & Talcott, 2001; Clark et al., 2003a; Clark et al., 2003b; Davison, So, & Goldenberg, 2007). However, such studies focused on men's decreased sexual capacity and its effect on masculinity. Otherwise, the findings discussed here suggest that there is dissociation between the physical side effects of RP from the concepts of masculinity.

Masculinity seems to be affected in more ways that can be described by this study. In a quantitative study that included an observational group of 349 prostate cancer patients and a reference group of 398 men without cancer, Clark et al., (2003b) found that the perception of cancer control was positively associated with sexual intimacy and masculinity scores, whereas self-appraised masculinity was positively associated with the belief that decision making was well informed. These findings suggest that non-physiologic related treatment outcomes may also affect how one perceives masculinity.

The present study took the distinctive path of utilizing subjects' own definition of masculinity as the cornerstone of data analysis. By doing this, the author of this study believes that many of the extraneous nuances suggested by the literature on masculinity have been avoided; and hence, truly focus on this particular population's perception of masculinity. The subjects in this study did not describe masculinity with adjectives denoting physical traits that include the ability to perform sexually. For the respondents, the concept of masculinity centered on the expected ways in which men were supposed to behave. That is, men compared their behaviors to a "standard" masculine behavior set by other men. Therefore, masculinity to these men has a large social component in its definition. Characteristics of masculine behavior given by subjects included "taking care of things", "protecting the family", and "the way a man should carry himself". These results lend support to Stansbury, Mathewson-Chapman, and Grant (2003), who investigated the gender schemas in veterans with PC. In their study, men stressed core ideals such as "responsibility", "trust", "integrity", "dependability", "honor", and "protector" when describing masculinity, and gave little importance to terms such as "athletic", "tough", "testicles", among others when describing the characteristics of masculinity (Stansbury et al., 2003). Such conceptualization of masculinity may not be exclusive to men with PC. In an

international study involving 27,839 men from eight countries (United States, United Kingdom, Germany, France, Italy, Spain, Mexico, and Brazil), of whom 16% reported ED; Sand, Fisher, Rosen, Heiman, and Eardley (2008) found that both men with and without ED identified honor, self reliance and respect as more important values of masculinity than being physically attractive, sexually active and successful with women. Thus, the conceptualization of masculinity may lean towards the behavioral aspects of manhood rather than the strictly male physical attributes, even before RP.

Because of the non-physical nature of their concept of masculinity, subjects in this study saw the body as a separate entity from masculinity, which were not necessarily related. This allowed men to reason that their masculinity was unaffected in spite of the physiologic changes incurred due to RP. This author reminds the reader that subjects' definitions of masculinity were obtained at least one year after prostatectomy. Consequently, a claim that men's ideas about masculinity remained unchanged since the time before surgery cannot be guaranteed. However, it is from the subjects' recollection that their notions and self perceptions regarding masculinity had not changed. These results contrast with the findings of Oliffe (2005), Chapple and Ziebland (2002), and Fergus et al., (2002a), who suggested that men treated for prostate cancer are likely to reevaluate their notions about masculinity in order to accommodate the side effects of prostate surgery. In so doing, men who have undergone surgical treatment for PC detach from a previously held phallogocentric idealization of masculinity and embrace a new, redefined concept of masculinity (Oliffe, 2005; Chapple & Ziebland, 2002; Fergus et al., 2002a). It would appear as though the latter studies assumed the concept of masculinity as an all encompassing term that included aspects of the physical (penis) and the ideological (phallus). This would explain why changes in the physical realm (i.e.: ED) were met by a reevaluation of masculinity in the cited

studies. A limitation to the present and the reviewed studies about the topic is that none have measured the meanings of masculinity before and after RP. Future studies may consider incorporating this suggestion to determine if masculinity does indeed change to accommodate for the undesired effects of PC treatment.

Yet masculinity may not be experienced equally in all men with cancer. In a qualitative study involving 40 men treated with testicular cancer, Gurevich, Bishop, Bower, Malka, & Nyhof-Young (2004) suggested that men with testicular cancer experienced masculinity differently. In their study, it was found that testicular cancer survivors were caught in an ambivalent position experiencing both a loss of masculinity and a justification to be exempt from the social definition of masculinity. The differences in perception of masculinity may be due in part to the age difference between Guverich et al., (2004) and the current sample, the former having a mean of 36 years and the latter of 65 years. Differences in the perception of masculinity after both types of cancer treatment may reflect a generational difference or that there are different values assigned to the sexual organs affected. In either case, there is room to speculate that the concept of masculinity does not necessarily have to be the same in men of different ages or with differing types of cancer.

#### *Adapting to penile length shortening*

Overall, men reported feeling “healthy” in spite of having been diagnosed of cancer. Except for mild urinary symptoms which caused some inconvenience (i.e.: having to change undergarments), men saw the surgical side effects as causing no pain or discomfort. Subjects in this study saw PLS and ED as failures of the body that did not threaten men’s core ideals of identity or personhood, nor did participants see themselves as handicapped.

These findings support the conclusions derived by Bokhour and associates (2001), Korfage and partners (2006), and Oliffe (2005) who reported that subjects did not see the consequences of RP (ED and incontinence) as issues related to ill health. This, however, raises a clinical issue when men report being in good health to their physicians in spite of enduring a range of possible side effects common to RP. Furthermore, the inconveniences from the side effects may affect future decision making regarding treatments if they too add to or overwhelm current side effects.

While urinary symptoms such as urgency, nocturia, slow urinary stream and stress incontinence produce physical discomfort, the lack of somatic discomfort associated with PLS may be one of the reasons why these men are not preoccupied by it. Another explanation to the little influence PLS has in men is the very rationalization of accepting the side effects of PC treatment as the price paid to prolong life. Such redefinition of concepts is explained by Korfage and team's (2006) findings that men adapt to the consequences of prostate cancer treatment by accepting its consequences; in so doing, they reframe sexual, urinary and bowel dysfunctions as non-health related issues and normalize the changes incurred with treatment for PC.

Another reason why men may not see PLS as a threat to their masculinity is the invisibility of the penis. Men are socialized to keep their genitals guarded since childhood as social norms regulate that it is inappropriate for men to demonstrate their penises to the public. The concealment of the physical characteristics of the penis can help men keep PLS a private issue within the individual and his spouse or significant other. By keeping PLS a hidden fact, men do not risk being compared to a "standard penis" and consequently labeled as inferior to other men. This may be a reason why PLS is not usually discussed, and as this author found, has not been discussed in MPCSG meetings.

Wives' little concern with the shortening of the penis further strengthened men's belief that penile size is unimportant. Moreover, erectile function was prioritized over regaining length back, as it was seen as the single most important item that would increase men's satisfaction with their genitals. This is evidenced by the fact that most men had already tried medications to help them achieve erections, while none of them saw the need to enquire about phalloplasties.

*Relationships with significant others and the opposite sex*

All of the married men in this study reported that spouses understood the severity of the diagnosis of cancer and its impact on sexual performance due to treatment. Consequently, men did not feel being expected to perform sexually by their wives. Similarly, in a qualitative study conducted by Milne et al., (2008) men treated with surgery for PC observed that their spouses gave little importance to male sexual performance while shifting focus to the absolute riddance of cancer. In another qualitative study by Butler and associates (2000), 20 of 21 partners of men who had undergone radical prostatectomy did not perceive the lack of intercourse as an important issue. This may be a factor that decreased men's anxiety about having to perform sexually and allowed them to continue perceiving their masculinities as unchanged. Age could also be a reason for the decreased sexual demand on men. Evidence suggests that long term relationships in ageing couples see the decrease of penetrative sex as a normal transition related to declines in physical fitness (Korfage et al., 2006; Oliffe, 2005), allowing men to downscale the importance given to sex in the relationship. The results of the current study regarding the impact of ED on the perception of masculinity are also commensurate to those found by Venkatesh (1990), who reported that the majority of the respondents in his study (n=6) did not see their masculinities affected in the presence of ED after RP. Additionally, Venkatesh (1990)

suggested that men maintain their masculinities intact by assigning little or no value to the act of sexual intercourse and by demanding less of themselves sexually.

Fergus and associates (2002b) found in a qualitative study involving thirty four men with PC and their spouses that the diagnosis of prostatic cancer served as a catalyst to strengthen couples' relationships in spite of the lack of penetrative sex. Likewise, married men in this study reported experiencing closer relationships with their spouses since the diagnosis of cancer. This was characterized by improvements in communication and greater reliance on shared decision making. Men also stressed the important role performed by their spouses in providing emotional support and in the acquisition of treatment related information, as they were seen as inquisitive entities gathering as much information as possible on men's behalf. These results add to the mounting evidence that female partners are seen as eager learners about their husbands' condition and treatment options in order to provide proper care for them (Davison et al., 2003; Rees, Sheard, & Echlin, 2003; Srirangam, Pearson, Grose, Collins, & O'Reilly, 2003).

None of the men in this study felt any differences in their interactions with women in general or felt that they were perceived differently by the opposite sex due to the consequences of RP. Men expressed feeling just as comfortable in the presence of women as they did before treatment for cancer. However, single men with ED may feel shorthanded around women they see as possible candidates of romantic relationships. The only bachelor in this study identified two reasons for this. The first reason is related to the assumed expectations about the ability to sexually satisfy a partner. Single men may find themselves in a tough situation when a female partner sees sexual intimacy as a prerequisite to having a romantic relationship. The gentleman also reported feelings of embarrassment and inadequacy when faced with the possibility of an intimate encounter and preferred to avoid such situations instead of escalating towards achieving

intimacy. This may be a reason for men to give up scouting for potential partners altogether. Similarly, Bokhour et al., (2001) found that unmarried men and men previously engaged in polygamous relationships who suffered from ED, no longer sought to create the conditions conducive to sexual intimacy with the women they met, and would likely find ways to extricate themselves from intimate interactions before the opportunity of sexual encounter was raised.

A second reason pointed out by the single individual was regarding the ability to guarantee that he was going to be in relatively good health in the coming years, as not to exhaust a partner's energies caring for him. In a systematic literature review conducted by Resendes and McCorkle (2006), spouses of men diagnosed with PC suffered from an array of stressors derived from diagnosis, treatment, and consequences from treatment. Surprisingly, quantitative studies measuring spousal distress of men with PC suggest that wives can experience more psychological distress than patients (Couper, Bloch, Love, Duchesne, Macvean, & Kissane, 2006; Eton, Lepore, & Helgeson, 2005; Kornblith, Herr, Ofman, Scher, & Holland, 1994). These findings may explain why some women may not be willing to invest emotionally on a man who is, or will be ill with a serious condition, making it even more difficult for single men with cancer to find mates. Although there is a growing body of literature concerning spousal perceptions on PC, current knowledge is confined mainly on topics such as depression, sexual function and marital interaction (McCorkle, Dowd, Pickett, Siefert, & Robinson, 2007), couples' problem solving and distress (Ko, et al., 2005), information needs and adaptation (Ezer et al., 2006; Mason, 2005; Rees et al., 2003), psychosocial impact (Banthia, Malcarne, Varni, Ko, Sadler, & Greenbergs, 2003; Couper et al., 2006; Eton et al., 2005; Rees, Clarke, Waldron, O'Boyle, Ewings, & MacDonough, 2005), and decision making (Davison et al, 2002; Davison et

al., 2003). Clearly, there is a need to explore the meanings of PC in single men and its effects on establishing intimate relationships.

### *Prostate specific antigen scores*

Participants in this study saw PSA values as a litmus test in forecasting and setting expectations of what is to come. Subjects planned activities (i.e.: cruises) around PSA testing schedules, and its scores influenced the planning of events. Decreasing scores or optimal levels were met with a sigh of relief and planning may include more ambitious activities, such as a trip overseas; while increasing or high values meant, for many men, greater worry about a the recurrence of cancer. Ambivalence towards the significance of PSA testing was also evident in this sample. Men reported feeling no physiologic changes that were commensurate to the changes reflected in PSA scores. This may increase the risk of noncompliance in some men who do not see the need to undergo further therapies for rising PSA levels. Men may feel ambivalent enough about PSA scores that they may come to believe that the side effects of further treatment outweigh the benefits of how “healthy” they are currently feeling.

Prostate specific antigen testing creates a sensation of uncertainty in men who notice that their levels of anxiety increase as their PSA test dates approach and lasts until results are known to them. Similar findings are also noted by Milne et al., (2008), who found that men live in a state of constant uncertainty that was heightened by the approach of PSA test dates. In their study, men described not having the confidence that the “battle” was over, and PSA results became a tool for keeping the score of a never ending match (Milne et al., 2008).

*Information related to treatment*

Although it was not this author's intention to know whether subjects were informed about the chance of PLS due to surgery, four of the six subjects confided without prompting that they were unaware of such a possibility. Similarly, Oliffe (2005) reported that of the men reporting PLS in his study, all disclosed being uninformed about it prior to RP and were taken aback by its sudden onset. The findings presented here contrast Oliffe's (2005) report in that all of the men in our study were not bothered by PLS at the time of the interview citing, however, that ED was a greater source of concern. It is possible, nonetheless, that subjects' acceptance of PLS is the result of men's adaptive measures that have been in place since prostate surgery, at least one year prior to the interviews.

Despite subjects' reports about not knowing enough regarding other PC treatment options available at the time of surgery, none of the interviewees expressed decisional regret for undergoing prostatectomy and experiencing its due side effects. Only one of them expressed ambivalence to having undergone RP due to ED, and would have preferred knowing more about other options available to him at the time of diagnosis. None thought PLS was a factor big enough not to undergo RP. Of note is that these men already had RP. Whether men would avoid undergoing RP if PLS was made known to them as a possible side effect remains to be explored. A number of studies inquiring about decisional regret in men who have had their prostates removed found that very few men lamented choosing RP as a method of treatment for PC (Clark & Talcott, 2006; Davison et al., 2007; Hu, Kwan, Saigal, & Litwin, 2003). Furthermore, the same studies also point to a possible relationship between being poorly informed and assuming a passive role in decision making with decisional regret (Clark & Talcott, 2006; Davison et al.,

2007; Hu et al., 2003), with Clark et al., (2003b) suggesting that decisional regret increases with greater health worry, but decreases with greater sexual intimacy.

It is not known how the interplay of masculinities affected the behaviors between subjects and their physicians regarding the ways in which men sought to take responsibility of their treatment. Behaviors such as acquiring information, disclosing of side effects, disagreeing priorities between the patient and the physician within a male social construct remain unclear. Further studies are warranted to understand how the male patient-physician relationship affects overall disease outcomes.

#### Primary Model: Becoming a Prostate Cancer Survivor

Through the course of data collection and analysis it became obvious that the basic social process experienced by interviewees in this study was that of becoming cancer survivors. Men settled into the inconveniences of living with the sequelae of cancer treatment, while trying to maintain as much as possible of a precancerous “self”. Even though men acknowledged they were no longer able to perform certain activities that have provided them with a sense of physical, emotional, and psychological satisfaction, and after noticing physiological changes that may be considered as threats to the concept of self by many, participants denied any major changes in how they perceived themselves.

Men who have undergone RP recognize that they were faced with a very serious threat that required a consequence laden treatment course. Through the evaluation of the possible outcomes of not treating cancer, men reasoned that the issues arising from treatment were minor, as they perceived that much more was at stake than the loss of sexual and urinary functions. In “becoming a survivor”, men adapt to the changes brought on by PC treatment while trying to preserve the same lifestyle they had always enjoyed. A way of doing this is by attempting to

maintain their identity in the midst of the many changes brought on by their disease. Men are actively seeking to extend the way how they think they were perceived by others before the diagnosis of cancer. Because the maintenance of an identity is not an end of its own, men are engaged in a never ending process of reaffirming one's identity through behaviors that reinforce the desired identity the individual yearns for. In maintaining the desired identity, men are realistic of the problems they face in the ability to perform the whole spectrum of activities they once performed, and settle for the maintenance of a "limited identity", which is their best attempt at reproducing the precancerous self. Similarly, Bokhour, Powel, and Clark (2007) suggested that men face a disruption in their identities in light of the problems derived from treating PC, and propose that men stress other discursive identities such as being a "professional" or a "provider for one's family" to compensate for the deficiencies noted in roles that call for the need of characteristics and/or behaviors no longer available since being treated for cancer.

Overall, the process of becoming a prostate cancer survivor is characterized by the interplay of three themes: resignation, adaptation, and outlook of the future. There does not seem to be a particular order in which these stages occur, however, it can be said that all three participate at the same time (See figure 6.1).

*Theme: Resigning*

In this study, resignation to one's condition as a cancer patient is evident by the time surgical side effects are manifested. In resignation, men do not become helpless beings due to the effects of treatment. Rather, men accept the changes brought on to them by the diagnosis and treatment of cancer and, while aware of their limitations, adapt to the effects of PC treatment by trying to obtain a grander view of life. These results support those found by Korfage and colleagues (2006), who investigated patients' perceptions of the side effects of prostate cancer

treatment. In their study, Korfage et al., (2006) found that men accepted treatment side effects as unavoidable outcomes that were preferred over the notion of not treating prostatic cancer. In their adaptation to the shortcomings, men reinforced the idea of living with the side effects of cancer treatment with a sense of relief from having survived a condition they identified as life threatening (Korfage et al., 2006). Although ideals about (hegemonic) masculinity have often been depicted as having a negative influence on men's health, this thesis suggests that they may, in fact, play a positive role in resignation. Hegemonic characteristics such as stoicism, dominance, toughness, and survivorship could foster men's acceptance and dealing with the consequences of cancer treatment in a straight forward manner instead of leaving them undecidedly frozen with the consequences of treatment. This was evidenced by subjects' attitude of "just deal with it" and "play your hand", which was seen within their construct of resignation. Men believed that in resignation, they could not escape the negative consequences of cancer treatment, therefore, resigned to "dealing" with them, rather than to avoid them.

By resigning to the consequences of diagnosis and treatment, men lower their expectations and plan realistically on achievable goals. In doing so, men decrease the risk of failure in the attempt to adapt. At the same time, resignation changes how men see their futures by recognizing that that many of their plans may have to be changed in order to accommodate for their new status as cancer survivors.

#### *Theme: Adapting*

Adapting to the consequences of RP has several features. First of all, men change how they view life in general and opt to include several other perspectives when assessing their situation or when making decisions. A broader scope of view is noted by men as the main feature of their new view of the world. The first characteristic of the grander view involves men taking

into consideration the interests of others when making decisions. No longer are men the only individuals that bear the grunt of the disease, but the people around them too become affected. The second characteristic is that men evaluate their lives as having been a “good” one; men see with satisfaction the achievements of their lives and reassure themselves they have done as much in life as they could. Thirdly, men acknowledge thinking about their own mortality, prompting them to evaluate their lives and to seriously consider that some of the goals they have set out to achieve previously will simply go unmet. In reflecting about their own mortality, men refocused on the “bigger picture”, becoming less obsessed with materialistic quests and more interested in human experiences.

By focusing on the bigger picture, men prioritize the events that give them the most satisfaction in life. Not surprisingly, men value personal relationships above all things, and are intent on pursuing them further with family and friends. Suddenly, many of the items that men thought were important before the diagnosis of cancer become irrelevant. This is due, in part, to the fact that subjects contemplated the prospect of dying “a little earlier” as a risk that may rob them from the experiences they had once taken for granted. By focusing on the bigger picture, the length of the penis, erectile function, and urinary continence become unimportant, and men expressed relief to having traded them for the right to be alive. These findings are consistent with Venkatesh’s (1990) in that, thoughts about one’s mortality prompted a reevaluation and reprioritization of “many of their needs, wants and relationships” (p. 130).

Men deny any negative effects of PLS or ED on their own evaluation of masculinity. Additionally, they believe that their masculinities remain intact in the eyes of others. This strengthened their belief that they remain the “same men” of yore (or at least, as much as possible), allowing for the continuation of the self. Moreover, by reframing PLS and ED as non-

threatening baggage that their masculinities have to carry, men are able to coexist with their altered genital looks and performance, maintaining that they are worthy men.

Adapting to the consequences of PC treatment may serve to reinforce the sense of resignation experienced by interviewees. As an example, some men were reminded of their condition as a cancer survivor every time they had to urinate in a sitting position, and as such, they were aware that they belonged to a special group of men that may not be able to do what others would take for granted. Therefore, participants resigned to their new way of voiding by normalizing it. Conversely, adaptation does not mean that men will do away with all previous habits in the name of adapting to the consequences of cancer. Men try to participate in as many of the same activities performed prior to cancer treatment in order to maintain a sense of ordinariness after cancer treatment. Routine is sought as a quality that provides men with a sense of familiarity, predictability and normalcy.

The outcomes of adaptation may serve as gauges of how successful men are at living with cancer. When men consider that they are not adapting properly, they may adjust strategies (i.e.: attempting new, reachable goals) to improve outcomes. Successful adaptation or achieving the goals set during adaptation may cue men into seeing a stable, predictable future. However, in spite of all the efforts to adapt, men may not be able to see a pattern, leading them to believe that they have little control over the future. This was seen in men who, after “doing everything right”, were subject to adjuvant treatments for rising PSA levels, expressing greater uncertainty and fear of a possible negative outcome, than those who did not.

*Theme: Looking at the future*

Men are cognizant of their condition as cancer survivors. To a degree, participants described living on borrowed time. This is most evident in men who have already received

complementary therapies for rising PSA levels. Prostate cancer survivors are acutely aware that at any given time, the recurrence of cancer is a possibility, even though they are not feeling ill. This leads men to believe that a downward spiral in their health status is unpreventable, and many are focused on postponing such a downturn for as long as possible by opting for healthier habits, such as consuming low fat-high fiber diets and/or exercising. A glimmer of hope, however, is noted in the men who reported feeling that a negative outcome is impending. This hope was related to the very uncertainty that PSA scores bring. The fact that PSA scores can unpredictably rise or decrease without somatic warning conferred participants with reasons to believe that their next PSA value could be within optimal levels or, lower than previous results.

Due to the very unpredictability of their PSA results, men become focused on living in the present and planning for the short term, as they find it difficult to plan long into the future. This in turn reinforces the sense of resignation to live in the present, as men see that their future is constrained by their condition. Consequently, men further adapt to the possible gloom that waits for them by pursuing the strategies mentioned under the adaptation stage.

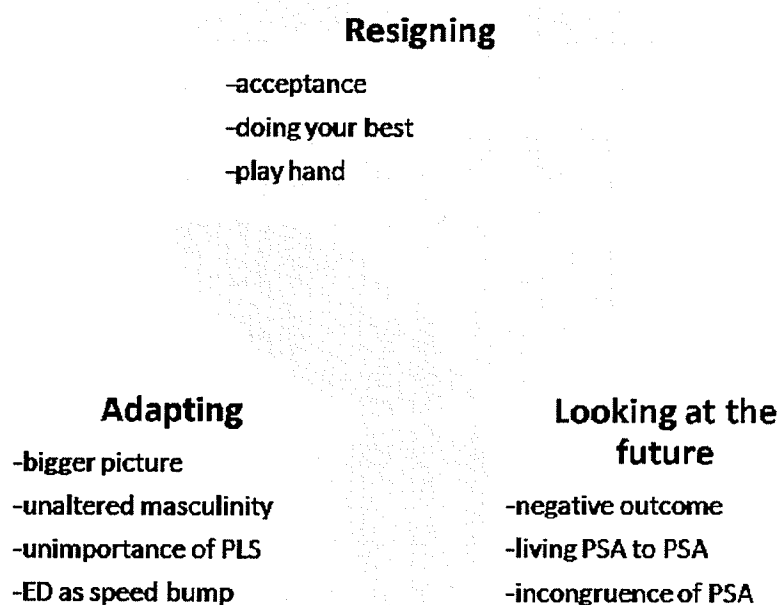


Figure 6.1. Primary Model: Becoming a Prostate Cancer Survivor

#### Secondary Model: Masculinity in Prostate Cancer Survivorship

The secondary model proposed in this thesis attempts to explain the mechanisms with which men maintain their masculinity through the changes brought on by RP. This particular model is made up of the following three elements: a) the individual, b) masculinity, and c) the group. Both, masculinity and the group can be classified as environmental factors surrounding the individual (see figure 6.2).

#### *The individual*

The individual in the model is the person of interest. It is assumed that the individual is a gregarious entity that desires to be accepted by a group (a congregation of fellow individuals) to

which he wishes to belong. A second assumption is that all individuals have an identity (abstract construct of who the individual is, or desires to be), which is complex in nature and serves to highlight each individual's uniqueness. In identity, men have characteristics that encompass concepts such as phallus (Chapter II) and gender (Chapter IV), which cannot be seen; and, penis (Chapter II), a physical characteristic that it is kept hidden from view.

### *Masculinity*

As discussed in Chapters II, IV, and V, masculinity is an abstract representation of the accepted rules of behavior that express a male identity. Masculinity is used by individuals as a bridge to connect to their social environment. The way male identity is expressed through masculine behaviors is determined by social expectations of what male behavior should be. Masculinity, therefore, changes over time along with societal changes and is often influenced by the media. Icons that have helped shape masculinity include: James Dean, Sylvester Stallone and the James Bond character. The way male identity is expressed through masculine behavior is scrutinized by the social group, which is, at the same time, the normative body of masculine rules.

Since the rules of masculinity represent the only legitimate method of expression, men are compelled to perform to the exacting demands of masculinity. This is because masculinity is socially regulated and imposed, exerting great influence on how individuals evaluate their own constructs of penis, phallus and gender, as depicted in the model by the large left pointing arrow. Consequently, masculinity becomes a norm to which men must adhere because "everybody else does" and find themselves comparing their own masculine attributes with other "normal" men to measure their own level of "masculine appropriateness". However, as an individual, a man is not able to exert the same level of leverage on what the rules of masculinity should be. It is most

likely that individual men follow the rules rather than make them, as depicted by the thin, right pointing arrow.

### *The group*

Social acceptance is provided by the group of individuals to which men aspire to belong to. The group sets the norms of what is acceptable from the range of behaviors displayed by men. Men displaying behaviors in line with set norms are rewarded with social acceptance. Whereas, men displaying nonstandard behaviors are not allowed to join or maintain their relationship with the group.

### *The model at work*

Men who experience changes in their genitalia do not consider that their masculinities are affected because their concepts of phallus, penis and gender are independent from the concept of masculinity. Men experiencing PLS and/or ED can comfortably claim that they are masculine simply because a) they have not experienced a change in their gender or sexual orientation, b) the side effects have not forced any changes in how they must display masculine behaviors to their social group, and c) the social group has not changed the rules for displaying masculine behaviors, reinforcing the belief that men's perception of masculinity remain unchanged.

None of the men in this study expressed experiencing changes in their perception of their gender or sexual orientation. There is acknowledgement that in spite of ED, men preferred to have women as their romantic and/or intimate partners, and held that they would like to enact a male role during penetrative sex, if they were able to achieve erections. In no way did men believe that they felt more feminine or less masculine due to PLS or ED, preserving the solid perceptions about their own masculinity.

It is known from the interviews that men feel unable to fully express their masculinity due to the onset of ED; however, they reject the idea of being less masculine. An explanation for this seemingly contradicting position is that sexual performance is expressed in an intimate environment, away from the public's scrutinizing gaze. Men in this study confirmed not publicizing their inability to perform penetrative sex because they felt vulnerable to being labeled as inferior by others. And yet, none of them felt that because of ED, they were prevented from performing other activities that they had always associated with masculinity (i.e.: doing physical work, sports, etc). For that reason, knowledge about the lack of erectile function is kept a "secret" within the individual (and his partner), while at the same time abiding by the rules of masculine behavior (i.e.: maintaining the role of "protector" for the household). This allows men to be perceived as masculine, which is confirmed by the social group, in granting acceptance to the individual as a masculine person.

The model also explains why PLS does not seem to affect men's perceptions of masculinity. The key is in the separation of individual attributes from masculinity. Men with PLS do not see their masculinities affected because penile length is not required to perform masculine roles or behaviors. Furthermore, social acceptance is not granted on the basis of penile length or sexual function. Therefore, when men demonstrate masculine behaviors, the social group will grant acceptance as it sees no "apparent" reason to bar the individual from liaising. Acceptance confirms one's identity as a masculine person, reinforcing the individual's perception that his masculinity remains intact.

Masculinity as a behavior determines social acceptance into a specific group. Other examples highlighting the impact of masculinity and the relationship between penis, gender, phallus, and group acceptance involve homosexual men in the armed forces. Homosexual

military personnel have the undeniable characteristics of penis, gender and phallus. However, if their identity as non-heterosexual men is revealed to their social group (the military detachment in which they serve), they will no longer be accepted in that particular group because their masculinity (behavior) is deemed unacceptable. In contrast, men with ED (altered concepts of penis and phallus) do not feel discriminated against or rejected by their social group as long as they display socially acceptable roles and/or behaviors of masculinity, even though those who suffer from it feel unable to fulfill all of the expected masculine behaviors. This is due to the intimate nature of coitus, which, although expected, does not have to be proven to the social group. A different example is that of men undergoing phalloplasties. Men who increase penile dimensions use masculinity to reflect their new status: a higher standing through an “upgrade” of the phallus.

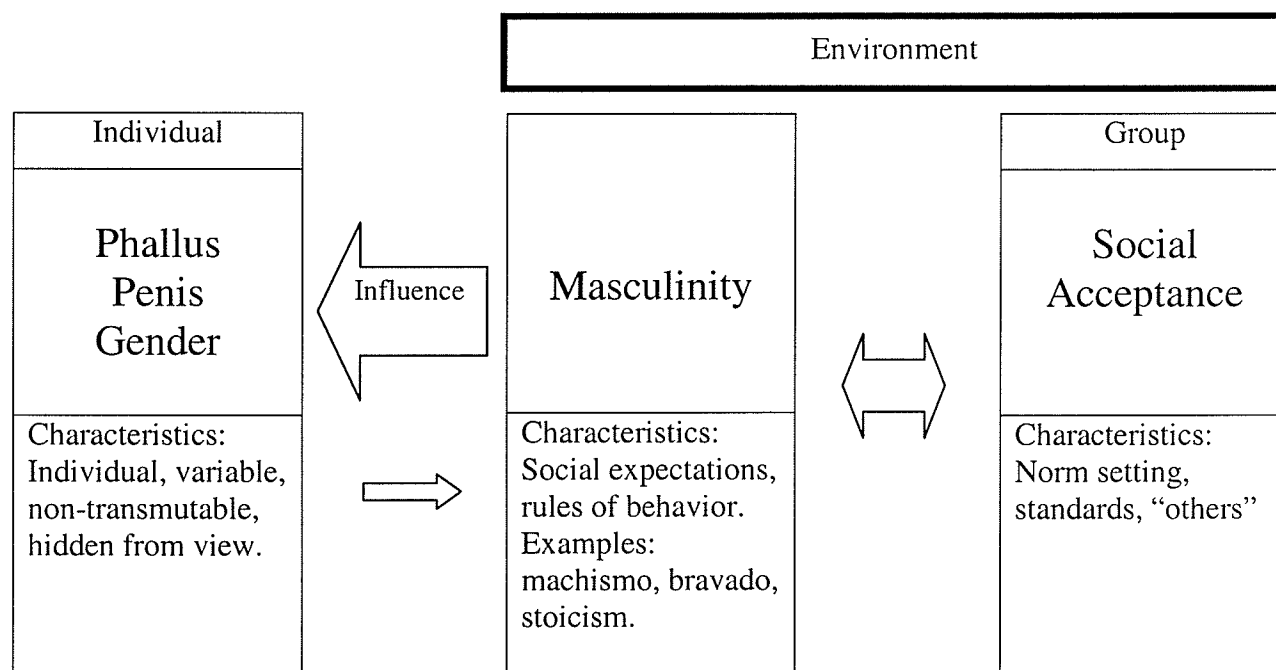


Figure 6.2. Secondary Model: Masculinity in Prostate Cancer Survivorship

### Strengths and limitations

Although the results of qualitative studies do not present statistically significant validity to the topic under study, they provide theoretical validity on quantitatively immeasurable items. In this sense, qualitative methods are best suited to extract information about lived experiences, affording both, the investigator and the subject, the luxury to record details that make the study whole. Using a qualitative methodology known as grounded theory, this study proposes two key models that describe the experience of PLS after RP.

A characteristic of the grounded theory approach is that it seeks freedom from any predetermined theoretical model or framework to conduct data collection and analysis. This allowed the main author to be free from any preconceived logic regarding the phenomenon under study. One of the greatest applications of the grounded theory is in the study of social processes. In light of the social underpinnings of the perception of masculinity, grounded theory has been deemed appropriate for this study.

The current sample was obtained from a community support group setting, where men with all stages in their experience with prostate disease gather in monthly meetings. Additionally, great range has been noted in the characteristics of PLS and the length of time before the interview was conducted. Recruiting from this setting gives a better representation of the “cases out there” in terms of the stages of the disease that range from the acute to the dormant. Whilst recruitment via physician referrals is also valuable source of participants it was not possible due to time constraints. Future studies should include samples from both sources to better document differing experiences of the phenomenon of interest.

A significant limitation to this study is that no observations regarding the process of “becoming a cancer survivor” and “maintaining masculinity” was conducted. The main objective

of participant observation is to witness the unfolding of events related to the phenomena under investigation. Doing this allows the researcher to better capture the realities of the experience and add context to the participant's statements. However, this investigator is confident in the quality of the data gathered from the participants as results have been confirmed by all participants in a second meeting.

Contrary to quantitative methods, where a greater the number of subjects in a study is desired, qualitative studies do not necessarily benefit from large number of participants. Recruitment of subjects usually stops at a time when no new information is being extracted from them, also known as saturation. In this case, recruitment was conducted until saturation plus one subject was achieved. However, the author does not feel this study is truly representative of the population with PC. A greater number of subjects with different characteristics would have been preferred.

Whilst every effort was made to obtain a diverse sample, this author acknowledges that no gay men, men with erectile function intact, nor representatives of ethnic minorities were included in this study. These are not intentional omissions, but rather, chanceful occurrences related to the seemingly homogeneous public attending monthly meetings. Therefore, the results of this report should be read taking these issues into consideration.

### Implications

Patients confer a lot power to the medical establishment when it comes to making decisions regarding treatment. Men, in particular, seem to be lacking information concerning other types of treatment options for PC at the time of decision making. Often, patients are overwhelmed by the amount of information given to them upon diagnosis of cancer, and it is understandable, that they are not able to digest the sudden information overload. When

appropriate, it is up to the health service providers to duly inform patients regarding all possible consequences of treatment, in a manner that is clear, direct and thorough. The need to remain informed is evident even after treatment. Ng and partners (2006) found that PC survivors felt compelled to have the maximum amount of information that would give them an idea of what is to come. The role of wives or partners should also be acknowledged when providing information, as they are often seen as the person giving patients the most support.

Health care providers need to be aware of the social norms regarding masculinity as men will often choose not to ask about or disclose information regarding aspects of their health in order to conform to the strict regulations of masculine behavior. Male physicians and male nurses should also be aware that their own masculinities may represent a threat to the patient's own masculinity, to the extent where patients may concede authority to the former. Therefore, male health care providers should be able to provide a safe environment to patients, where they do not feel pressured into conforming to masculine attitudes, ignoring their own health concerns.

Prostate specific antigen levels may remain a misunderstood topic to many men, even years after being diagnosed with PC. Making sure that the patient is aware of the significance and implications of PSA testing is paramount in planning for future interventions. The lack of symptoms associated with increasing levels may be confusing for many patients. It is under these circumstances that "healthy feeling" men may refuse to accept further treatments related to increasing PSA levels, as they fear the addition of more side effects from adjuvant therapies to the ones currently endured. Health care providers must enquire the reasons why men decline further treatments for rising PSA levels, reminding patients that PSA scores are not an indicator of physical wellbeing, but of active cells of prostatic origin.

Men are at a point of reevaluating and trying to maintain their concepts of identity after treatment for prostatic cancer. Health care workers should be aware of the non-physiologic issues that afflict men with regards to changes in body image. Nurses, specially, are best situated to provide support to men who are trying to maintain their concepts of self: they should be able to reassure patients that, in many cases, the penis will suffer changes in shape or size after radical prostatectomy. Nurses must acknowledge patients' concerns and demonstrate sympathy to those who suffer from both, PLS and ED. It should also be made clear to patients that, although unfortunate, PLS is a physiologic response to surgery that does not seem to cause pain or discomfort, nor affects the perception of gender and/or masculinity.

Some men may feel embarrassed about disclosing information pertaining prostatectomy side effects to women. Health care workers, whether they are male or female, must be aware that some men may simply feel uncomfortable talking about their struggles with the consequences of RP. Nurses, in particular should respect patients' unwillingness to disclose such information, and provide them with ample opportunities to build a trusting relationship that will facilitate open and honest communication between patients and nurses.

Helping to raise awareness of PLS is an activity that health care workers may consider performing. This could potentially decrease the levels of anxiety in men who suddenly experience it, and are too embarrassed to inquire about it. Although none of the men in this study reported being negatively affected due to shortening, we must remember that the possibility exists for some men to be extremely concerned about the sudden reduction in penile length.

By better understanding the concept of masculinity in illness, health care workers can improve outcomes with interventions that best suits the specific needs of convalescent men. Most of this would be around the areas of information seeking, compliance and openness to disclose

symptoms to health care workers. In a study conducted by Mahalik and colleagues (2007), men's health behaviors were found to be predictable by their perceptions of other men's health behaviors. If the findings are correct, then a comprehensive change in male normative behaviors towards health should be aimed at. Interventions devised in this respect should include the media's broad reach and powerful influence on the concepts of masculinity.

#### Future Research Recommendations

It is not known whether men who retain erectile function after RP would share the same views about PLS as the men in this study. It is possible that the attribute of achieving erections may be upset by a shorter penis that is deemed inadequate to perform coitus. Future studies should consider recruiting men who have retained erectile function after RP, and have also noticed PLS. Although anecdotal evidence exists suggesting those who can achieve erections after RP could see the return of original penile size during an erection, there is no concrete evidence to support such claims. Therefore, it is suggested here that the dimensions of penile size should also be measured in both, tumescent and non-tumescent states prior to and after RP.

It is known that social expectations of masculinity evolve over time. How men perceive and define masculinity may also change as men live through changing social norms. Knowing how different cohorts see masculinity would be of great assistance in public health planning that invites men to increase their health seeking behaviors.

Many men could be spared the surprise of sudden onset of PLS if they are told about the possibility. Although PLS seems to pose little or no impact to those who already have it, it is not known whether men would decline RP if PLS is discussed soon after diagnosis, when choosing a treatment for PC. Further studies are warranted in this area.

Further studies with greater sample sizes and in other areas such as heart disease, work safety, or other cancer groups ought to be considered to solidify the findings presented in this thesis. Consideration to test the two models suggested here should be pursued to develop interventions that could be applicable to the male population in general. Specifically, studies should explore how “expected” behaviors could be of use in improving men’s attitudes towards health.

Future interventional studies should include the populations of men in the armed forces, police and fire departments. These institutions portray an image where hegemonic masculinity is the norm in their operations. They also provide a well structured organizational framework with which interventions can be implemented, followed and evaluated. Aware of the disparities between the sample limitations provided by these institutions and the representativeness of the general male population in society, the benefits of measuring intervention outcomes may well outweigh the restrictions and deserve serious consideration.

## Chapter VII

### Reflection and Reflexivity

Reflexivity is a crucial concept in qualitative data collection. By reflexivity, the researcher performs an evaluation of how his or her participation may have influenced the data collected (Polit & Beck, 2004). These may be thoughts, behaviors or preconceptions of what the researcher expects to gather. In order to remain close to the participants' experiences, researchers need to be aware of the part they play in their own study, and document the ways that their involvement in the study may influence the data obtained. It is the qualitative researcher's responsibility to recognize his or her role and impact on the research process through reflection.

The present author became interested in male related health issues since practicing as a registered nurse. Through his practice as a general float nurse (working in all areas of direct patient care), and later emergency nurse, he found that there was an imbalance in the literature and public awareness on the issues specific to men's health. Finding that men were simply less educated than women regarding health issues, the author conducted presentations at the hospital where he worked regarding couvade syndrome (expecting fathers' behavioral changes prior to the birth of a child) and andropause (or "male menopause"). He also embarked on finding opportunities to provide general information on male specific health promotion through health fairs and community presentations on testicular self examinations, the importance of the digital rectal examination, PSA tests, among other issues. However, this author always felt that men often chose to ignore urologic and reproductive health conditions due to strong social schemas that muffled the inquiries men had on these issues. Furthermore, he found that most of the nursing literature focusing on male specific conditions was written by female researchers that center on prostatic disease and erectile dysfunction, further stigmatizing the male populous

afflicted by it. As a graduate student, this writer took the initiative of exploring men's perceptions on other, lesser known side effects of treatment for PC with the intention to defocus the assumption that ED is the lone inevitable consequence of prostatic cancer treatment.

Initially, this author believed that the sudden shortening of the penis was a sizeable threat to men's perceptions of self and masculinity. This view was shared by several other men with whom this author casually conversed. Through the interviews, however, this researcher realized that men are not as vulnerable as they are often portrayed in the nursing literature. Erectile dysfunction, although unwanted, is not seen by sufferers as a terminal condition. The length and girth of the penis, assumed by most people to be of extreme importance in male identity, was not given much significance by interviewees. Overall, at least for the participants of this study, men treated for PC seem to fare better than described in some of the qualitative publications. This may be due to the relatively few physical consequences demonstrated in this sample. Lastly, this humble author realized that men may show a lot more flexibility in the rigidity of social expectations of how men should be like.

## Chapter VIII

### Conclusions

Diagnosis and treatment of PC is seen as a turning point in life for many men. Although physiologic side effects such as ED and urinary symptoms are well known to men, many are unaware of PLS before RP. Contrary to anecdotal statements about PLS by men without PC, PLS is not seen as detrimental by the men who experience it. Rather, it is seen as a fatefully accepted occurrence that is embraced as the result of treatment for PC. In such an acceptance, men did not perceive that their masculinity was affected. Men seemed to dissociate physical attributes from what they believed masculinity truly is.

Because of the lack of physical discomfort, none of the men saw PLS as a source of concern. All participants believed that the shortened penis did not affect them or their partners/spouses. Without the ability to attain erections, men saw no need to worry about penile length or size. There is a possibility that men may desire an increase of penile length or size if erectile function returned. But this is due to the penile physical dimensions required to perform intercourse. However, ED is seen as the single most important issue that, if reversed, would greatly improve men's satisfaction with penile function.

Based on the grounded theory approach, this study has resulted in the development of two models that describe how men live with the consequences of being treated for cancer of the prostate. The first model pertains to the process of becoming and sustaining life as a cancer survivor. The second model attempts to explain how men see themselves as masculine beings. Utilizing a qualitative research design yielded findings that were detailed and rich, allowing for the observation of concepts and themes of both models.

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**Appendix 1**  
Consent Form

## RESEARCH SUBJECT INFORMATION AND CONSENT FORM

Research Project Title: Penile Length Shortening Post-Radical Prostatectomy: A qualitative study on the perceptions and responses of men

Researcher: Wellam F. Yu Ko R.N., B.N.  
Graduate Student  
Faculty of Nursing  
University of Manitoba  
Winnipeg, Manitoba

**This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

### **Purpose**

The purpose of this study is to generate knowledge that will provide an account of patients' perceptions and responses that allow them to cope with penile length shortening after radical prostatectomy. This research is being conducted to complete the requirements for a Master's of Nursing Degree at the University of Manitoba, under the Supervision of Lesley Degner, R.N., PhD.

### **Procedure**

You are required to read and sign this consent form. Please remember to put your initials at the bottom of each page as an indicator that you have read and understood the information and/or questions on each page. Once your consent form is completed you will be asked to complete a survey, participate in an interview, and complete a final survey. The first survey will give the researcher general information (such as age or gender). The interview will focus on how you feel about the physical changes that occurred to your penis, after radical prostatectomy. The interview will last from 40 minutes to about one hour. Lastly, you will be asked to complete a two-question survey regarding further participation in the study and agreement to receive the published results of the present study.

### **Risks**

There are no risks associated with participation in this study, but being asked about your current feelings may cause you additional distress. If this happens to you, you may talk with the nurse to debrief.

Initials \_\_\_\_\_

**Benefits**

Although this study has no direct benefit to you, you may find that confiding about the perceived penile changes may help you vent your emotions. Furthermore, the information collected for this study will contribute to a better understanding of the physical and emotional experience patients undergo after radical prostatectomy. The information obtained from this study will be helpful to health care professionals (e.g. nurses) who would like to know how to improve the care they give patients.

**Recording**

An audio tape recorder will be used to record the interview. Personal information such as your name will not be recorded. The tape will be incinerated after a word by word transcript is obtained.

**Confidentiality**

This study is designed to protect your confidentiality. In no way will your personal information be linked to the data collected. The information collected in the second survey (name and address) will only be used to contact you (should you agree to participate again in this study) and/or mail a copy of the published results of this study to you. Information gathered from this study (from interview) may be published; however, your name and identifying data will never be revealed.

**Remuneration**

You will be provided with a parking pass as a token of gratitude for participating in this study. A gift certificate will be offered to you, if you did not use the parking services.

**Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.**

You can reach the researcher, Wellam F. Yu Ko,

You can reach the researcher's advisor, Dr. Lesley Degner

Initials \_\_\_\_\_

**This research has been approved by the Education and Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122, or e-mail [margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca). A copy of this consent form has been given to you to keep for your records and reference.**

---

Participant's Signature

Date

---

Researcher and/or Delegate's Signature

Date

**(In Studies Involving Vulnerable Populations**

*For research with persons who are unable to give valid, informed consent for reasons of age, disability, or other vulnerability, the signed informed consent of a substitute decision-maker should be obtained. The consent form should indicate the legal relationship by which power to consent has been delegated. In addition, the researcher shall, as much as possible, explain to such prospective subjects the research and involvement being requested, and seek their cooperation (i.e., assent) both at the outset of and throughout the project. The researcher should also remain vigilant and be prepared to discontinue the research immediately if there are any indications that continued participation is becoming distressing and/or harmful to such persons.)*

**Appendix 2**

Manitoba Prostate Cancer Support Group: Newsletter advertisement

# Men Wanted!!!

Wellam Yu Ko (a graduate student) wants to learn about your experience with Radical Prostatectomy. He is currently doing his thesis on prostate cancer survivors, and is looking for volunteers to conduct brief interviews focusing on issues related to sexuality and sexual functioning. For more information, please call: [redacted] email: [redacted]

**Appendix 3**

Future Contact Form

Future Contact Form

Please circle either "Yes" or "No"

- I would like to participate in a future review of results

Yes,

Name: \_\_\_\_\_

Phone number: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

No

- I would like to receive the published results of the study

Yes,

Address: \_\_\_\_\_

\_\_\_\_\_

No

Thank you very much for participating in this interview. Your contribution is highly appreciated!

**Appendix 4**

Demographics Questionnaire

## Demographic Information Form

Please circle and/or write the answer that best applies to you.

1. Age \_\_\_\_\_

2. Marital status:

- a) Single/Never married
- b) Married/Common Law
- c) Divorced/Separated
- d) Widowed
- e) Other (specify): \_\_\_\_\_

3. Highest education:

- a) Less than high school
- b) High school
- c) Community/Technical college
- d) University
- e) Other (specify): \_\_\_\_\_

4. Employment status:

- a) Full-time
- b) Part-Time
- c) Retired
- d) Unemployed
- e) Disability/Medical leave

5. Ethnic background:

- a) Aboriginal
- b) Asian
- c) African descent
- d) Caucasian
- e) Latin American
- f) Middle Eastern
- g) Other (specify): \_\_\_\_\_

6. Date of radical prostatectomy (day/month/year): \_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_

7. Previous and/or ongoing treatments for prostate cancer:

a) Hormone therapy (year): \_\_\_\_\_

b) Radiation therapy (year): \_\_\_\_\_

c) Chemotherapy (year): \_\_\_\_\_

d) Other (specify): \_\_\_\_\_ Year: \_\_\_\_\_

**Appendix 5**

Interview Questionnaire (Original)

## Examples of interview questions:

### General questions

- a) Tell me about how you felt when you were first told you had prostate cancer.
- b) How did you decide to have your prostate taken out?
- c) How did you fare out after surgery?

Probes on:

#### Self Image

- 1) Have you noticed any differences with your penis after radical prostatectomy?

Probe: In what ways?

Can you elaborate?

If erectile dysfunction is not mentioned: Do you suffer from erectile dysfunction?

If yes: Did you suffer from erectile dysfunction before or after RP?

- 2) How important is the size of your penis to you?
- 3) How manly do you feel in relation to the size of your penis?
- 4) How masculine do you think you are with respect to other men?

#### Importance

- 1) How important was penile length/size to you before surgery?
- 2) How important is penile length/size to you now?
- 3) How important do you think penile length is to your spouse/partner?

#### Satisfaction

- 1) How satisfied are you with the way your penis works?
- 2) How satisfied do you think your spouse/partner is with the way your penis works?
- 3) Is there anything that would improve your satisfaction with your penis?

#### Coping

Tell me how you adapted to the changes after surgery.

- 1) How did you deal with the perception of a smaller penis?

Probe: Can you elaborate?

- 2) How do you think things will go in the next months-years?

- d) After all that has happened to you since learning that you had cancer: How are you faring out now?
- e) Would you recommend surgery to people in your situation?

#### Closure

- 1) What advice would you give other men who are diagnosed with prostate cancer?
- 2) What would you advice men who are about to undergo radical prostatectomy?

3) Is there anything else you would like to tell me about your experience of a shortened penis or anything else we talked about?

**Appendix 6**

Interview Questionnaire (Modified)

## Examples of interview questions:

### General questions

- a) Tell me about how you felt when you were first told you had prostate cancer.
- b) How did you decide to have your prostate taken out?
- c) How did you fare out after surgery?

#### Probes on:

##### Self Image

- 1) Have you noticed any differences with your penis after radical prostatectomy?
- 2) What was your reaction when you first noticed penile changes?

Probe: In what ways?

Can you elaborate?

- 3) How did radical prostatectomy affect sexuality and sexual performance?
- 4) Do you suffer from erectile dysfunction?

If yes: Did you suffer from erectile dysfunction before or after RP?

- 5) How would you describe masculinity/manliness? What characteristics make a man masculine/manly?
- 6) How manly do you feel in relation to the size of your penis?
- 7) How masculine do you think you are with respect to other men?
- 8) How important is the size of your penis to you?
- 9) How does a shortened penis affect you?

##### Importance

- 1) How important was penile length/size to you before surgery?
- 2) How important is penile length/size to you now?
- 3) How important do you think penile length is to your spouse/partner?
- 4) How has the side effects affected your spouse or partner?

##### Satisfaction

- 1) How satisfied are you with the way your penis works?
- 2) How satisfied do you think your spouse/partner is with the way your penis works?
- 3) Is there anything that would improve your satisfaction with your penis?
- 4) If you were still able to attain erections, would the length of your penis still be important to you?

##### Coping

How has the diagnosis of cancer changed your of life?

How has the diagnosis of cancer changed your view of life?

Tell me how you adapted to the changes after surgery.

What would be worse than what you are currently experiencing?

What would be worse than the side-effects you are currently having?

Probes:

1) How did you adapt to erectile dysfunction?

2) How did you adapt to a perceived smaller/shorter penis?

3) How did you deal with the perception of a smaller penis?

Probe: Can you elaborate?

4) How do you think things will go in the next months-years?

d) After all that has happened to you since learning that you had cancer: How are you faring out now?

e) Would you recommend surgery to people in your situation?

Closure

1) What advice would you give other men who are diagnosed with prostate cancer?

2) What would you advice men who are about to undergo radical prostatectomy?

3) Is there anything else you would like to tell me about your experience of a shortened penis or anything else we talked about?

**Appendix 7**

## Theoretical Schema A

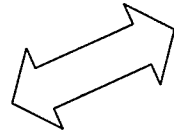
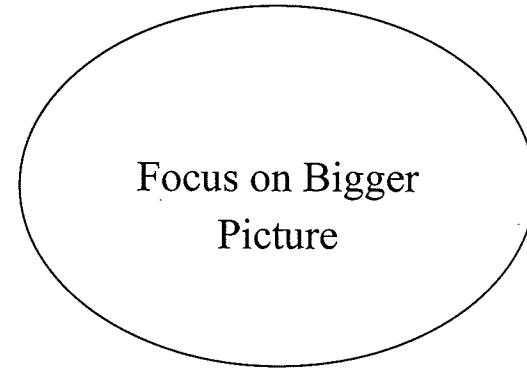
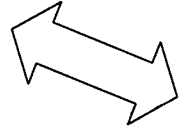
Unimportance of PLS  
Unaffected masculinity  
ED as a speed bump



Resignation



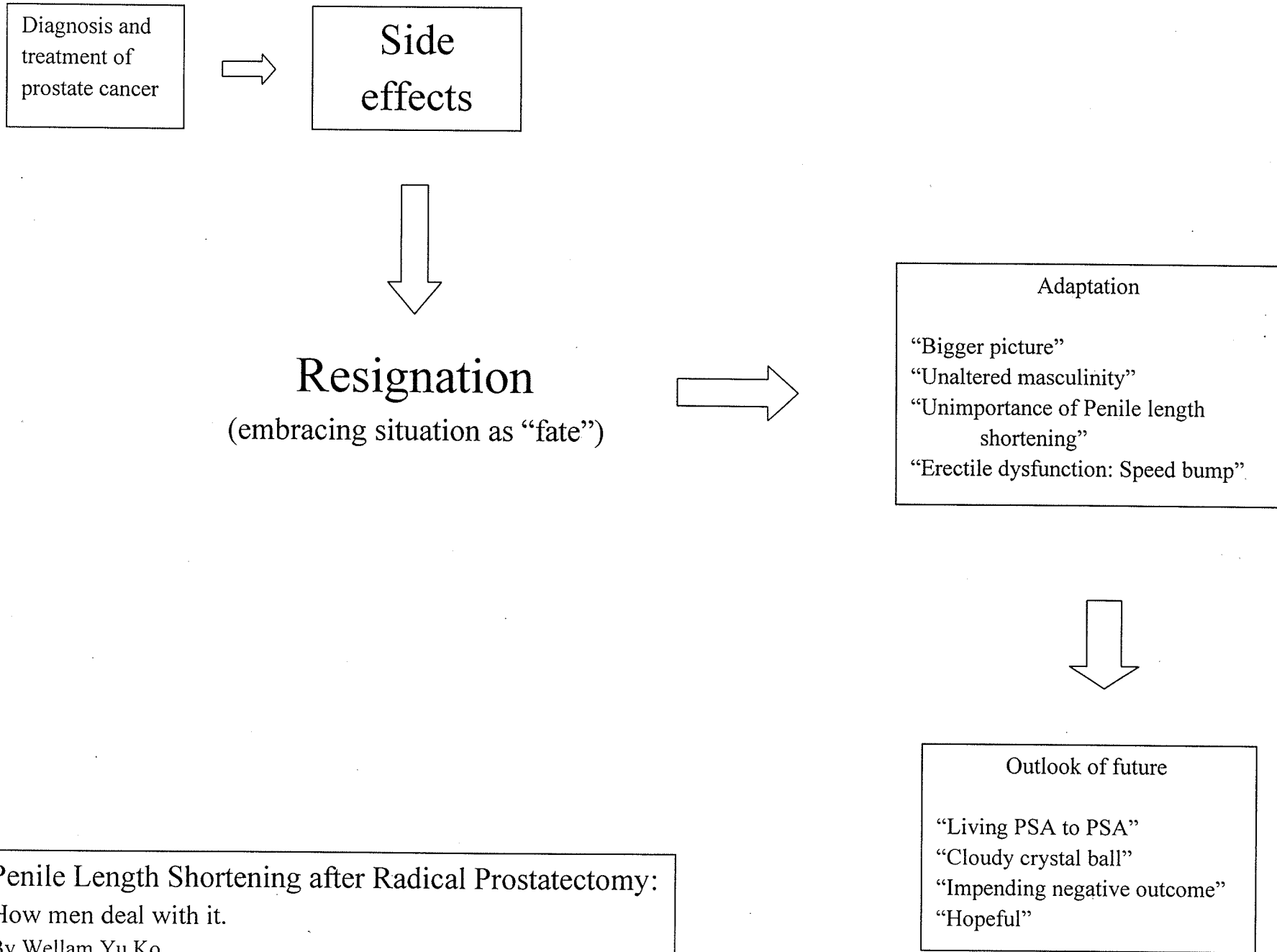
Living PSA to PSA  
Play your hand  
Normalcy/Routine  
Taking care of things



Perceptions and responses of men to RP and its side effects  
By Wellam Yu Ko.

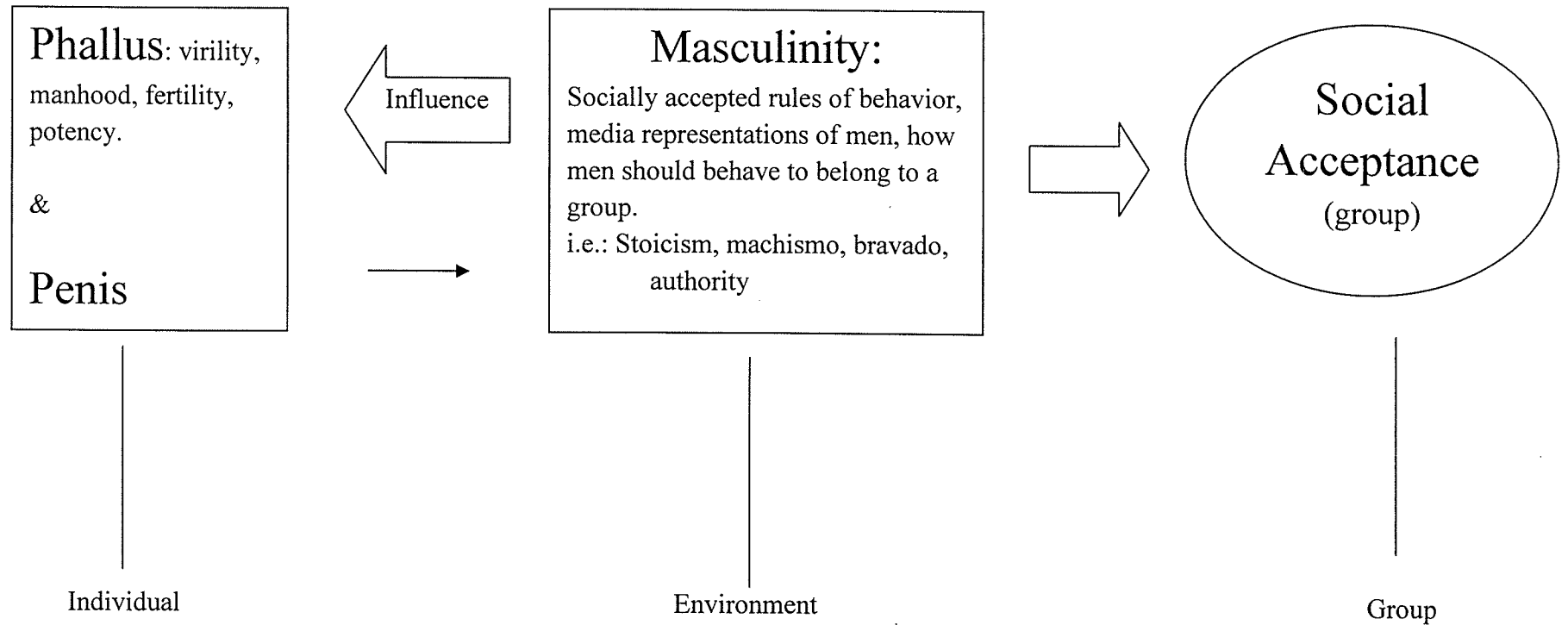
**Appendix 8**

Theoretical Schema B



**Penile Length Shortening after Radical Prostatectomy:**  
How men deal with it.  
By Wellam Yu Ko.

**Appendix 9**  
Theoretical Schema C



### Relationship between Phallus, Penis, and Masculinity:

Accommodating for side effects of prostatectomy.

By Wellam Yu Ko.

**Appendix 10**

Education/Nursing Research Ethics Board Letter of Approval



UNIVERSITY  
OF MANITOBA

OFFICE OF RESEARCH  
SERVICES

Office of the Vice-President (Research)

CTC Building  
208 - 194 Dafoe Road  
Winnipeg, MB R3T 2N2  
Fax (204) 269-7173  
[www.umanitoba.ca/research](http://www.umanitoba.ca/research)

**APPROVAL CERTIFICATE**

11 April 2008

**TO:** Wellam F. Yu Ko  
Principal Investigator (Advisor L. Degner)

**FROM:** Stan Straw, Chair  
Education/Nursing Research Ethics Board (ENREB)

**Re:** Protocol #E2008:031  
"Penile Length Shortening Post-Radical Prostatectomy: A  
Qualitative Study on the Perceptions and Responses of Men"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note:**

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Ethics Board requests a final report for your study (available at [http://umanitoba.ca/research/ors/ethics/ors\\_ethics\\_human\\_REB\\_forms\\_guidelines.html](http://umanitoba.ca/research/ors/ethics/ors_ethics_human_REB_forms_guidelines.html)) in order to be in compliance with Tri-Council Guidelines.

**Appendix 11**

Manitoba Prostate Cancer Support Group Letter of Permission

Mr. Wellam Yu Ko,

The Executive Board of the Manitoba Prostate Cancer Support Group met on May 8<sup>th</sup>, 2008 and supported your request to ask for volunteers from our members. We understand that you are doing some research on patients who have had a radical prostatectomy for your thesis. Please come prepared to do an oral presentation to the assembled group on May 15<sup>th</sup>.

You may also submit a written request for volunteers and we will have it published in our upcoming newsletters. We are most pleased that you are taking an interest and have a desire to learn about prostate cancer and if we can be of any assistance, please do not hesitate to contact us further.

Wishing you well in your thesis study,

Kindest regards,

Norm Oman  
Chairman, Events Coordinator.

Brian Sprott  
Executive Member.



**Appendix 12**

Faculty of Nursing Thesis Committee Approval



UNIVERSITY  
OF MANITOBA | Faculty of Nursing

Graduate Programs Assistant  
Helen Glass Centre for Nursing  
Winnipeg, Manitoba  
Canada R3T 2N2  
Telephone: (204) 474-6216  
Fax: (204) 474-7682

**DATE:** May 23, 2008  
**TO:** Wellam F. Yu Ko  
**FROM:** Pam Begg, Acting Graduate Program Assistant, Faculty of Nursing  
**SUBJECT:** THESIS COMMITTEE

This is to advise you that the Graduate Studies Committee of the Faculty of Nursing has approved your thesis committee as stated below. The Master's Thesis/Practicum Title and Appointment of Examiners' form will be signed and sent to the Faculty of Graduate Studies for processing. If there are any concerns you will be contacted

Advisor: Dr. Lesley Degner, Faculty of Nursing  
Examiner: Dr. Thomas Hack, Faculty of Nursing  
External Member: Dr. Garry Schroeder  
Department of Radiation Oncology  
675 McDermot Avenue  
Winnipeg, MB  
R3E 0V9

I wish you every success in your thesis/practicum endeavour.

Cc: Dr. Lesley Degner

**Appendix 13**

Faculty of Nursing Thesis/Practicum Proposal Approval Form