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The Influence of Cancer Fatalism and Prostate Cancer Knowledge on Sexual Function and Bother after Treatment for Prostate Cancer: A Moderation Model to Explain Ethnic Differences

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The Influence of Cancer Fatalism and Prostate Cancer Knowledge on Sexual Function and Bother after Treatment for Prostate Cancer: A Moderation Model to Explain Ethnic Differences (August 2012)

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Research conducted with prostate cancer (PC) survivors has previously noted ethnic disparities in knowledge about PC, fatalism about a PC diagnosis, and linked these disparities to poor adherence to PC screening recommendations. This poor adherence may be an important factor explaining why Black and Hispanic men tend to present for treatment at a more advance stage that is more likely to be fatal. While 5 year survival rates for PC approach 100%, men often report problems with sexual function that they are quite bothered by and which negatively affect their overall quality of life. However the evidence for ethnic disparities in post treatment sexual function has yielded mixed results while examinations of disparities in sexual bother are few in number.

This study examined the influence of cancer fatalism and prostate cancer knowledge before treatment on sexual function and sexual bother after treatment for localized PC. Exploratory analyses sought to determine if race/ethnicity moderates any relationship between cancer fatalism or PC knowledge and sexual function and bother. The participants included approximately 60 ethnically diverse men diagnosed with localized prostate cancer within the past month who

were recruited prior to receiving any treatment. Participants were drawn from the Prostate Cancer and Treatment Health Study (PATHS), a prospective observational study funded by the National Cancer Institute to determine the influence of ethnic group membership on quality of life and disease related outcomes among men diagnosed with PC.

Results of this study did not demonstrate any ethnic differences in cancer fatalism or PC knowledge prior to treatment for PC. Likewise, no ethnic differences in sexual function or sexual bother were evidenced one month after treatment. After controlling for age, co-morbid conditions and years of education, treatment type was the only significant predictor of sexual function one month after treatment. Descriptive analyses indicated that men who received internal or external radiation experienced the least decline in sexual function. Post hoc analyses conducted with men treated using radical prostatectomy, demonstrated that Black men reported the lowest levels of PC knowledge along with the highest co-morbid condition severity scores. These findings underscore the importance of including Black men in programs designed to improve the PC knowledge of men at increased risk for the disease. Limitations and ideas for future work are elaborated on in the discussion section.

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Chapter 1: Introduction

Prostate Cancer

Prostate cancer (PC) is the most frequently diagnosed non-skin cancer among American men. The American Cancer Society estimates that in 2009 there will be 192,280 new cases of PC diagnosed, and that 27,360 men will die from the disease, making it the second leading cause of cancer death after lung cancer (American Cancer Society [ACS], 2009). The 5 year survival rate for PC that is diagnosed while still localized to the prostate gland approaches 100%. As a result, factors which adversely affect the decision to seek treatment early are an important focus of research studies. The process of screening for and diagnosing PC typically begins with a blood test for prostate specific antigen (PSA) and also includes a digital rectal examination (DRE) and a biopsy of the prostate gland. Current guidelines suggest yearly screenings beginning at the age of 50 for men of average risk for PC, and age 45 for men at higher risk due to African ancestry or a strong family history (ACS, 2009).

African American and Afro-Caribbean men have the highest incidence of PC in the world, and are twice as likely to die from the disease as non-Hispanic White men (ACS, 2009). There are a number of potential contributing factors to this disparity including: genetic factors, higher levels of testosterone, diets high in saturated fat, high PSA counts, and a lack of access to healthcare (Williams & Powell, 2009). While most existing data reports that non-Hispanic White men have the second highest incidence rates of PC in the US, one study found that

among elderly men (75-84) Hispanics actually had higher incidence rates than non-Hispanic Whites (Cheng, et al., 2009) Also, despite lower overall incidence rates, the mortality rate of Hispanics from PC is close to that of non-Hispanic Whites, suggesting that some Hispanic men are not receiving adequate treatment to reduce mortality (Wilkinson, et al., 2002). Along with Hispanic men, African American men are more likely to be diagnosed with advanced stage PC than non-Hispanic Whites (Hoffman et al., 2001). The likelihood to present with advanced stage PC is also related to: not having a previous PSA test, not having insurance, and being unemployed (Hoffman et al., 2001).

Hispanic men may be at a particular disadvantage in PSA screening rates. A recent public health dissertation by Hossain (2009) utilized a sample of 935 prostate cancer patients treated at hospitals in the Texas Medical Center in Houston Texas, and found that only 42.3% of Hispanics in his sample reported having a previous PSA test before they were diagnosed with PC versus 54.4% of African Americans and 63.2% of non-Hispanic Whites (Hosain, 2009). Furthermore, Hispanics in this sample were 40% less likely than non—Hispanic Whites to have had a PSA test even after adjusting for age, income and education. Other research examining trends in PSA testing rates among African Americans has demonstrated past downward trends in screening rates for African American men in 2004 and 2006 when compared to screening rates in 2002 (Ross, Meade, Powe, & Howard, 2009). When taken together, these findings regarding screening rates for Hispanic and African American men

underscore the need to better understand what may be influencing prostate screening behaviors for these men.

Screening frequency has been shown to be influenced by a number of factors including: socio-economic status (SES), access to healthcare, prostate cancer knowledge, and health beliefs (Kudadjie-Gyamfi, Consedine, & Magai, 2006). Research conducted by Kudadjie-Gyamfi et al. (2006), has demonstrated that greater use of problem solving coping and less use of avoidance coping are also associated with greater PSA test frequency. Furthermore, minority men (e.g. Haitian, Dominican, and Puerto Rican) in their sample were more likely than European Americans to report avoidance as a coping style, a factor which may adversely impact screening frequency for minority men of African and Hispanic descent (Kudadjie-Gyamfi et al., 2006). Perceptions of risk may also play a role in screening behavior and research conducted by Shavers et al. (2009) suggests that few African American men (18%) believe they are at a higher than average risk for developing PC. In contrast, 21.6% of Hispanic men perceive their risk as higher than average, despite actual incidence rates lower than African Americans and non- Hispanic Whites (Shavers, Underwood, & Moser, 2009). These findings highlight the need for greater PC education and suggest African American and Hispanic men may be at a particular disadvantage regarding PC knowledge. After being screened for prostate cancer, some men delay treatment and continue to monitor their prostate cancer using PSA tests and biopsies in a process called active surveillance. However, other men diagnosed with PC

make the decision to begin active treatment and choose from a wide range of treatment options.

Treatment for Prostate Cancer

There are a number of treatments for newly diagnosed PC, with the most prevalent being radical prostatectomy, external beam radiation, brachytherapy, and androgen deprivation or hormone therapy. Undergoing any of the several treatments for PC is often a complex decision. Physicians incorporate a knowledge of the location, stage and type of cancer in their decisions to recommend treatment. Patient preference is often a significant part of the decision. PC can be a slow growing cancer and as a result, some men decide not to have treatment immediately, instead deciding on active surveillance or watchful waiting.

Delayed evaluation of abnormal PSA results has been explored as a potential factor in the observation that African American men present with PC at a more advanced stage than non-Hispanic Whites. Turner et al. (2011) examined a sample of 724 men recruited from 46 primary care practices over a 4.5 year period and found an average delay of 3 months in their sample. While they did not find any differences in delay based on race, they did find that men over the age of 75 tended to delay treatment more than men aged 74 or less.

Research which examines the role of race or ethnicity in prostate cancer treatment selection has demonstrated that ethnic minority men may be more

likely to choose non-surgical therapies than non-Hispanic White men (Moses, Paciorek, Penson, Carroll, & Master, 2010). Moses et al. (2010) examined data from CaPSURE and found that African American men were more likely to be diagnosed at younger ages and with higher risk disease compared with non-Hispanic White men, but were less likely to have radical prostatectomy. African American men were more likely to receive radiation therapy and were also more likely to receive androgen deprivation therapy even for low risk PC compared to non-Hispanic Whites (Moses et al., 2010).

Xu et al. (2011) conducted semi structured interviews with 21 men recently diagnosed with localized PC and found that physician recommendation, patient self perception, and beliefs about PC were all influential to treatment decisions. More specifically men who chose surgery were more likely to report concern over the cancer spreading in the future along with a focus on a cure for their cancer. However men who chose radiation indicated that this option also offered a cure with fewer side effects (Xu, Dailey, Eggly, Neale, & Schwartz, 2011).

Surprisingly, whether men undergo treatment or not, research suggests that general quality of life is equivalent to age matched men without PC (Bloom, Petersen, & Kang, 2007). Research into disease specific domains of quality of life, however, has shown that treatment is associated with significant decrements in sexual functioning (Hoffman, Gilliland, Penson, Stone, Hunt, & Potosky, 2004).

Sexual Function After Prostate Cancer Treatment

Erectile function has been shown to be among the most important predictors of sexual satisfaction for PC survivors along with relationship closeness and depression or anxiety symptoms (Nelson, Choi, Mulhall, & Roth, 2007). Research which examines changes in sexual function within six month after PC treatment are limited, however Ball et al. (2006) conducted one such study and reported on sexual function and bother at 1, 3 and 6 months post-treatment (Ball, et al., 2006). Their results were separated into subgroups based on the type of treatment received. Men who underwent radical prostatectomy (RP) were further broken down by type of surgery received (i.e. open RP, laparoscopic RP and da Vinci RP). Their findings indicated that 14%-19% of men had recovered to their baseline sexual function one month after treatment, which increased to 24%-35% after 3 months and 33-43% after 6 months.

Litwin et al. (2007) examined a sample of localized PC survivors treated with radical prostatectomy and found slower recovery with only 5% reporting return to baseline sexual function after one month, 10% after two months, 15% at four months, 20% at eight months, and 25% at 12 months (Litwin, et al., 2007). When taken together these results indicate a range of 5%-19% of men recover to pre-morbid levels of sexual function one month after RP. This increases to between 10%-35% after 3 months, and 15%-43% after 6 months.

The Prostate Cancer Outcomes Study (PCOS) was a large population based cohort study of sexual function after PC treatment (Potosky et al., 1999). This study assessed urinary, bowel and sexual functioning for more than 3,500 men identified through the National Cancer Institute's Surveillance Epidemiology and End Results Registries (SEER; Landis, Murray, Bolden, & Wingo, 1999) as having been diagnosed with PC between 1994 and 1995. These men resided in various areas across the nation including Connecticut, New Mexico, Utah and the metropolitan areas of Atlanta, Los Angeles, and Seattle. They were followed for a 5 year period and urinary, bowel, and sexual functioning outcomes were reported at two and five years post-diagnosis.

Research conducted by Penson et al. (2008) with participants in the Prostate Cancer Outcomes Study (PCOS) who received radical prostatectomy, indicated that 81% of their sample reported having erections firm enough for intercourse before diagnosis. This number declined to 9% 6 months after diagnosis and rebounded somewhat to 17% at one year, 22% at 2 years and 28% at five years (Penson, et al., 2008). These results related to one aspect of sexual function (i.e. erectile function) and thus are difficult to directly compare to the results of the Ball et al. (2006) or Litwin et al. (2007). However the research by Penson et al. (2008) does suggest that men who undergo surgery usually experience a sharp decline in sexual function within 6 months after treatment which recovers gradually over time. Rates of impotency may vary largely based on treatment type. One study indicates that 79% of surgery patients reporting

impotency after 5 years compared with only 64% of men treated with external radiation (Stanford, et al., 2000).

The variability in rates of recovery is also underscored by Ball et al. (2006). Among men receiving cryotherapy, Ball et al. (2006) found that 13% recovered sexual function after one month, 18% after 3 months, and 43% after 6 months (Ball, et al., 2006). Furthermore, men who received brachytherapy reported faster recovery than those who underwent RT or cryotherapy. More specifically, 56% recovered sexual function after one month, 63% after 3 months, and 72% after 6 months. However, Litwin et al (2007) reported much lower recovery of function rates for men who underwent brachytherapy. Their results indicate that 25% of men receiving brachytherapy recovered after one month, 35% after two months, 45% at four months, 50% at 8 months, and 55% at 12 months. When taken together these results show that a range of 25%-56% of men recover to pre-morbid levels of sexual function one month after brachytherapy. Men who underwent radiation therapy appeared to recover most quickly, with 40% recovering to baseline sexual function after one month, 50% after two months, 60% after 4 months, 65% after 8 months, and 70% after 12 months (Litwin et al., 2007). In order to put the change in erectile function for men who underwent treatment in context, Hoffman et al. (2004) examined a subset from the PCOS and compared men diagnosed with prostate cancer with age and race matched men without PC. They found that over the 5 year course

of their study, the percentage of men treated for PC reporting no erections increased 31.6% compared to an increase of only 5.1% for controls.

Among men reporting sexual dysfunction, sexual bother is a common measure of the individual's distress over the loss of sexual function. In most measures, men are asked about their distress related to difficulty maintaining an erection, difficulty in achieving orgasm, and decreased sexual desire. Research shows that sexual bother may naturally decrease over time for some men with sexual dysfunction, while for others it remains a significant problem. Many studies include sexual bother in measures of sexual function, however Ball et al. (2006) reported on sexual bother at 1, 3 and 6 months post-treatment (Ball, et al., 2006). Their results indicated that for men receiving radical prostatectomy, 34%-40% had recovered to their baseline sexual bother one month after treatment, which increased slightly to 28-43% after 3 months and leveled off at 27%-38% 6 months post treatment.

Among men receiving cryotherapy, Ball et al. (2006) found that 54% recovered sexual bother after one month, 58% after three months, and 55% after six months (Ball, et al., 2006). Among men receiving brachytherapy, 69% recovered to baseline sexual bother after one month, 65% after 3 months, and 70% after 6 months. These results demonstrated that in the Ball et al (2006) sample, men who underwent brachytherapy recovered most quickly followed by men who received cryotherapy, then those who received radical prostatectomy.

Additionally, the recovery of sexual bother remained similar across multiple time points within the 6 month period.

Longer term follow-up shows similar findings, as in the sample studied by Cooperberg et al. (2003). In their sample of PC survivors, 61% reported ED as a moderate or large problem 6 months after surgery, a percentage which declines to 52% after one year, and 42% after 2 years (Cooperberg, et al., 2003). Similar results were reported by Litwin et al. (2001) in another sample of men treated with radical prostatectomy who were also followed for a 2 year period. They found that about 50% of men recovered to baseline sexual bother one year after treatment and that this number increased to 60% after 2 years and then leveled off (Litwin, Melmed, & Nakazon, 2001).

Mohamed et al. (2011) examined a group of men diagnosed with PC and conducted a pre-treatment assessment as well as an assessment 6 months post treatment. Their sample included men treated with radical prostatectomy, external radiation and brachytherapy, and their results indicated that PC survivors reported significant increases in sexual dysfunction and sexual bother 6 months after treatment (Mohamed, Bovberg, Montgomery, Hall, & Diefenbach, 2011). Mohamed at al. (2011) also found a significant interaction such that the increases in sexual dysfunction and bother were greater for men treated with radical prostatectomy than those treated with external beam radiation or brachytherapy (Mohamed et al., 2011). Gore et al. (2010), examined sexual function and bother in another sample of PC survivors and found that observed

declines in sexual bother were somewhat independent of sexual function and suggested that most men are able to accept long term sexual function decrements after 24 months (Gore, Gollapudi, Bergman, Kwan, Krupski, & Litwin, 2010).

Sexual bother has been shown to be among the most common causes for decrements in overall quality of life (Robinson, Moritz, & Fung, 2002). Research conducted by Katz et al. (2007) has demonstrated that even men who have abnormal PSA or DRE results but have negative biopsies tend to have more sexual bother compared to men with normal PC screening results (Katz, Jarrard, McHorney, Hillis, Wiebe, & Fryback, 2007). Sexual desire is also an important factor in the relationship between sexual function and quality of life. Research conducted by Dahn et al. (2004) on a sample of men treated for localized PC demonstrated that there is a significant interaction between sexual function and sexual desire such that men who reported lower functional scores had lower quality of life as their level of sexual desire increased (Dahn, et al., 2004). This finding was replicated in a study conducted in France by Messaoudi et al. (2011) who found that men who were more sexually motivated were more likely to report a loss of masculine identity, loss of self esteem, and anxiety about sexual performance compared to men with low sexual motivation (Messaoudi, Menard, Ripert, Parquet, & Staerman, 2011).

Research has shown that for men, cognitive factors (e.g. beliefs about sexuality and automatic thoughts during sex) were among the best predictors of

sexual desire (Carvalho & Nobre, 2011). Specifically, Carvalho & Nobre (2011) found that restrictive attitudes about sex, concerns about achieving an erection and not having erotic thoughts while engaging in sexual activity were important influences on sexual desire for a general population of men with an average age of 35 (Carvalho & Nobre, 2011). When taken together, these findings highlight the importance of sexual desire and erectile function in examinations of sexual bother. When taken together, these findings highlight the importance of sexual desire and erectile function in examinations of sexual bother. As a result of the importance placed on erectile function by PC survivors, treatment of ED becomes very important for many PC survivors.

Treatment of Erectile Dysfunction

Many treatments exist to help patients regain sexual function lost following treatment for prostate cancer. These include penile implant surgery, the use of vacuum pumps as well as the use of injected medications (e.g. Muse) or oral medications (e.g. Viagra, Cialis). Tal et al. (2011) examined the use of penile implant surgery using the SEER national database of Medicare beneficiaries. Among the 68,558 subjects in the database, They found relatively low utilization rates (i.e. 0.8%) for all PC survivors, with significant differences in utilization for men who underwent external radiation (0.3%) verses 2.3% for those treated with RP. Tal et al. (2011) also examined predictors of penile implant use and found that method of treatment, younger age, African American or Hispanic ethnicity, single marital status, and living in the South and West were all important predictors of penile implant utilization (Tal, Jacks, Elkin, & Mulhall, 2011).

While many men could potentially benefit from medications such as Viagra after treatment Hall et al. (2009) assert that only a small percentage of men are actually receiving the recommended drug treatments. More specifically, Hall et al. (2009) examined data from a sample of 2,301 men and women ages 30-79 who were part of the Boston Area Community Health Survey from 2002 to 2005. They found that among the approximately 20% of men reporting moderate to severe erectile dysfunction, only 7.9% were taking medications to improve erectile function (Hall, Link, Hu, Eggers, & McKinlay, 2009). The main predictor of medication use was more frequent visits to their healthcare provider. Hall et al. (2009) did not find any statistically significant differences in medication use by race/ ethnicity, lack of health insurance, low SES or economic hardship, but did report a pattern of greater use amongst non-Hispanic Whites compared to ethnic minorities (Hall et al., 2009). Schover et al. (2002) examined a sample of PC survivors who were sent surveys asking about their use of erectile dysfunction treatments. They did not report differences in treatment utilization by ethnicity but did find that men who were younger, were in newer relationships, men who were in committed relationships and were sexually active, and men who underwent prostate surgery were more likely to have tried at least one treatment for erectile dysfunction (Schover, et al., 2002).

Regarding reasons that many men discontinue ED medications, McCullough et al. (2002) found that men tended to discontinue use due to co-morbid health conditions, not using the medication the suggested minimum of eight attempts, not titrating the medication dose as directed, a lack of partner engagement in medication use and a lack of follow-up with their physician (McCullough, Barada, Fawzy, Guay, & Hatzichristou, 2002). In sum, research evaluating samples of PC survivors to determine if ethnic

differences exist in the utilization of ED medications is limited but does not suggest large differences between racial/ethnic groups. Other factors such as relationship factors, medication knowledge, co-morbid conditions and a lack of medical follow-up appear to better explain why men do not find ED medications effective in the long term.

Co-morbid Conditions and Sexual Function

Co-morbid conditions have been associated with increased mortality rates for individuals with a wide range of diseases including cardiovascular disease, diabetes, and cancer (Putt, et al., 2009). Research conducted with a large sample of Medicare beneficiaries has also demonstrated that co-morbid conditions are more prevalent for African Americans than non-Hispanic Whites. Putt et al. (2009) suggest that this increased rate of co-morbid conditions partially explains the increased all cause mortality rates for African Americans with PC compared to other ethnic groups. Moreover, Putt et al. (2009) demonstrated that the magnitude of the racial disparity in mortality rates decreased as the number of co-morbid conditions increased (Putt, et al., 2009).

Co-morbid conditions have also been associated with male erectile dysfunction and sexual bother (Bhojani, et al., 2008). Major depression and diabetes have been shown to be among the most important co-morbid conditions that have a detrimental impact on erectile function (Bhojani, et al., 2008). Other research has found that having diabetes is significantly associated with greater sexual dysfunction/bother in men diagnosed with PC prior to treatment (Pinkawa, et al., 2008; Latini, et al., 2006). In another study by Weber et al. (2008),

depressive symptoms were shown to be four times more likely in men treated for PC versus men without PC (Weber, Roberts, Mills, Chumbler, & Algood, 2008). Men reporting more anxiety symptoms were also shown to have more distress about the potential for PC recurrence after treatment (Gore, et al., 2010).

Men with diabetes who receive treatment for PC may be at a particular disadvantage. Pinkawa et al. (2008) found that men with diabetes who were treated with radiation therapy experienced greater erectile dysfunction after treatment than men without diabetes (Pinkawa, et al., 2008). Furthermore, the presence of diabetes was associated with erectile dysfunction in a large sample of men treated with radical prostatectomy who were followed for a two year period (Marien et al., 2009). Other factors associated with maintaining potency in this study included age and the preservation of nerve bundles during surgery (Marien et al., 2009). Penson et al. (2009) examined a sample of men with diabetes who reported significant rates of erectile dysfunction (34%), orgasmic dysfunction (20%) and decreased libido (55%). They demonstrated that erectile dysfunction had the strongest association with overall sexual bother compared to both orgasmic dysfunction and decreased libido (Penson et al., 2009). While co-morbid conditions may affect sexual function through physiological mechanisms, sexual function has also been in directly linked to socio-economic status.

Socio-economic Status and Sexual Function

A broad look at epidemiological data relating socio-economic status (SES) to treatment outcomes for men diagnosed with PC has found that lower SES is associated with higher PC mortality rates (Cheng, et al., 2009). Karakiewicz et al. (2008) examined both the role of SES and co-morbid conditions on health related quality of life (HRQOL), which includes urinary, bowel, and sexual function. They found that both SES and co-morbid conditions were significantly associated with self reported HRQOL. Moreover, the presence of co-morbid conditions was associated with up to a 10% decline in HRQOL scores, while higher SES was associated with up to an 8% higher HRQOL score (Karakiewicz, et al., 2008).

Researchers who have examined income and education independently have found that men with less education may experience greater declines and take longer to recover physical function and general health (Knight et al., 2007; Eton, Lepore, & Helgeson, 2001). One study of men treated in the Veterans Health Administration (VHA) demonstrated that men who did not complete high school had urinary, bowel and sexual function scores in some areas that were at least one standard deviation below men who completed college (Knight, et al., 2007). Knight et al. (2007) found that these results remained significant even after controlling for age, ethnicity, income, and year of diagnosis. Other research conducted by Augustus et al. (2009) found no differences in sexual bother or self-efficacy between men with disparate levels of educational attainment.

However, these results were conducted with a sample of low-income, uninsured men in a large metropolitan area. Thus researchers acknowledge that their findings may not be generalizable to other PC patients and suggest further research is necessary (Augustus, Kwan, Fink, Connor, Maliski, & Litwin, 2009).

Examinations of the relationship between SES and sexual bother must also address the lack of access to healthcare that often results from having lower income but is not solely related to SES. Some research suggests that among Hispanics gains in SES often occur in the context of small business growth and are often not associated with increased health insurance coverage (Angel & Angel, 1996). As a result, Hispanics have lower rates of health insurance coverage than non-Hispanic Whites or African Americans (Angel & Angel, 1996). The lower rate of health insurance coverage among Hispanic Americans is important to understanding disparate screening rates in this minority group. However, even in keeping these indirect effects, SES and its influence on health related quality of life does not completely explain ethnic differences in treatment outcomes after PC treatment.

Race, Ethnicity and Sexual Function

Research in racial and ethnic differences in sexual function, is dependent on the definitions used to create racial and ethnic groups, which have varied in the literature. For the purpose of this study racial categories (e.g. Black, White) are defined as unique groups with common physical traits (e.g. skin tone, eye

color, hair color and texture) which stem from genetic similarities based in common ancestry (William Collins Sons & Co. Ltd., 2009). However this categorization obscures within group differences among individuals who are physically similar in relation to skin tone or hair texture, but come from different ethnic or cultural backgrounds. As a result, there has been a shift more recently to compare individuals by psychosocial variables like ethnicity instead (Helms, Jernigan, & Mascher, 2005).

Recent research published in the Journal of the American Medical Association by Alemozaffar et al. (2011) demonstrated that race/ ethnicity was an important predictor of erectile function 2 years after treatment for PC. Other variables including pre-treatment sexual function, age, PSA, BMI, and treatment details were also important predictors (Alemozaffar, et al., 2011). Multiple studies examining ethnic differences in PC incidence and outcomes have demonstrated that African American PC survivors tend to present with more advanced PC, more bodily pain, poorer general health and more concern over their general health than non-Hispanic White men (Lubeck, et al., 2001; Powe, et al., 2007). However the findings related to ethnic differences in sexual function are mixed.

Johnson et al. (2004) examined data from the Prostate Cancer Outcomes Study (PCOS) and found that African American men reported greater recovery in their sexual function scores than non-Hispanic White men five years after treatment with radical prostatectomy (Johnson, et al., 2004). Despite higher

functional scores, African American men in this sample were also more likely to report sexual function as a moderate to big problem. A closer look at their findings also shows that ethnic differences in sexual function were only shown among men receiving radical prostatectomy, and not those receiving radiation therapy (Johnson, et al., 2004). Furthermore, African American men had significantly higher baseline sexual function, and individual change scores were not reported, nor were sexual function scores at shorter term follow-ups.

More recent research by Rice et al. (2010) replicated the finding that African American men reported poorer physical function as well as worse urinary function compared to non-Hispanic White men prior to treatment. More specifically, at 12 months after biopsy African American men receiving RP reported worse physical functioning while those receiving RT reported worse urinary function. However, this study did not find differences in sexual function between ethnic groups before or after treatment (Rice, et al., 2010). However this study was also limited since researchers did not report on any statistically significant differences in clinical stage at diagnosis or average PSA between ethnic groups.

Kimura et al. (2011) analyzed data from a group of PC survivors and found that African American ethnicity was associated with greater declines in sexual function 3 months after surgery as well as 20 months post surgery compared to men of other ethnicities (Kimura, et al., 2011). These findings stand in contrast to the findings of Johnson et al. (2004) and Rice et al. (2010) and

suggest that further research is needed in this area in order to make clear conclusions regarding the incidence of sexual dysfunction/bother for African American men.

Research which compares the sexual function of Hispanic and non-Hispanic White men has also been limited. It has been demonstrated that up to 20% of research studies examining sexual function do not report ethnicity, and that among those that do, Hispanic and Asian men are underrepresented (Ramsey, Zeliadt, Hall, Ekwueme, & Penson, 2007). Research which has included adequate numbers of Hispanic men has found that Hispanic men were more likely to report ED than non-Hispanic White men after controlling for age, body mass index, and number of cigarettes smoked (Saigal, Wessells, Pace, Schonlau, & Wilt, 2006). Research that has included larger numbers of Hispanic PC survivors has found that Hispanic men also report worse general health than non-Hispanic Whites (Krupski, et al., 2005). However, Krupski et al. (2005), were careful to point out that Hispanic men may be less likely to report excellent health even though they have fewer co-morbid conditions due to culturally based health beliefs (Krupski, et al., 2005). These culturally based beliefs likely include a construct known as cancer fatalism.

Cancer Fatalism

Cancer fatalism is the belief that death is unavoidable when cancer is present (Powe & Finnie, 2003). Researchers have suggested that older African

Americans may have a more fatalistic view of cancer than non-Hispanic Whites and that fatalism is an important factor explaining the lower rates of cancer screening seen in some minority populations (Powe, et al., 2007). Powe et al. (2007) explains this link by suggesting that for some African Americans, death and suffering are seen as integral and unavoidable parts of life and thus less emphasis is placed on the concept of battling cancer. This fatalistic view of the world has also been shown to be more prevalent for Hispanic, and Asian Americans when compared to non-Hispanic White men.

A review conducted by Espinosa et al. (2009) found several studies which reported a relationship between increased fatalism and decreased or delayed screening behavior for Latina women even after controlling for age, SES, and access to health care (Espinosa de los Monteros & Gallo, 2010). Research with women undergoing screening for breast cancer has demonstrated that fatalism is related to delays in getting mammography for some samples of women. In particular, Baron-Epel et al. (2009) examined a group of women in Israel and found that Arab and immigrant women were more likely to demonstrate a relationship between fatalism and delays in screening. However, this relationship was not found among Jewish Israeli women. Authors suggest that the relationship between fatalism and delays in screening may not generalize to all ethnic groups of women and may have more to do with lower levels of education and more fatalistic beliefs about external forces causing cancer than any cultural beliefs (Baron-Epel, Friedman, & Lernau, 2009).

A comparison of African American and Hispanic PC survivors conducted by Powe et al. (2009) demonstrated that Hispanic men in their sample had more fatalistic views of cancer than African Americans along with less education and less prostate cancer knowledge (Powe, Cooper, Harmond, Ross, Mercado, & Faulkenberry, 2009). Fatalism has also been found to be associated with lower SES, more pessimism about cancer, greater distrust of physicians and lower levels of acculturation (Meyerowitz, Richardson, Hudson, & Leedham, 1998).

There are a few theories that seek to explain relationships between cancer fatalism, low SES and demographic factors such as ethnicity. Freeman (1989) hypothesized that poverty contributed to fatalistic beliefs and also predisposed individuals to under education and poor healthcare (Freeman, 1989). Freeman (1989) elaborated that the focus on daily survival may lead individuals to disregard their health and neglect regular screening activities. This neglect of regular screening causes cancers to only be detected when they cause symptoms – often when they move past the localized stage. Cancers that have metastasized present a greater risk to general health and thus reinforce the belief that cancer is a death sentence.

Other theoretical formulations include the one espoused by Powe and Johnson (1995) which conceptualizes the culture specific underpinnings of fatalism for African Americans (Powe & Johnson, 1995). They suggest that angst and nihilism are important factors that result from the experience of poverty, discrimination and lack of access to health care. They go on to assert

that for some a diagnosis of cancer is seen as a losing fight which leads to feelings of helplessness and that these feelings may be reinforced by seeing family members or friends die from cancer. In the theory asserted by Straughan and Seow (1998) fatalism is linked to beliefs in an external health locus of control which results in patients believing that cancer is beyond human control and that screening has no purpose (Straughan & Seow, 1998). They also link the idea of fatalism with cultural beliefs found in Asian cultures such as fate, destiny and predestination (Straughan & Seow, 1998).

Peek et al. (2008) developed a theoretical model based on themes derived from a series of semi-structured interviews with low income African American women undergoing breast cancer screening. Their model emphasized that negative health experiences that may have been due to poor communication between patient and provider led to stories spread throughout the community which create a fear of physicians and the healthcare system (Peek, Sayad, & Markwardt, 2008). They assert that women cope with this fear by denial of the need to participate in breast cancer screening, and fatalism regarding their prognosis after treatment which each contribute to delays in screening. These delays in screening can then lead to diagnoses which occur in the later stages of cancer which come with a higher risk of mortality or metastasis (Peek et al., 2008).

Research which examines relationships between fatalism, demographic factors and participation in screening has demonstrated associations between

fatalism and increased age, race, doctor's recommendation and lower educational level. There was also a relationship between fatalism and non-compliance with screening. However after adjusting for each of these covariates, fatalism was no longer associated with screening (Mayo, Ureda, & Parker, 2001).

Research into the fatalistic beliefs of individuals recently diagnosed with cancer is much more limited both in terms of cancer populations and research studies. Research conducted with a sample of individuals recently diagnosed with head and neck cancer found that those who were still smoking and those in the early stages of readiness to quit were more likely to report fatalistic beliefs and lower levels of self efficacy (Schnoll, et al., 2002). However, the majority of their sample consisted of married, non-Hispanic White individuals which may limit the generalizability to samples of ethnic minority men. Other research examined a sample of men diagnosed with prostate cancer and found a positive correlation between fatalism and age (Bjorck, Hopp, & Jones, 1999).

When taken together, this area of research suggests that older, Black and Hispanic men with lower levels of income, education and PC knowledge are more likely to report higher levels of cancer fatalism. This cancer fatalism may also be associated with feelings of fear and helplessness, which they cope with using avoidance of medical screenings and appointments. This avoidance and delay may result in individuals waiting to present for treatment when they have more significant symptoms such as worse sexual dysfunction/bother. This relationship between fatalism and screening rates has been demonstrated by

multiple studies (Baron-Epel et al., 2009; Espinosa de los Monteros & Gallo, 2010; Kudadjie-Gyamfi et al., 2006; Mayo et al., 2001).

After treatment for PC, studies have shown that the majority of men prescribed medications for ED do not continue the medication past several attempts which may be due to a lack of knowledge about medication use (McCullough et al., 2002). Men with fatalistic beliefs about cancer may also be less likely to pursue ED treatments because they view ED as a long term problem for which there is no solution. The negative outcome of long term sexual dysfunction only serves to reinforce fatalistic views about PC which, according to Peek et al. (2008) result in increased fear and fatalism within friends and family members who may also be at risk for PC.

Prostate Cancer Knowledge

Low health literacy is a common problem in America, and recent estimates report that around 47% of adults in the US have low literacy skills (Mohrmann, et al., 2000). Health literacy refers to both the basic reading and math skills needed to identify and understand heath information (Parker, et al., 1999). One study found that up to 42% of patients sampled from the primary care clinics had inadequate health literacy (Guerra, Dominguez, & Shea, 2005). Problems with health literacy have been shown to be related to age, with research showing that over 80% of adults over the age of 65 have low literacy (Michielutte, Alciati, & El Arculli, 1999). Additionally, ethnic minorities and recent immigrants may be at

increased risk for low literacy (Michielutte et al., 1999). Literacy is an important factor in maintaining good health and has been related to poor compliance with treatment recommendations including cancer screenings due to confusion or lack of interest (Glazer, Kirk, & Bosler, 1996). While low literacy is more common for individuals of lower socio-economic status, Michielutte et al. (1999) assert that it may affect individuals at all levels of SES (Michielutte et al., 1999).

Health literacy has been associated with less knowledge about colorectal cancer screening as well as lower levels of education and Latino ethnicity (Guerra, Dominguez, & Shea, 2005). However, of the patients in this sample who had not undergone colorectal cancer screening, nearly 90% stated that they would be screened if it was recommended by a doctor. This finding highlights the importance of the doctor patient relationship in facilitating cancer screening. Communicating complex health information may be especially challenging with immigrant populations due to language barriers and cultural barriers to seeking care (Kreps & Sparks, 2008). For example, research has demonstrated that people tend to seek out health care providers with similar cultural backgrounds because they believe they have similar cultural values (Kreps & Sparks, 2008). This may pose a significant challenge to immigrants who cannot easily find a healthcare provider from their background and thus fail to receive important messages about healthcare and advice about screening.

Prostate cancer knowledge has been shown to be an important predictor of screening behavior (Kudadjie-Gyamfi et al., 2009). Research conducted by

Kilbridge et al. (2009) with a sample of African American men recruited from low income clinics demonstrated that less than 50% of men in their sample understood common terms such as “erection” or “impotent,” while only 5% of men in their sample understood the term “incontinence”. These results were strongly associated with reading level, the median of which was between fourth and sixth grade for their sample. Despite the low reading level, this finding suggests that a significant portion of low income men may have low levels of prostate cancer knowledge that can present as a barrier to understanding treatment and treatment related side effects (Kilbridge et al., 2009)

Another study conducted at a low income clinic which included larger numbers of Hispanic men found that increasing age and having less than a high school education were associated with lower PC knowledge (Deibert, Maliski, Kwan, Fink, Connor, & Litwin, 2007). Among Hispanic women, research conducted by Ramirez et al.(2000) found that gynecologic cancer knowledge was related to age, income, education, language preference, and screening history. They also found that Cubans had the highest levels of knowledge concerning gynecological cancer screenings, while Mexican American and Puerto Rican women in their sample had the least knowledge (Ramirez, Suarez, Laufman, Barroso, & Chalela, 2000). The importance of educational level in predicting knowledge about prostate cancer was also underscored by Winterich et al. (2008) who found that education and not race or screening status were associated with prostate cancer knowledge (Winterich, et al., 2009).

Multiple studies have demonstrated that college educated men are more knowledgeable about PC than those without a college degree (O'Dell, Volk, Cass, & Spann, 1999; Lepore, Helgeson, Eton, & Schulz, 2003). An individual's style of gaining and applying health information may be important in determining who will most benefit from educational interventions designed to improve PC knowledge. More specifically, a survey of men participating in a prostate cancer informed decision making intervention found that men who had a passive health information style showed the lowest level of knowledge increase six months after the intervention (Williams-Piehota, McCormack, Treiman, & Bann, 2008).

In general, research examining prostate cancer knowledge in diverse samples is limited, but suggests that men with low levels of education may be at increased risk for poor health literacy. Additionally, older adults and ethnic minorities may be over represented among individuals reporting poor health literacy. This poor health literacy may pose a barrier to receiving appropriate cancer screening and may influence the treatment decisions of individuals who are diagnosed with cancer.

Polacek et al. (2007) examined ethnic disparities in breast cancer treatment decision making and found that high proportions of minority women continue to choose mastectomy versus breast-conserving therapy despite similar survival rates (Polacek, Ramos, & Ferrer, 2007). This treatment choice goes against the recommendation of many physicians and also results in significant disfigurement. Polacek et al. (2007) posit that this choice may be influenced by

low levels of health literacy and breast cancer knowledge. Additionally breast conserving therapy requires additional treatments that may be disruptive to work and childcare. This study provides interesting evidence regarding breast cancer knowledge and treatment decisions for minority women. However, the influence of prostate cancer knowledge on screening behavior and treatment decisions, as well as the resulting decrements in disease specific quality of life outcomes such as sexual dysfunction/bother have not been adequately explored.

Rationale

Past research in health disparities has often focused on the influence of socio economic status as the major factor underlying the disparities seen in minority groups (Kudadjie-Gyamfi et al., 2006). However, many researchers have begun to acknowledge that SES is not the only underlying factor and suggest that other factors should be considered such as knowledge of common health concerns and attitudes about illness and health behaviors (Powe & Finne, 2003). Also, much of disparities research has been conducted by separating participants into racial groups. However, these groupings do not allow for the consideration of cultural differences among people with similar physical traits. This is especially true among more racially heterogeneous ethnic groups such as Hispanics (Phinney, 1996). As a result, a more specific approach to health disparities is required which examines differences in beliefs and attitudes common to particular ethnic groups and relates these differences to health disparities (Meyerowitz et al., 1999).

Research by Powe et al., (2007) demonstrated that African American and Hispanic men report greater cancer fatalism and lower PC knowledge compared to non-Hispanic White men. This fatalism and lack of PC knowledge have been related to delays in screening (Powe et al., 2007; Kudadjie-Gyamfi et al., 2006) that are likely to contribute to African American and Hispanic men presenting to treatment with more advanced (and more life threatening) cancer (Hoffman et al., 2001). Presenting with more advanced cancer is often related to more invasive treatment choices for breast cancer survivors (Polacek et al., 2007), In men diagnosed with localized PC, radical prostatectomy is the most invasive treatment and has been shown to be associated with higher rates of long term sexual dysfunction compared to other treatment options (Ball et al., 2006; Litwin et al., 2007).

Evidence linking ethnic group membership to sexual dysfunction is mixed, but at least one study has demonstrated that African American men experienced greater declines in sexual function at 3 months and 20 months after radical prostatectomy compared to non-Hispanic White men (Kimura et al., 2011). Moreover, studies which found no differences in sexual function between ethnic groups examined these differences at least one year post-treatment and did not report on ethnic differences within a few months of treatment when most men are still in post-treatment recovery.

Sexual bother has generally been examined as a subscale within broader sexual function scales, however this study examines this as a separate outcome

since there is at least one study that suggests this variable is largely independent of sexual function (Johnson et al., 2004). Sexual bother is important to consider independently since Robinson et al. (2002) reported that sexual bother was among the most common causes of decrements in overall quality of life (Robinson et al., 2002). Furthermore, Jenkins et al. (2004) suggest that African American and Hispanic men report higher levels of sexual bother than non-Hispanic Whites, a finding which may have been obscured in other studies by only measuring sexual bother as part of sexual functioning.

At least one study (Hall et al., 2009) has reported a trend relating ethnicity to lower utilization of medication regimens. However, Hall et al. (2009) asserted that more frequent visits to a health care provider were more strongly associated with greater adherence to medication regimens. Given that Hispanics have been shown to have lower rates of health insurance compared to non-Hispanic Whites and African Americans (Angel & Angel, 1996), they may be at increased risk for a lack of follow-up with the same health care provider and by extension, at increased risk for poor adherence. As a result, Hispanic men may be at increased risk for slower recovery of function after treatment for prostate cancer.

Existing research has yet to examine the relationship between pre-treatment PC knowledge and cancer fatalism and post-treatment outcomes such as sexual function and sexual bother while controlling for treatment type. Research into the influence of ethnicity, cancer fatalism and PC knowledge on

sexual function and bother is also limited by a few key factors. Hispanic participants are under-represented in this research compared to the overall population of PC survivors. By incorporating more Hispanic men in the sample, there is a chance to gain more information about this large and diverse ethnic group. Additionally, this study will follow participants from the time of their initial diagnosis to one month after treatment in order to truly control for baseline sexual function and bother. A conceptual model used to guide the overall analyses of the study can be found in Figure 1.

Aims and Hypotheses

Specific Aim 1: To determine if there are racial/ethnic differences in cancer fatalism and prostate cancer knowledge after being diagnosed with localized prostate cancer.

***Hypothesis 1*:** Black and Hispanic men will report greater cancer fatalism and less PC knowledge after diagnosis than non-Hispanic White men.

Specific Aim 2: To determine if there are racial/ethnic differences in sexual function and sexual bother one month after treatment for localized prostate cancer.

Hypothesis 2: Black and Hispanic men will report significantly lower sexual function and lower sexual bother scores one month after treatment than non-Hispanic White men after controlling for baseline scores.

Specific Aim 3: To determine if cancer fatalism and prostate cancer knowledge are associated with changes in sexual function and sexual bother.

Hypothesis 3a: Higher cancer fatalism and lower prostate cancer knowledge scores will be associated with declines in sexual function scores one month after treatment for prostate cancer after controlling for pre-treatment scores.

Hypothesis 3b: Higher cancer fatalism and lower prostate cancer knowledge scores will be associated with declines in sexual bother scores one month after treatment for prostate cancer after controlling for pre-treatment scores.

Exploratory Aim: To determine if the relationships between cancer fatalism, prostate cancer knowledge and sexual function and bother scores are moderated by ethnicity.

Exploratory Hypothesis 1a: The associations between greater cancer fatalism and declines in sexual function scores will only be significant among Black and Hispanic participants when compared with non-Hispanic White men.

Exploratory Hypothesis 1b: The associations between greater cancer fatalism and declines in sexual bother scores will only be significant

among Black and Hispanic participants when compared with non-Hispanic White men.

Exploratory Hypothesis 2a: The associations between lower prostate cancer knowledge scores and declines in sexual function scores will only be significant among Black and Hispanic participants when compared with non-Hispanic White men.

Exploratory Hypothesis 2b: The associations between lower prostate cancer knowledge scores and declines in sexual bother scores will only be significant among Black and Hispanic participants when compared with non-Hispanic White men.

Chapter 2: Methods

Participants

Participants in the current study were drawn from the Prostate Cancer Assessment and Treatment Health Study, (PATHS) a 6 year prospective observational study funded by the National Cancer Institute to determine the relationship between ethnic group membership, specific ethnic and cultural beliefs and general as well as disease specific quality of life. Men were recruited from various hospitals, community agencies and urology clinics in the South Florida area.

Inclusion/exclusion criteria.

The study included men over the age of 45 who reported fluency in English or Spanish at a 6th grade reading level. Participants were required to have a diagnosis of localized prostate cancer or a positive prostate biopsy that was confirmed by medical record review and to not have begun any treatment for localized PC. Also, they were required to be available in the South Florida area to participate in the follow-up components of the study which lasted about 24 months post-baseline. Participants were judged ineligible if they reported a recent history of cancer other than skin or prostate cancer, an active psychotic disorder, current alcohol dependence, active suicidal ideation, or symptoms of dementia. These criteria were designed to ensure that participants could fully

understand the questions in the psychosocial assessments and were not limited by cognitive deficits or severe psychopathology.

For the present study, participants were included only if they received active treatment. Men who received chemotherapy were excluded from the final sample since this treatment is only used for men with more advanced cancer. For the purposes of the ensuring that men in our sample were interested in sexual function, only those reporting some level of sexual desire were included in the final sample. This was accomplished by excluding men who indicated a zero meaning 'very poor to none' on a question in the Expanded Prostate Cancer Index (EPIC; Wei J. T., Dunn, Litwin, Sandler, & Sanda, 2000) which asked them to rate their level of sexual desire in the past four weeks.

Measures

A set of psychosocial and health related quality of life measures were administered over multiple time points to satisfy the aims of this study. All measures were also translated into Spanish, by an IRB approved Spanish language translator using a forward-backward translation procedure (Univeristy of Miami Human Subjects Research Office, 2012). The translator was fluent (i.e. able to speak, read and write) in both English and Spanish and first translated the study materials from English into Spanish based on their in-depth knowledge of both languages. The translated study materials were then back translated from Spanish to English and re-evaluated for the match between the original

English materials and the back translated materials. This process was completed prior to using any of the Spanish language materials to assess participants, and participants who preferred to complete the assessment in Spanish were able to do so with a Spanish speaking assessor. The English language versions of all measures used within the study are in Appendices A-G.

Demographic and Medical Variables.

Demographic information was collected for all participants using a standard socio-demographic 19-item questionnaire. Participants were asked to report their age, race, ethnicity, country of origin, and religious group identification. Socio-economic status was assessed using items from the MacArthur Foundation Socio-demographic questionnaire (Seeman, T. & The Psychosical Working Group, 1998). This measure included 10 items which assess both subjective social status as well as objective information on education, individual and household annual income. Sample items included: "How many years of education have you completed" and "How much did you earn, before taxes and other deductions, during the past 12 months?" In order to develop a continuous variable for SES that was suitable for correlation analyses, references provided on the MacAurthur Foundation website (Seeman et al., 1998) were examined to determine a strategy for developing a continuous variable. Based on this review, it was determined that two separate subscales should be developed from the main measure. The strategy used to develop the composite subscales of the MacArthur was based on methods used by

researchers studying the relationship between SES and health in a sample of older Taiwanese adults using the MacArthur scale (Goldman, Cornman, & Chang, 2006).

The first of the subscales is the objective social status composite which was calculated based on annual gross personal income and annual gross family income. The mean of the objective social status composite was 11.62 (*SD* = 4.94; *Range* = 2-22). The second of these subscales was the subjective social status composite. This composite was calculated based on the two items of the MacArthur socio-demographic questionnaire which ask the participant to mark an 'x' on a picture of a ladder which represents where they see themselves in relation to their community and in relation to the entire US population. The step of the ladder they selected was assigned a numerical value from 0 to 10 and included in the two-item subjective social status composite. The average of this subjective social status composite was 13.0 (*SD* = 3.44; *Range* = 3-20). Reliability analyses were not conducted on the objective or subjective social status subscale since these scales assess demographic data.

Co-morbid conditions were assessed using the Charlson Scale (Charlson, Pompei, Ales, & MacKenzie, 1987). This measure consisted of 14 items that ask respondents to mark a 'yes' or 'no' if they have ever had any of the serious chronic conditions listed (e.g. diabetes, cardiovascular disease, hepatitis, and HIV). This scale was also weighted in main analyses to account for the seriousness of the reported condition(s) following the method suggested by the

authors (Charlson et al., 1987). This method assigns a weight of 1 to a history of heart attack, congestive heart failure, peripheral vascular disease, stroke, diabetes, memory problems, lung disease, connective tissue disease/lupus/arthritis, and ulcers. History of any kidney problems, and kidney problems due to diabetes received a weight of 2, while hepatitis A, B and C received a weight of 3. A history of cancer other than skin, prostate and bladder cancers as well as a history of AIDS received a weight of 6. A total score was calculated from each participant's responses and used in the main analyses. Due to the nature of this scale as a measure of largely unrelated health concerns, reliability analyses were not conducted.

Sexual Function and Bother.

All participants were administered the Expanded Prostate Cancer Index (EPIC; Wei, Dunn, Litwin, Sandler, & Sanda, 2000). The EPIC consists of 50 items that are separated into 3 subscales that assess urinary, sexual, and bowel function and bother during the past 4 weeks. For the baseline assessment, the 4 weeks prior to their assessment also included time before they were diagnosed with PC which allowed for a true baseline assessment. Only the sexual function and bother subscales were utilized. The sexual function subscale asked participants to rate how often they had experienced a certain sexual symptom in the past four weeks on a scale from zero to four. Examples included: "How would you rate your level of sexual desire during the past four weeks," and "During the last four weeks, how often did you have any sexual activity."

The second part of each subscale asks them to rate how big a problem each aspect of sexual function has been in the past four weeks. Examples included: “How big a problem has your ability to have an erection been in the past four weeks?” and “Overall, how big a problem has your sexual function or lack of sexual function been for you in the past four weeks?” Subscale scores were used in the main analyses and were calculated by recoding each response from a zero to four scale to a zero to 100 scale (e.g. 0 = 0, 1 = 25, 2 = 50, 3 = 75, 4 = 100) and then taking an average. This method of subscale calculation was done for both the sexual function and sexual bother subscales in line with methods utilized by the authors of the measure (Wei et al., 2000). The reliability of the sexual function subscale in our sample was good in both the main sample and the Spanish language sample (Chronbach’s α = .910 and .919 respectively). The reliability of sexual bother subscale was also good in both the main sample and the Spanish language sample (Chronbach’s α = .926 and .880 respectively). Each subscale in the EPIC has demonstrated high internal consistency in previous research and has been validated in diverse populations of prostate cancer patients (Wei et al., 2000).

Cancer Fatalism.

Cancer fatalism was measured with the Powe Fatalism Inventory (Powe B. D., 2001). This measure consisted of 15 items that assess an individual’s agreement with statements indicating that negative outcomes are inevitable when cancer is detected. Each item is scored from 1 “Very much in

disagreement" to 5 "Very much in agreement." Sample items include: "I think if someone is meant to get prostate cancer, they will get it no matter what they do," and "I think if someone gets prostate cancer, their time to die is soon." Total scores were utilized in the main analyses which were calculated by adding together all the individual item responses. This measure has demonstrated good reliability in both the main sample and the Spanish language sample (Chronbach's α = 0.833 and .905 respectively) as well as in past research (Chronbach's α = 0.80) which also validated the measure in diverse samples of men and women with and without chronic illnesses (Lopez-McKee, McNeill, Eriksen, & Ortiz, 2007).

Prostate Cancer Knowledge.

Knowledge of Prostate Cancer was evaluated using a 27 item scale which included items from a 12-item measure originally developed for use in a one day educational program targeting African American men (Wilkinson, List, Sinner, Dai, & Chodak, 2003). Additional items were added to this measure by the research team based on information obtained from the American Cancer Society website. Participants responded to each of the 27 items using the responses 'true', 'false,' and 'don't know.' A total number correct score was used in analyses. Items marked "don't know" were scored as incorrect. Sample items included: "Prostate cancer is the most common cancer, excluding skin cancer, in men living in the U.S.," and "A Gleason score indicates how large a prostate cancer tumor is." The internal consistency of this measure in our sample was acceptable in both the main sample and the Spanish

language sample (Chronbach's α = 0.65 and 0.70 respectively). Due to the addition of items to the original 12 item scale, the reliability of this new measure has not been examined in past literature.

Procedure

Recruitment.

Study participants were recruited from various Urology clinics in the South Florida area with some affiliation to the University of Miami. These clinics included the department of Urology at the University of Miami's Miller School of Medicine, The University of Miami's Sylvester Comprehensive Cancer Center (Miami and Deerfield Beach locations), The Miami VA Healthcare System, and Jackson Memorial Hospital. Recruitment was done using a number of strategies. Direct recruitment was done by the clinic staff (i.e. administrative staff, nurses, physicians) at each recruitment site. Trained and fully bilingual research associates were at each clinic when possible to inform patients about the study and provide flyers and pamphlets to patients and clinic staff. The Project Manager for the PATHS project was also approved to access medical charts of patients seen at the Sylvester Comprehensive Cancer Center in order to search for patients who may be eligible for the study. Potentially eligible patients were approached with information about the study after obtaining consent from their attending physician and only screened for the study if they consented. All recruitment procedures were in full accordance with the University of Miami IRB

(Institutional Review Board) and HIPAA (Health Information Portability and Accountability Act) guidelines for the protection of confidential patient information.

Recruitment was also conducted by providing information to community organizations that conduct PC screenings. Medical staff at these facilities provided their patients who have elevated PSA counts information about the study and asked them to contact research staff if they were interested in participating. Once a participant contacted our research staff, the staff member obtained their permission to contact them after the follow-up appointment regarding their elevated PSA result. When they were re-contacted and reported that they had a positive biopsy result, they underwent a preliminary screen over the phone to determine their initial eligibility (e.g., diagnosis of PC, willingness to be followed over 24 months) for the research study. A third method of recruitment was utilized which involved trained research staff participating in community health events that included members of our target population (i.e. male older adults with elevated PSA counts).

Full Screening.

Participants who met initial eligibility criteria were screened during their next clinic visit. If face to face screening was not possible, then a brief phone screen was conducted. In either case, the diagnosis of PC was confirmed along with fluency in spoken English or Spanish and availability to attend the 5

psychosocial assessments over the two year course of the study. If there were concerns about a participant's reading comprehension during a face to face screening they were asked to read a portion of the informed consent form and paraphrase the main idea of this passage in their own words. If there were concerns about a participant's reading comprehension and they were not able to attend a face-to face screening, the informed consent was mailed to them and they were asked to paraphrase over the phone in a follow-up call to complete the screening. Individuals who had difficulty paraphrasing in either English or Spanish were excluded from participation in the study.

Participants were asked about symptoms of psychosis, suicidal ideation, and substance dependence using questions from the Structured Clinical Interview for DSM-IV (First, Spitzer, & Gibbon, 1997). Cognitive impairment was assessed using the Folstein Mini Mental Status Exam (MMSE; Folstein, Folstein, & McHugh, 1985). Participants who did not meet eligibility criteria due to psychiatric symptoms were given referrals to mental health services as needed and reimbursed $50 for their participation in the screening process. Participants who were determined to be eligible in the face to face screening were given the informed consent form to sign and invited for the baseline assessment prior to PC treatment. Participants who were screened over the phone were mailed the informed consent to sign and bring for their first assessment or given the informed consent to sign just before their baseline assessment. Participants were

also asked to give authorization to access their medical records to obtain information related to prostate cancer diagnosis and treatment.

Assessment.

Participants were recruited to take part in 5 assessments over the two-year course of the study from which this sample was selected. The first of these assessments (T1) took place after they had been diagnosed with PC. The second assessment (T2) occurred one month after treatment. The third, fourth and fifth assessments took place at 6 - (T3), 12 - (T4), and 21 - (T5) months after their initial treatment date respectively. Responses from the second assessment (one month after treatment) were used in the main analyses to provide post-treatment follow-up data. This decision limited the time for natural recovery of sexual function to occur, but was necessary to achieve the power necessary for the main analyses. A complete breakdown of the power required for the main analyses is included at the beginning of the statistical analysis plan.

Each of the two assessments used in this study took place at one of the sites affiliated with the research study. Assessments were conducted by trained research associates and consisted of a psychosocial battery of questions that were completed in an interview format. In an effort to reduce participant burden, a segment of the psychosocial battery involved a take-home packet that participants were asked to take home and return to our research offices by mail. However, none of the measures used in the present study were contained within

this take home packet. Participants were compensated $50 for their participation in each assessment, and some also qualified for reimbursement of travel related expenses.

Statistical Analysis Plan

Power Calculations.

In order determine how many participants were necessary to accomplish the aims of this study, a series of calculations were performed using an online sample size calculator (Soper, 2009) as well as the statistical program G*Power (Erdfelder, Faul, & Buchner, 1996). These calculations were performed assuming medium effect sizes (Cohen's f^2= 0.25), a power level of 0.95, and three racial/ethnic groups. The first analysis was completed to determine the sample size necessary for a bivariate correlation, which was 49 participants (Erdfelder et al., 1996). The required sample size for a one way ANOVA was at least 102 participants when the effect size was large (e.g. Cohen's f^2= 0.40) and increased to 252 when the estimated effect size was medium (Cohen's f^2= 0.25). The suggested sample size for the multiple regression used to test the exploratory aim was calculated at 129 participants. This calculation was based on the inclusion of 2 control variables (e.g. co-morbid conditions, type of treatment) and 2 predictors (e.g. cancer fatalism, PC knowledge). When the number of predictors increased to 5 (as in the exploratory analyses) the suggested sample size increased to 153.

It is important to note that these calculations were not used as the only factor in determining analyses because the precise effect size for the proposed analyses has not been established in the literature. As a result, these calculations were used purely as a guideline to assist in the creation of the statistical analysis plan.

Preliminary Analyses.

Before addressing formal hypotheses, frequency distributions, reliability analyses and descriptive statistics were calculated for all measures used in subsequent analyses. These descriptive statistics were also broken down by ethnic group. The frequency distributions of the main continuous variables (i.e. cancer fatalism, PC knowledge, sexual function, and sexual bother) were tested for normality and those distributions that did not meet these assumptions were considered for transformation using a log base 10 or a square root transformation.

Past research cited in the literature review has demonstrated that age, SES, co-morbid conditions, and marital status have all been shown to be related to sexual function after PC treatment. As a result bivariate correlations were conducted which related these variables to our outcome measures (sexual function and bother). Significantly related variables ($r > .30$, or $p < .10$) were included as control variables in the final regression model.

These correlations were repeated with ethnicity to determine if age, SES, co-morbid conditions were related to racial/ethnic group. In this study the three largest groups racial/ethnic groups in our sample were the primary focus of our analyses. Ethnic groups with small numbers of participants (i.e. Afro-Caribbean men) were included with men of the same race in order to maximize statistical power when testing between group differences. These groups utilized in this study include a racial group of non-Hispanic Whites with predominantly European ancestry, a racial group of African Americans (including Afro- Caribbean men) with predominately African ancestry, and an ethnic group of Hispanics with predominant ancestry from Latin American countries.

A series of ANOVAs was conducted to determine if men of differing marital and occupational statuses differed in their sexual function and bother after treatment. ANOVAs were also conducted for men of different ethnic groups to determine if they differed by marital or occupational status. If any of the aforementioned ANOVAs demonstrated significant between group differences the variable with the between group difference was dummy coded for inclusion in the final regression model as a control variable.

Prior research has demonstrated that men with varying levels of sexual desire and men receiving differing types of treatment for PC may experience substantial differences in their sexual function and bother after PC treatment. As a result, ANOVAs were conducted to confirm that these differences were observed within our sample and also in order to provide statistical justification to

the decision to only include men with some level of sexual desire in the final sample. The ANOVA which compared sexual function and bother between treatment types was also used to identify which treatment types have similar post treatment sexual function and bother scores. Consideration was given toward combining treatment groups with small sample sizes who had similar treatment modalities and similar post treatment function and bother scores. Tukey post-hoc comparisons were conducted to follow-up on significant between group differences.

Additional preliminary analysis were conducted to determine if cancer fatalism and PC knowledge changed over time from T1 to T2. This was accomplished using a paired sample t-test. Any significant changes in cancer fatalism or knowledge would provide information about whether these variables remain stable over the course of diagnosis, treatment and recovery and suggest an area for post-hoc testing.

A comparison was also made between the sexual function and sexual bother scores of our sample in comparison with scores reported in similar research studies. This was accomplished by subtracting T1 sexual function and sexual bother scores from T2 sexual function and bother scores in order to determine how many participants had returned to their baseline function and bother scores one month after treatment. Return to baseline was indicated by a positive change score since higher scores indicate better sexual function and less sexual bother (the bother subscale is reverse coded). These analyses

helped to better describe the prevalence of sexual problems of our sample in comparison to others. These change scores were also used as the final outcome measure in order to effectively control for baseline sexual function and bother. Recovery to baseline sexual function and bother scores was also calculated based on racial/ethnic group.

Main Analyses.

Hypothesis 1: Ethnic differences in prostate cancer fatalism and prostate cancer knowledge.

In order to address the first hypothesis that Black and Hispanic men would report greater cancer fatalism and less PC knowledge at baseline than non-Hispanic White men, two separate ANOVAs were conducted. Consideration was given to conducting ANCOVAs however, due to limitations in power resulting from missing data, ANCOVAs were not conducted. Each ANOVA used ethnic/racial group as the between group variable while the within group variable was total scores on the cancer fatalism scale and total scores on the PC Knowledge scale. The *F*-value and *p*-value were reported for the main ANOVA along with the mean and standard deviation of cancer fatalism and PC knowledge scores for each ethnic group. A Tukey post-hoc analysis was also conducted in order to determine which groups had significant differences between them. This hypothesis will be supported if the *F*-value for either ANOVA is statistically significant (i.e. $p < .05$).

Hypothesis 2: Ethnic differences in sexual function and sexual bother.

To test the second hypothesis that Black and Hispanic men would report lower sexual function and lower sexual bother scores one month after treatment than non-Hispanic White men, two ANOVAs were conducted. Each ANOVA used ethnic/racial group as the between group variable while the within group variable was total scores on the sexual function and bother subscales of the EPIC. Higher scores on the sexual function subscale indicate better function, while higher sexual bother scores indicate that individuals view their sexual symptoms as less problematic. The *F*-value and *p*-value were reported for each ANOVA. This hypothesis will be supported if the *F*-value for either ANOVA analysis is statistically significant (i.e. $p < .05$).

Hypothesis 3a: Association between cancer fatalism, prostate cancer knowledge and sexual function.

Hypothesis 3a stated that greater cancer fatalism and less PC knowledge would be associated with declines in sexual function. In order to test this hypothesis, a hierarchical regression was conducted. In block one control variables were added, followed in block two by treatment type which was dummy coded into two separate terms. Term one coded surgery as a '1' external and internal radiation as a '0' and all other types of treatment as a '-1'. Term two coded surgery as a '0' external and internal radiation as a '1' and all other

treatment types as a '-1'. This approach was taken to properly account for the influence of treatment type and in order to allow for interpretation of a categorical predictor variable. Block three of this regression contained cancer fatalism and PC knowledge scores. The outcome variable was T2 sexual function scores. This hypothesis will be supported if either cancer fatalism or prostate cancer knowledge are significant predictors of sexual function at $p < .05$.

Hypothesis 3b: Association between cancer fatalism, prostate cancer knowledge and sexual bother.

Hypothesis 3b stated that high levels of cancer fatalism and low levels of PC knowledge would be associated with declines in sexual bother scores. In order to test this hypothesis, a hierarchical regression was conducted. In block one control variables were added, followed in block two by the two dummy coded terms representing type of treatment. Block three included cancer fatalism and PC knowledge scores. The outcome variable was T2 sexual bother scores. This hypothesis will be supported if either cancer fatalism or prostate cancer knowledge are significant predictors of sexual bother at $p < .05$.

Exploratory Hypothesis 1a: Moderation of the association between cancer fatalism and sexual function by race/ethnicity.

Exploratory hypothesis 1a states that the associations between greater cancer fatalism and declines in sexual function will only be significant among Black and Hispanic participants when compared with non-Hispanic White men.

This will be tested using hierarchical regression using Holmbeck's (1997) approach. As part of this approach, ethnicity will be dummy coded such that one dummy coded ethnicity term is created. This term will assign a zero to non-Hispanic White men, and assign a one to Black and Hispanic men. An interaction term will then be computed by multiplying the ethnicity term by T1 cancer fatalism scores. Predictor variables will be added in blocks starting in block one with control variables followed in block two by cancer fatalism and the dummy coded ethnicity term. Block three will contain the interaction term which multiplies cancer fatalism by the dummy coded ethnicity term. The hypothesis will be supported if the interaction term is a significant predictor of sexual function at $p < .05$.

Exploratory Hypothesis 1b: Moderation of the association between cancer fatalism and sexual bother by race/ethnicity.

Exploratory hypothesis 1b states that the association between greater cancer fatalism and declines in sexual bother will only be significant among Black and Hispanic participants when compared with non-Hispanic White men. This will be tested using hierarchical regression using Holmbeck's (1997) criteria. This regression will include the dummy coded ethnicity term and an new interaction term will also be computed by multiplying the ethnicity term by T1 cancer fatalism scores. Predictor variables will be added in blocks starting in block one with control variables followed in block two by cancer fatalism and the dummy coded ethnicity term. Block three will contain the interaction term which multiplies

cancer fatalism by the dummy coded ethnicity term. The hypothesis will be supported if the interaction term is a significant predictor of sexual bother at $p < .05$.

Exploratory Hypothesis 2a: Moderation of the association between PC knowledge and sexual function by race/ethnicity.

Exploratory hypothesis 2a states that the association between less PC knowledge and declines in sexual function will only be significant among Black and Hispanic participants when compared with non-Hispanic White men. This will be tested using hierarchical regression using Holmbeck's (1997) approach. An interaction term will be computed by multiplying the dummy coded ethnicity term (discussed in exploratory hypothesis 1a) by T1 PC knowledge scores. Predictor variables will be added in blocks starting in block one with control variables followed in block two by PC knowledge and the dummy coded ethnicity term. Block three will contain the interaction term which multiplies PC knowledge by the dummy coded ethnicity term. The hypothesis will be supported if the interaction term is a significant predictor of sexual function at $p < .05$. The squared semi-partial correlation of the interaction term will be used to determine the amount of the variance in sexual function scores accounted for by the interaction term.

Exploratory Hypothesis 2b: Moderation of the association between PC knowledge and sexual bother by race/ethnicity.

Exploratory hypothesis 2b states that the association between less PC knowledge and declines in sexual bother will only be significant among Black and Hispanic participants when compared with non-Hispanic White men. This will be tested using hierarchical regression with Holmbeck's (1997) approach to compute an interaction term by multiplying the dummy coded ethnicity term (discussed in exploratory hypothesis 1) by T1 PC knowledge scores. Predictor variables will be added in blocks starting with control variables followed in block two by T1 PC knowledge scores and the dummy coded ethnicity term. Block three will contain the interaction term which multiplies T1 PC knowledge scores by the dummy coded ethnicity term. The hypothesis will be supported if the interaction term is a significant predictor of sexual bother at $p < .05$.

Chapter 3: Results

Sample Descriptive Statistics

The sample used in the main analyses began with 134 men who completed some part of a T1 assessment and received some form of treatment by the time of their T2 assessment. Of these men 11 were excluded due to receiving chemotherapy while another two men were excluded for having previous cancers. Another 41 were excluded because they reported no sexual desire at T1 which left a total sample of 80. However, there were significant amounts of missing data points for our outcome variables which left approximately 60 cases with complete data.

A lack of sexual desire was determined by their response to an item of the EPIC which asks them to rate the level of sexual desire in the past four weeks. This was done to ensure that all men in the sample were still interested in sexual relations prior to treatment due to the significant influence of sexual desire on sexual function and bother (Dahn et al., 2004). Research has also shown that sexual desire remains relatively intact even after radical prostatectomy (Le et al., 2010). This suggests that men with a lack of desire prior to treatment may have other medical or psychological concerns that impacted their sexual desire prior to treatment (Carvalho et al., 2011).

The average age of men in the sample was 61 years (*SD* = 9.12) and the group was ethnically diverse with 46.9% non-Hispanic White men, 29.3%

Hispanic men, and 23.2% Black men. The majority of the sample was married or in an equivalent relationship (74.4%). Regarding their education, the majority of men in our study (54.2%) completed at least two years of college courses in the U.S. Occupationally, a large portion of men in our sample (51.2%) were working at least part time, while 30.5% of the sample was retired. Regarding socioeconomic status, 22.0% of men where in the low income category and had a yearly total family income of less than $25,000. In contrast 19.5% of men had a yearly total combined family income of at least $100,000. Table 1 provides complete demographic information for the sample and also details the number of men reporting common co-morbid conditions. The most common co-morbid conditions were connective tissue disease (e.g. lupus or arthritis; 14.9%) and diabetes 28.4%.

These descriptive statistics were repeated and broken down by racial/ethnic group in order to determine if there were any ethnic differences in demographic or disease related variables. These results can be seen in Table 2 and demonstrated significant ethnic differences in years of education ($F(2, 52) = 5.855$, $p < .01$) such that non-Hispanic White men completed an average of 15 years of school followed by Black men who completed an average of 13 years of school and Hispanic men who completed an average of 12 years of school. No ethnic differences were demonstrated in co-morbidities, marital status, age, occupational status, or total family income. In order to determine if prostate cancer knowledge and cancer fatalism change over time from baseline to one

month after PC treatment a paired samples t-test was conducted. The results indicate that neither prostate cancer knowledge nor cancer fatalism, changed significantly from T1 to T2.

Sexual Function and Sexual Bother

At baseline (T1), men in the sample reported a mean sexual function score of 59.95 on the EPIC (*SD* = 20.92) with higher scores indicating better sexual function. Their mean sexual bother score was 73.11 (*SD* = 31.50) with higher scores indicating that they viewed their sexual function as less problematic. The absolute range of each EPIC subscale is 0-100. Table 3 provides mean and standard deviation scores of T1 and T2 sexual function and bother by treatment type. To place these baseline scores in context, we utilized published normative data for the EPIC. These norms are based on a sample of men receiving various forms of treatment whose sexual functioning was assessed approximately 2 years after treatment (Wei et al., 2000). Their mean sexual function was 29.5, while their mean sexual bother was 85.3.

This study assessed men one month after treatment, when a significant portion of men were likely to still be recovering from treatment. The mean sexual function of our sample was 25.33 while the mean sexual bother was 48.79. This indicates that this sample was slightly below norms regarding sexual function. Concerning sexual bother, high scores indicate less distress therefore this

sample was much more distressed that the normative sample which is likely to be related to being assessed so soon after treatment.

In order to compare the sexual function and bother scores of our sample to those found in other samples which were assessed within a few months after treatment, our scores were converted to a percent recovery of function score by subtracting T1 sexual function scores from T2 sexual function scores then conducting a frequency analysis to determine the number of participants with a positive change score and dividing this number by the total number of participants. Similarly, recovery of sexual bother was measured by subtracting T1 sexual bother scores from T2 sexual bother scores. Men whose sexual function scores at T2 were greater than or equal to their scores at T1 were considered to have recovered to their baseline sexual function. Men whose sexual bother scores at T2 were greater than their scores at T1 were considered to have recovered to their baseline sexual bother. Since normative samples reported recovery of function and bother for only certain treatment types, the same approach was used with our sample.

The results of this analysis indicated that none of the men in our sample who received surgery recovered to baseline sexual function one month after surgery compared with between 14-19% of men in the Ball et al. (2006) sample. Regarding sexual bother, 26% of men in our sample who underwent surgery recovered to baseline values compared to approximately 34-40% of the Ball et al. (2006) sample.

The racial/ethnic differences in recovery of sexual function and bother were also assessed to better describe our sample. This was done by adding up all the participants with zero or positive change scores, which would indicate that their T2 function or bother scores were higher than their T1 scores. The result demonstrated that men in our sample from different ethnic groups recovered sexual function similarly. More specifically, 21.6% of non-Hispanic Whites recovered to baseline sexual function followed by 20.0% of Hispanic men and 19.0% of Black men. An ANOVA was conducted to determine if there were statistically significant differences in recovery of sexual function between ethnic groups, and the results did not demonstrate any statistically significant differences. Regarding sexual bother, 68.0% of Black men, 34.2% of non-Hispanic White men, and 27.8% of Hispanic men reported recovering to baseline sexual bother scores. However, racial/ethnic differences in recovery of sexual bother were also not statistically significant based on an ANOVA analysis, possibly due to inadequate sample size.

Preliminary Analyses

Continuous variables in the main analyses were all evaluated for skewness and kurtosis to determine if they met the assumption of normality (Innes, 2009). It was demonstrated that all variables met the assumption of normality except for T1 PC knowledge scores which were negatively skewed (*Skewness* = -.639, *SE* = .274) and T1 and T2 Sexual bother scores which were platykurtic (i.e. flattened distribution; *T1 Kurtosis* = -1.146, *SE* = .545, T2 *Kurtosis*

= -1.412, *SE* = .618). Furthermore, T2 sexual function scores were positively skewed (*Skewness* = 1.00, *SE* = .316). Initially, each of the non-normal variables were transformed using a square root transformation. However, this transformation did not yield a normal distribution for T1 PC Knowledge or T1 sexual bother. As a result, a log base 10 transformation was conducted; however this did not result in a normal distribution either as measured by the KS statistic. Since neither of the transformation techniques attempted resulted in sexual function or bother scores that were normally distributed other techniques were considered.

These techniques included creating a median split to divide participants into high and low PC knowledge groups, or using a cut-off score based on prior research to divide the sample into groups with adequate versus inadequate PC knowledge. However, after examining the frequency distribution for PC Knowledge scores (which appeared visually to be close to a normal curve), and reviewing the existing literature on this measure (which did not report cut-off scores), each of these approaches was decided against. As a result, non-transformed total scores for T1 PC knowledge were utilized in main analyses.

To address the skewness and kurtosis in T2 sexual function and bother scores, change scores were calculated by subtracting T2 sexual function and sexual bother scores from T1 sexual function and bother scores. The resulting change scores were then re-examined for violations of normality (e.g. skewness or kurtosis) and each was found to be normal. However, the calculation of a

change score also resulted in a reduction of the complete cases used for final analyses due to missing data and was an important reason that the final sample size was approximately 60 participants. In order to compensate for missing data, a mean substitution approach was considered, however this approach was not taken due to high variance in sexual function and bother scores caused by differing treatment types. Since this variance is directly related to the type of treatment received as well as individual participant characteristics (e.g. age, co-morbid conditions), the decision was made that mean substitution was not appropriate and that the reduced sample size was acceptable. Change in sexual function and sexual bother scores were utilized as the main outcome variables instead of using T2 sexual function scores and controlling for T1 sexual function.

A series of Pearson bivariate correlations were conducted to determine if any continuous demographic variables (e.g. age, co-morbid conditions, years of education, subjective social status) were related to T1 sexual function or T1 sexual bother. The results indicate that older age was correlated with lower T1 sexual function (r = -.261, p < .05). However, none of the continuous demographic variables were correlated with T1 sexual bother.

Demographic variables were also correlated with change in sexual function or change in sexual bother. The results indicated that older age was associated with less decline in sexual function (r = .290, p < .05), while increased severity of co-morbid conditions (r = .319, p < .05) was related to less decline in sexual bother. In order to determine if any categorical demographic data (e.g.

marital status, occupational status, educational attainment) were related to change in sexual function or sexual bother, separate ANOVAs were conducted. The results indicated no differences in change in sexual function or sexual bother between men of differing marital statuses, occupational statuses or educational attainment levels. As a result of correlations between age, co-morbid conditions and sexual function and bother, these variables will be included as a control variables in exploratory analyses along with type of treatment. Years of education will also be included as a control variable since there was a significant racial/ethnic difference in this variable.

Main Analyses

Hypothesis 1: Ethnic/Racial differences in prostate cancer fatalism and prostate cancer knowledge.

In order to test the first hypothesis that Black and Hispanic men would report significantly more cancer fatalism and less PC knowledge than non-Hispanic White men an ANOVA was conducted which can be seen in Table 4. The results demonstrated that there was no difference in cancer fatalism or PC knowledge between ethnic groups prior to PC treatment.

Hypothesis 2: Ethnic/Racial differences in sexual dysfunction and bother.

In order to address the second hypothesis, that Black and Hispanic men would report significantly lower sexual function and sexual bother scores one month after treatment than non-Hispanic White men, an ANOVA was conducted which can be seen in Table 5. Due to the non-normality of T2 sexual function and bother scores and the need to control for baseline scores, this ANOVA was conducted using change in sexual function and change in sexual bother scores as the within group variable. The results indicated that there were no statistically significant differences in T2 sexual function between men of different ethnic groups.

Hypothesis 3a: Association between cancer fatalism, prostate cancer knowledge and sexual function.

Hypothesis 3a stated that high levels of cancer fatalism and low levels of PC knowledge would be associated with declines in sexual function. In order to test this hypothesis, a hierarchical regression was conducted as seen in Table 6. The results indicated that one of the dummy coded terms for treatment type (β = 0.682, $p < .01$) was significantly associated with change in sexual function. More specifically, the term compared men who underwent brachytherapy or external radiation with men receiving cryotherapy, hormone therapy, and hormone therapy with radiation. A positive association between this term and change in

sexual function suggests that men who underwent some form of radiation had less decline in sexual function scores. Pre-treatment cancer fatalism and PC knowledge were not statistically significant predictors of change in sexual function.

Hypothesis 3b: Association between cancer fatalism, prostate cancer knowledge and sexual bother.

Hypothesis 3b stated that high levels of cancer fatalism and low levels of PC knowledge would be associated with declines in sexual bother. In order to test this hypothesis, a hierarchical regression was conducted which can be seen in Table 7. The results indicated that neither cancer fatalism nor PC knowledge were significantly associated with change in sexual bother after controlling for co-morbid conditions and type of treatment. The dummy coded term for treatment type which compared men who received some form of radiation therapy to men who underwent other non-surgical treatments was a significant predictor of positive change in sexual bother scores. This suggests that men who underwent some form of radiation also experienced less decline in sexual bother scores.

Exploratory Analyses

Exploratory Hypothesis 1a: Moderation of the relationship between cancer fatalism and sexual function by race/ethnicity.

Exploratory Hypothesis 1a states that the associations between greater cancer fatalism and declines in sexual function will only be significant among Black and Hispanic participants when compared with non-Hispanic White men. In order to test this hypothesis a hierarchical regression was conducted as seen in Table 8. In block one were control variables (age, co-morbid conditions, years of education) followed in block two by the two dummy coded terms for type of treatment. Cancer fatalism and the dummy coded term representing ethnicity were originally added in block three.

After completing the exploratory analyses with a single dummy coded ethnicity term it was demonstrated that this term did not predict change in sexual function or bother. As a result the decision was made to adopt a more specific dummy coding method. This method used two dummy coded terms. The first assigned '-1' to non-Hispanic Whites, a '1' to Hispanics and a '0' to Blacks. The second dummy coded ethnicity term assigned a '-1' to non-Hispanic Whites, a '0' to Hispanics and a '1' to Black participants. This method allowed for a more direct interpretation of any significant findings since negative associations would suggest a stronger relationship with non-Hispanic Whites while a positive

association would suggest a stronger association with either Hispanic men or Black men (depending on the term).

Block four contained two interaction terms which multiplied cancer fatalism scores by dummy coded ethnicity term 1 and dummy coded ethnicity term 2. The results of this analysis demonstrated that ethnicity did not moderate any relationship between cancer fatalism and change in sexual function for our sample. A dummy coded term for type of treatment was the only statistically significant predictor of sexual function and again suggested that men who underwent radiation had less of a decline in sexual function.

Exploratory Hypothesis 1b: Moderation of the relationship between cancer fatalism and sexual bother by race/ethnicity.

Exploratory hypothesis 1b states that the relationship between greater cancer fatalism and a greater decline in sexual bother scores will only be significant among Black and Hispanic participants when compared with non-Hispanic White men. In order to test this hypothesis another hierarchical regression was conducted. In block one were control variables (age, co-morbid conditions, years of education) followed in block two by dummy coded treatment type and in block three by cancer fatalism and the two dummy coded terms representing ethnicity. Block three contained the two interaction terms which multiplied cancer fatalism total scores by dummy coded ethnicity term 1 and dummy coded ethnicity term 2. The results can be seen in Table 9 and

demonstrate that ethnicity did not moderate any relationship between cancer fatalism and change in sexual bother for our sample. Type of treatment remained a significant predictor (as in previous analyses).

Exploratory Hypothesis 2a: Moderation of the relationship between prostate cancer knowledge and sexual function by race/ethnicity.

Exploratory Hypothesis 2a states that the association between lower prostate cancer knowledge scores and declines in sexual function will only be significant among Black and Hispanic participants when compared with non-Hispanic White men. This hypothesis was tested using a hierarchical multiple regression. In block one were control variables (age, co-morbid conditions, years of education) followed in block two by treatment type and in block three by cancer fatalism and the two dummy coded terms representing ethnicity. Block four added the two interaction terms which multiplied prostate cancer knowledge total scores by dummy coded ethnicity term 1 and dummy coded ethnicity term 2. The results can be seen in table 10 and demonstrated that ethnicity did not significantly moderate the relationship between prostate cancer knowledge and sexual function. As seen in the first exploratory hypothesis, type of treatment was the only statistically significant predictor of sexual function ($\beta = .673$, $p < .01$), which provides more evidence for the importance of the type of treatment received on sexual function one month after treatment.

Exploratory Hypothesis 2b: Moderation of the relationship between prostate cancer knowledge and sexual bother by race/ethnicity.

Hypothesis 2b states that the association between lower prostate cancer knowledge scores and declines in sexual bother will only be significant among Black and Hispanic participants when compared with non-Hispanic White men. The regression to test this hypothesis included control variables in block one followed in block two by treatment type and in block three by PC knowledge and the two dummy coded terms representing ethnicity. Block four included the two interaction terms which multiplied prostate cancer knowledge total scores by dummy coded ethnicity term 1 and dummy coded ethnicity term 2. The results can be seen in Table 11 and did not demonstrate any significant moderation effect. Treatment type remained the sole statistically significant predictor of change in sexual bother scores.

Post hoc Analyses.

The type of treatment received was the most significant predictor of change in sexual function. As a result, additional post-hoc analyses were conducted with only men who underwent surgery since they were the largest single treatment group. Moreover, prior research which demonstrated racial/ethnic differences in sexual function after PC treatment (e.g. Johnson et al., 2004) included only men who received radical prostatectomy. The test conducted was an ANOVA to determine if there were racial/ethnic differences in

co-morbid conditions, sexual function, sexual bother, fatalism or PC knowledge that would be more prominent when looking at only men receiving the same treatment. These results were not repeated for other treatment groups due to their insufficient sample size.

The results of these ANOVAs demonstrated racial/ethnic differences in T1 PC knowledge ($F(2, 55) = 5.595$, $p < .01$) among men who underwent surgery with non-Hispanic White men demonstrating the most PC knowledge ($M = 17.13$) followed by Hispanic ($M = 14.67$) and African American men ($M = 13.44$). There were also racial/ethnic differences in co-morbid conditions ($F(2, 55) = 3.760$, $p < .05$) with non-Hispanic White men demonstrating the lowest burden from co-morbid conditions ($M = .79$) followed by Hispanic ($M = 1.94$) and African American men ($M = 2.50$). However, there were no racial/ethnic differences found in T1 fatalism scores or change in sexual function or sexual bother scores among men treated with radical prostatectomy. The total number of participants in these analyses was larger than the sample used in the main analyses since there were fewer difficulties posed by missing data. Thus more participants could be included who still met the exclusion criteria.

Chapter 4: Discussion

Findings

This study sought to explore ethnic differences in cancer fatalism and prostate cancer knowledge as well as their influence on sexual function and sexual bother in a sample of men recently diagnosed with localized prostate cancer. The first hypothesis was that Black and Hispanic men would report higher levels of cancer fatalism and lower levels of PC knowledge than non-Hispanic White men. This hypothesis was based on previous research by Powe et al. (2007, 2009) who found that both African American and Hispanic men in their samples reported higher levels of cancer fatalism and less PC knowledge than non-Hispanic White men (Powe et al., 2007; Powe et al., 2009). Furthermore, other researchers have found that African American and Hispanic men are at a greater risk for poor health literacy in general (Michielutte et al., 1999), and poor knowledge of PC specifically (Kilbridge et al., 2009; Powe et al., 2009). However, our results did not replicate this finding and did not demonstrate any significant ethnic differences in cancer fatalism or PC knowledge prior to treatment.

While statistically non-significant, these results may not completely rule out ethnic differences because of limited numbers of Black and Hispanic men in our final sample. The number of participants in our final sample size (N = 60) was also lower than the number suggested in preliminary power analyses (N = 102) which may have made it difficult to adequately test our hypothesis. Various

methods were considered to compensate for missing data, however each was decided against because of the wide variability in our outcome measures like sexual function based on treatment type as well as co-morbid conditions. At the time of this manuscript however, the main study remains in active data collection which opens the possibility that future studies with a similar aim may have enough participants to detect smaller effect sizes.

The second hypothesis was that Black and Hispanic men would report lower sexual function and higher sexual bother one month after treatment for prostate cancer compared to non-Hispanic White men. Past research which relates differences in sexual function to ethnic group membership has been mixed. Johnson et al. (2004) found that African American men reported greater recovery of sexual function five years after radical prostatectomy compared with non-Hispanic White men. Rice et al. (2010) found no ethnic differences in sexual function between ethnic groups, while Kimura et al. (2011) found that African American men reported lower sexual function compared to men of other ethnicities and Saigal et al. (2006) found that Hispanic men in their sample reported more erectile dysfunction compared to non-Hispanic White men. Findings related to ethnic differences in sexual bother were very limited but also noted that Black and Hispanic men reported greater sexual bother after treatment (Jenkins et al., 2004; Johnson et al., 2004).

The results for the second hypothesis indicated that there were no statistically significant differences between men of different ethnic groups

regarding change in sexual function or change in sexual bother one month after treatment. Our lack of significant results should be interpreted cautiously because our final sample again fell short of the suggested 102 participants. Moreover, since the largest treatment group in our study were men who received radical prostatectomy, it is likely that assessing our sample so soon after treatment resulted in a sample that is skewed toward lower functional scores with limited variability.

The third hypothesis was that high levels of pre-treatment cancer fatalism and low levels of pre-treatment PC knowledge would be associated with lower sexual function and sexual bother one month after treatment. This hypothesis is depicted in Figure 1 and was based on research by Powe et al., (2007) who demonstrated that African American and Hispanic men reported greater cancer fatalism and lower PC knowledge compared to non-Hispanic White men. High levels of fatalism and low levels of PC knowledge have, in turn, been related to delays in screening (Powe et al., 2007; Kudadjie-Gyamfi et al., 2006) and these screening delays are likely to contribute to African American and Hispanic men presenting to treatment with more advanced (and life threatening) cancer (Hoffman et al., 2001). Also, Jenkins et al. (2004) suggest that African American and Hispanic men report higher levels of sexual bother than non-Hispanic Whites, which are independent of their sexual function (Johnson et al., 2004).

Our results did not support the third hypothesis that high fatalism and low PC knowledge would be related to declines in sexual function and sexual bother.

Type of treatment and co-morbid conditions were the most significant predictors of post treatment change sexual function, while none of the predictors tested in hypothesis three were predictors of sexual bother. Type of treatment predicted sexual function such that men who received external or internal radiation demonstrated less decline in sexual function than men receiving all other treatment types. This result is consistent with the findings of Litwin et al. (2007) who reported that 40% of men who underwent radiation recovered to baseline sexual function one month after treatment compared with only 5% of men in their sample who received radical prostatectomy.

Other factors which may have influenced the findings on sexual function and bother include screening behavior and post treatment medication adherence. Analyses designed to determine if African American and Hispanic me tended to delay treatment more than their non-Hispanic White counterparts were considered, however the necessary data was not available at the time of this manuscript. Specifically, a retrospective review of the participant's medical charts is a part of the PATHS study, however this review is set to occur when participants approach the end of their two year involvement with the study. This remains an important area for future work. Regarding medication adherence, only 9 men in the final sample reported being prescribed medications to treat ED, and specific data related to their medication use was not collected. This data would be essential to fully assess if ED medication utilization was a factor in the

recovery of sexual function and bother after PC treatment and is another important area for future work.

Our exploratory analyses took the third hypothesis a step further by testing ethnicity as a moderator to any relationship between cancer fatalism, PC knowledge and change in sexual function and bother. These analyses were deemed exploratory because there was no evidence in the literature to suggest that including ethnicity as a moderator to any association between cancer fatalism, PC knowledge and sexual function and bother would better explain this relationship. Moreover, there was some concern that the actual sample size would not be adequate to properly test this relationship since the suggested sample size was 153 participants. The results indicated that race/ethnicity did not moderate the relationship between PC knowledge and sexual bother. Type of treatment remained the best predictor of sexual function one month after treatment with men who received external or internal radiation demonstrating the least decline in sexual function compared to men receiving all other treatment types.

Due to the influence of treatment type, post hoc analyses were conducted with only men treated with radical prostatectomy. These results found racial/ethnic differences in pre-treatment PC knowledge scores and in the severity of co-morbid conditions. In each case Black men were at the greatest disadvantage with the lowest overall PC knowledge scores and the highest co-morbid condition severity scores among men treated with radical prostatectomy.

These findings are consistent with the findings of Kilbridge et al. (2009) and Jenkins et al. (2004). These findings are also in keeping with the findings of Powe et al. (2009) and provide additional evidence that Black men in particular should be targeted for interventions designed to increase the PC knowledge of men at risk for the disease.

Significance

This study was unique in its goal to report on the relationship between knowledge of prostate cancer, culturally based constructs like cancer fatalism, and disease specific quality of life measures like sexual function and bother which have been shown to be among the most important post-treatment problems to most PC survivors (Robinson et al., 2002). This study sought to describe these changes with a diverse sample including Black, Hispanic, and non-Hispanic White men. Hispanics make up the fastest growing ethnic minority group in the U.S., yet they are underrepresented in the prostate cancer literature (Ramsey et al., 2007).

This manuscript was also able to assess cancer fatalism and PC knowledge for men actually diagnosed with prostate cancer, and not a general sample of African American and Hispanic men as in the Powe et al. (2009) or the Kilbridge et al. (2009) studies. Assessing men who actually have cancer during this critical period when the diagnosis is still new may have a number of advantages. For example, even at baseline some participants in our sample

were likely thinking about treatment options and deciding whether or not to undergo treatment. In this stage perceptions and knowledge of prostate cancer diagnosis and treatment were likely to be critical to their eventual treatment decisions.

This study was distinctive because it analyzed sexual function and bother scales separately. Our approach was based on research which demonstrated that African American men may be at greater risk for sexual bother independent of their sexual function (Johnson et al., 2004).This manuscript was also unique in its ability to test for differences in sexual function and bother after controlling for baseline functioning which was actually reported prior to treatment instead of using a retrospective recall. Moreover, the use of change in sexual function and sexual bother scores as outcome measures, allowed us to use what is perhaps a more relevant measurement of functionality for most men (i.e. return to baseline function).

An understanding of how cancer fatalism and PC knowledge influence sexual function and bother could help to inform future interventions aimed at improving outcomes for PC survivors. PC knowledge is an important measure of how informed men are about the disease and lends insight into frequently misunderstood aspects of PC diagnosis and treatment. An understanding of the areas in which men diagnosed with PC lack knowledge would be crucial to creating more effective campaigns designed to assist in informed decision making for African American men.

Limitations and Future Work

The limitations to our findings include a relatively small sample size (*N* = 60) which limited the power of our statistical analyses. Also, the fact that sexual function and bother were assessed one month after treatment may not have allowed for much natural recovery to occur, especially in the case of men treated with surgery who made up 75% of the sample. Much of the theoretical support for our hypotheses is able to relate cancer fatalism and PC knowledge to deficits in screening that result in Black and Hispanic men presenting for treatment at a more advanced stage. However, our sample limited our ability to actually test this relationship because all men had been previously screened (and diagnosed). Future work could seek to include men who had not been screened for PC prior to enrollment in the study to determine if African American and Hispanic men do in fact delay screening tests.

The review of the literature also discusses the importance of adherence to medication regimes for ED to aid in the recovery of sexual function. Analysis of medication utilization was considered as a post-hoc analysis, however only 9 of the participants in the final sample actually reported that they had been prescribed these medications. It is possible that additional participants were prescribed the medications but did not report this information. Moreover, an assessment of how often ED medications were used was not collected as part of the main study.

Future work should include the replication of the findings from the current study using a larger sample drawn from the PATHS study that will allow for the detection of even smaller effect sizes. With a larger sample size, more predictor variables can be included in the model which will further our understanding of the influence of other cultural factors such as masculinity and acculturation on sexual function and bother after treatment for prostate cancer. Future studies should either examine men treated with different types of treatment separately or utilize data obtained at least 6 months after treatment to allow men treated with surgery more time to recovery naturally. Data obtained six months post treatment would also allow for a better understanding of the longer term changes in sexual function which occur after treatment.

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Figure

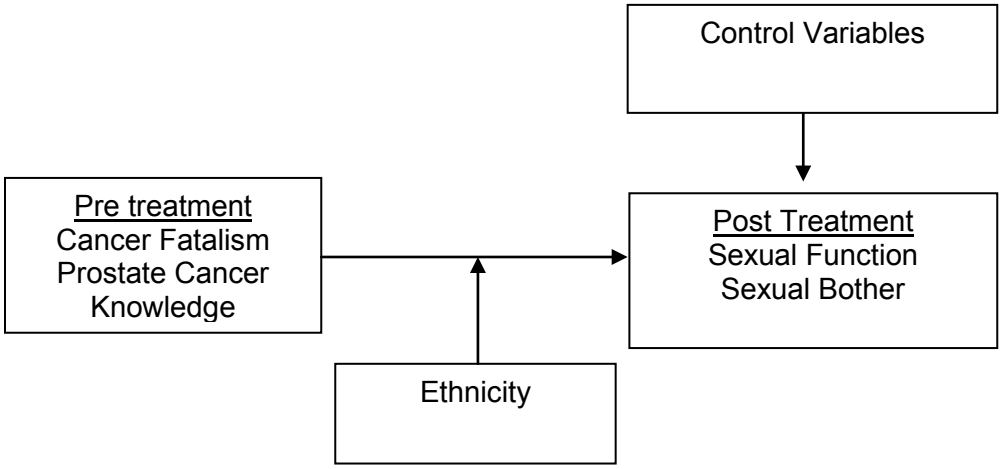

*Figure 1.*Theoretical model for the relationship between cancer fatalism, prostate cancer knowledge, and sexual function/bother. This figure asserts that this relationship will be moderated by ethnicity such that it will be more prominent among Black and Hispanic men compared to non-Hispanic White men even after controlling for relevant control variables.

Tables

Table 1.
Sample Descriptive Statistics

Variable	*N*	Percentage
Ethnicity	82	
Non-Hispanic White	38	46.90%
Hispanic	24	29.30%
Black	19	23.20%
Marital Status	82	
Single, never married	5	6.10%
Dating	1	1.20%
Married or living together	61	74.40%
Separated	4	4.90%
Divorced	11	13.40%
Highest level of education in USA	43	
Less than 12 years	5	20.80%
High School	6	25.00%
Associate's Degree	7	29.20%
Bachelor's Degree	5	20.80%
Master's or Doctorate Degree	1	4.20%
Current daily activities	82	
Working full time	33	40.20%
Working part time	9	11.0%
Unemployed or laid off	13	15.90%
Looking for work	1	1.20%
Keeping house	1	1.20%
Retired	25	30.50%
Total Combined Family income	82	
Less than 24,999	18	22.00%
25,000-49,999	20	24.30%
50,000-74,999	13	15.90%
75,000-99,999	7	8.50%
100,000 and greater	16	19.50%
Co-morbid conditions	67	
Heart Attack	3	4.50%
Congestive Heart Failure	1	1.50%
Peripheral vascular disease	7	10.40%
Brain Stroke	2	3.00%
Diabetes	19	28.40%

Memory problems	1	1.50%
Lung illness	4	6.00%
Connective tissue disease	10	14.90%
Stomach ulcers	5	7.50%
Hepatitis A or fatty liver	3	4.50%
Hepatitis B or C or cirrhosis	4	4.90%
Kidney problems	6	9.00%
Other Cancer	0	0.00%
HIV or AIDS	0	0.00%

Note: Some analyses have smaller numbers of participants due to missing data.

Table 2.
ANOVA of Demographic Variables and Co-morbid Conditions by Ethnic/Racial Group

Variable	Mean (SD)	df	F	p
Age		2, 61	0.002	0.998
non-Hispanic White	60.47 (12.23)			
Hispanic	60.58 (6.36)			
Black	60.63 (5.90)			
Highest year of school completed		2,52	5.855**	0.005
non-Hispanic White	15.68 (2.53)			
Hispanic	12.50 (3.57)			
Black	13.29 (3.15)			
Co-morbid conditions		2,61	2.986	0.058
non-Hispanic White	0			
Hispanic	0			
Black	0.12			
Marital Status		2,63	.111	.895
Current daily activities		2, 61	.337	.715
Total combined family income		2, 61	.415	.662

Note: Some analyses have smaller degrees of freedom due to missing data. Means were not reported for variables which were measured categorically.
*$p < .05$, **$p < .01$.

Table 3.
T1 andT2 Sexual Function and Sexual Bother Scores by Treatment Type

Treatment type (N)	T1 Sexual Function M(SD)	T1 Sexual Bother M(SD)	T2 Sexual Function M(SD)	T2 Sexual Bother M(SD)
Surgery (37)	60.93 (19.38)	69.41 (27.29)	15.19 (15.57)	32.89 (31.26)
External Radiation (12)	44.83 (23.09)	56.25 (40.42)	43.43 (22.07)	76.56 (23.56)
Hormone Therapy (2)	38.89 (39.28)	100.00 (0)	22.67 (32.06)	21.88 (13.26)
Brachytherapy (5)	52.04 (28.83)	73.75 (42.02)	46.33 (29.14)	82.5 (16.18)
Chemotherapy (4)	62.5 (8.64)	82.81 (22.46)	47.92 (19.00)	51.56 (28.58)
All Treatment Types (62)	56.34 (21.67)	69.56 (31.31)	25.28 (22.95)	45.67 (34.76)
No treatment (40)	52.42 (30.13)	66.70 (33.61)	43.19 (32.50)	65.99 (35.57)

Table 4.
ANOVA of T1 Cancer Fatalism and PC Knowledge Scores by Ethnic/Racial Group

	Mean	df	F	P
Cancer Fatalism		2, 82	0.266	0.767
non-Hispanic White (35)	31.39			
Hispanic (17)	32.36			
Black (15)	30.35			
PC Knowledge		2,84	1.09	0.341
non-Hispanic White (35)	15.31			
Hispanic (17)	13.74			
Black (15)	14.16			

*Note: *p* < . 05; ***p* < .01

Table 5.
ANOVA of Change in Sexual Function and Change in Sexual Bother by Ethnicity

	Mean	df	F	P
Change in sexual function		2, 64	1.06	0.352
non-Hispanic White (35)	-25.61			
Hispanic (17)	-36.78			
African American (15)	-32.16			
Change in sexual bother		2,67	1.06	0.351
non-Hispanic White (35)	-22.4			
Hispanic (17)	-33.2			
African American (15)	-14.24			

*Note: *p* < . 05; ***p* < .01

Table 6.
Hierarchical Multiple Regression of Change in Sexual Function on Cancer Fatalism and PC Knowledge

	Predictor variables	B	SE B	B	R^2
Block 1	Age	0.546	0.632	0.135	0.078
	Co-morbid Conditions	1.573	2.195	0.112	
	Years of Education	1.857	1.467	0.188	
Block 2	Treatment dummy 1	-4.527	6.842	-0.095	0.620
	Treatment dummy 2	33.955	6.536	0.682**	
Block 3	Cancer Fatalism	0.422	0.301	0.141	0.641
	PC knowledge	0.436	0.683	0.069	

*Note: *p* < . 05; **p* < .01

Table 7.
Hierarchical Multiple Regression of Change in Sexual Bother on Cancer Fatalism and PC Knowledge

	Predictor variables	B	SE B	β	R^2
Block 1	Age	-0.671	0.941	-0.109	0.099
	Co-morbid Conditions	7.511	3.345	0.341	
	Years of Education	0.698	2.240	0.045	
Block 2	Treatment dummy 1	16.137	13.572	0.215	0.348
	Treatment dummy 2	48.803	13.381	0.621**	
Block 3	Cancer Fatalism	0.466	0.600	0.099	0.361
	PC knowledge	0.735	1.348	0.076	

*Note:*p* < . 05; **p* < .01

Table 8.
Moderation of the Relationship Between Cancer Fatalism and Sexual Function by Ethnicity

	Predictor variables	B	SE B	β	R^2
Block 1	Age	0.546	0.632	0.135	0.078
	Co-morbid Conditions	1.573	2.195	0.112	
	Years of Education	1.857	1.467	0.188	
Block 2	Treatment dummy 1	-4.527	6.842	-0.095	0.620
	Treatment dummy 2	33.955	6.536	0.682**	
Block 3	Cancer Fatalism	0.465	0.319	0.156	0.641
	Ethnicity dummy 1	2.384	4.823	0.075	
	Ethnicity dummy 2	0.062	4.236	0.002	
Block 4	Fatalism x Ethnicity dummy 1	-0.207	0.515	-0.202	0.647
	Fatalism x Ethnicity dummy 2	0.383	0.501	0.408	

*Note: *p* < . 05; **p* < .01

Table 9.
Moderation of the Relationship Between Cancer Fatalism and Sexual Bother by Ethnicity

	Predictor variables	B	SE B	β	R^2
Block 1	Age	-0.671	0.941	-0.109	0.099
	Co-morbid Conditions	7.511	3.345	0.341	
	Years of Education	0.698	2.240	0.045	
Block 2	Treatment dummy 1	16.137	13.572	0.215	0.348
	Treatment dummy 2	48.803	13.381	0.621**	
Block 3	Cancer Fatalism	0.646	0.627	0.137	0.383
	Ethnicity dummy 1	-1.160	9.571	-0.023	
	Ethnicity dummy 2	9.707	8.245	0.212	
Block 4	Fatalism x Ethnicity dummy 1	-0.238	1.027	-0.758	0.416
	Fatalism x Ethnicity dummy 2	1.410	0.977	0.976	

*Note: *p* < . 05; **p* < .01*

Table 10.
Moderation of the Relationship Between PC knowledge and Sexual Function by Ethnicity

	Predictor variables	B	SE B	β	R^2
Block 1	Age	0.938	0.572	-0.109	0.098
	Co-morbid Conditions	0.859	2.116	0.341	
	Years of Education	1.576	1.413	0.045	
Block 2	Treatment dummy 1	-3.394	6.931	0.215	0.605
	Treatment dummy 2	33.293	6.533	0.621**	
Block 2	PC Knowledge	0.216	0.709	-0.084	0.610
	Ethnicity dummy 1	-1.399	4.434	0.074	
	Ethnicity dummy 2	-1.098	4.179	0	
Block 3	PC Knowledge x Ethnicity dummy 1	-0.390	1.006	-0.725	0.617
	PC Knowledge x Ethnicity dummy 2	-0.416	1.006	0.481	

*Note: *p* < . 05; **p* < .01*

Table 11.
Moderation of the Relationship Between PC Knowledge and Sexual Bother by Ethnicity

	Predictor variables	B	SE B	β	R^2
Block 1	Age	-0.255	0.868	-0.043	0.097
	Co-morbid Conditions	7.229	3.327	0.322	
	Years of Education	-0.001	2.213	0.000	
Block 2	Treatment dummy 1	17.174	13.408	0.227	0.366
	Treatment dummy 2	50.873	12.967	0.646**	
Block 2	PC Knowledge	0.725	1.325	0.075	0.397
	Ethnicity dummy 1	-3.603	9.248	0.069	
	Ethnicity dummy 2	10.593	7.839	0.236	
Block 3	PC Knowledge x Ethnicity dummy 1	4.329	2.329	0.028	0.418
	PC Knowledge x Ethnicity dummy 2	14.445	3.867	0.602	

*Note: *p* < . 05; **p* < .01*

Appendix A

DEMOGRAPHICS

The first questions will be asking about your background. Please indicate in the boxes below the best answer for you.

1. What is your marital status?
   - **1 = Single, never married**
   - **2 = Married or in an equivalent relationship**
   - **3 = Dating**
   - **4 = Separated**
   - **5 = Divorced**
   - **6 = Widowed**

2. Do you have children?
   - **1 = Yes** 2a. If YES, how many?
   - **0 = No**

3. What is your age? (as of today; date of assessment)

4. What is your Date-of-Birth? (MM/DD/YYYY)

5. Approximately, what is the square footage of your home?

6. Have you completed any education outside the US?
   - **1 = Yes (Continue to questions 7 & 8)**
   - **2 = No (Continue to question 9)**

7. If yes, how many years of education did you receive *outside* the United States?

8. If yes, what was the highest level of education that you completed *in* the United States?
   - **1 = Less than 12 years of school**
   - **2 = High school diploma or GED**
   - **3 = 2-year technical degree**
   - **4 = 4-year Bachelor's degree**
   - **5 = Masters or Doctorate Degree**

9. What is your religious identification?
   - **1 = Roman Catholic**
   - **2 = Christian fundamentalist/evangelist**
   - **3 = Christian Other**
   - **4 = Jewish**
   - **5 = Muslim**
   - **6 = No religion**
   - **7 = Other (specify) _____**

10. What is your primary language?
    1 = English only
    2 = Spanish only
    3 = English and Spanish
    4 = Other (Please specify: _____)

11. With which of the following racial groups do you identify?
    1 = White
    2 = Black (See Question 11a)
    3 = Asian
    4 = Native American
    5 = Mulatto
    6 = Multiracial (Please specify what races _____)
        11a. If Black, are you?
        1 = Caribbean Black (Please specify_____)
        2 = Other Black (Please specify:_____)

12. Are you Hispanic or Latino?
    1 = Yes (Continue to question 13)
    2 = No (Continue to question 14)

13. If Hispanic-American, are you:

1 = Mexican	**7 = Nicaraguan**
2 = Puerto Rican	**8 = Other Caribbean country _____**
3 = Cuban	**9 = Other South American country ____**
4 = Colombian	**10 = Other Central American country___**
5 = Venezuelan	**11 = Other country_____**
6 = Argentinean	

14. Were you born in the United States?
    1 = Yes (Continue to question 18)
    2 = No (Continue to question 15)

15. In what month and year did you first enter the US?

16. Approximately, how much time in total have you lived in the US?

17. What was your reason for immigrating to this country? Check as many as apply:

    1 = Educational opportunities
    2 = Economic opportunities

3 = Political instability in country of origin
4 = Reuniting with family
5 = Health reasons
6 = Please specify _____

18. Indicate the generation that best applies to you.
1 = 1st generation (you were born in another country)
2 = 2nd generation (you were born in the USA; either parent born in another country)
3 = 3rd generation (you & your parents were born in the USA; grandparents born in another country)
4 = 4th generation (you & your parents were born in the USA and at least one grandparent born in another country with remainder born in the USA)
5 = 5th generation (you, your parents, and all grandparents born in the USA)

19. What is your sexual orientation?
1 = Heterosexual
2 = Homosexual
3 = Bisexual
4 = No answer

Appendix B

MACARTHUR NETWORK SOCIODEMOGRAPHIC QUESTIONAIRE

Think of this ladder as representing where people stand in their communities.

People define community in different ways; please define it in whatever way is most meaningful to you. At the **top** of the ladder are the people who have the highest standing in their community. At the **bottom** are the people who have the lowest standing in their community.

Where would you place yourself on this ladder?

Please place a large "**X**" on the rung where you think you stand at this time in your life, relative to other people in your community.

Think of this ladder as representing where people stand in the United States.

At the **top** of the ladder are the people who are the best off – those who have the most money, the most education and the most respected jobs. At the **bottom** are the people who are the worst off – who have the least money, least education, and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.

Where would you place yourself on this ladder?

Please place a large "**X**" on the rung where you think you stand at this time in your life, relative to other people in the United States.

3. What is the highest grade (or year) of regular school you have completed in the United States? (Indicate one.)

Elementary School	High School	College	Graduate School
01	09	13	17
02	10	14	18
03	11	15	19
04	12	16	20+
05			
06			
07			
08			

4. What is the highest degree you earned in the United States?

1 = High school diploma or equivalency (GED)
2 = Associate degree (junior college)
3 = Bachelor's degree
4 = Master's degree
5 = Doctorate
6 = Professional (MD, JD, DDS, etc.)
7 = Other specify _____
8 = None of the above (less than high school)

5. What is the highest degree you earned in your country of origin?

1 = High school diploma or equivalency (GED)
2 = Associate degree (junior college)
3 = Bachelor's degree
4 = Master's degree
5 = Doctorate
6 = Professional (MD, JD, DDS, etc.)
7 = Other specify _____
8 = None of the above (less than high school)

6. Which of the following best describes your current main daily activities and/or responsibilities?

1 = Working full time
2 = Working part-time
3 = Unemployed or laid off
4 = Looking for work
5 = Keeping house or raising children full-time
6 = Retired

7. How much did you earn, before taxes and other deductions, during the past 12 months?

1 = Less than $5,000
2 = $5,000 through $11,999
3 = $12,000 through $15,999
4 = $16,000 through $24,999
5 = $25,000 through $34,999
6 = $35,000 through $49,999
7 = $50,000 through $74,999
8 = $75,000 through $99,999
9 = $100,000 and greater
10 = Don't know
11 = No response

8. How many people are currently living in your household, including yourself?

8a. **Number of people?**
8b. **Of these people, how many are children?**
8c. **Of these people, how many are adults**
8d. **Of the adults, how many bring income into the household?**

9. Is the home where you live:

1 = Owned or being bought by you (or someone in the household)?
2 = Rented for money?
3 = Occupied without payment of money or rent?
4 = Other (specify) _____

10. Which of these categories best describes your total combined family income for the past 12 months? This should include income (before taxes) from all sources, wages, rent from properties, social security, disability and/or veteran's benefits, unemployment benefits, workman's compensation, help from relatives (including child payments and alimony), and so on.

1 = Less than $5,000
2 = $5,000 through $11,999
3 = $12,000 through $15,999
4 = $16,000 through $24,999
5 = $25,000 through $34,999
6 = $35,000 through $49,999
7 = $50,000 through $74,999
8 = $75,000 through $99,999
9 = $100,000 and greater
10 = Don't know
11 = No response

Appendix C

CHARLSON SCALE

Below are some questions about your past medical history. Please indicate whether you have a history or current evidence of the condition by CHOOSING either YES or NO.

0 = No

1 = Yes

1. Have you ever had a heart attack?	**0**	**1**
2. Has the doctor ever told you that your heart is working less than 30% or that you have congestive heart failure?	**0**	**1**
3. Have you ever had or are presently having circulatory problems in the legs or arms (peripheral vascular disease)?	**0**	**1**
4. Have you ever had a brain stroke?	**0**	**1**
5a. Have you ever been told you have diabetes?	**0**	**1**
5b. If yes, have you had problems with your kidneys, vision, or any other organ in your body?	**0**	**1**
6. Have you ever been diagnosed with memory problems?	**0**	**1**
7. Have you ever had or have a lung illness?	**0**	**1**
8. Have you ever been told you have connective tissue disease, lupus, or arthritis?	**0**	**1**
9. Have you ever had stomach ulcers?	**0**	**1**
10. Have you ever had hepatitis A or fatty liver?	**0**	**1**
11. Have you ever had hepatitis B or C or cirrhosis?	**0**	**1**
12. Have you ever had kidney problems?	**0**	**1**
13. Do you have a history of cancer other than skin, prostate, or invasive bladder cancer?	**0**	**1**
14. Have you ever been told you have HIV or AIDS?	**0**	**1**

Appendix D

EPIC

Directions: For the following items, write the <u>one number</u> that best indicates how that item applies to you using the scale provided.

<u>URINARY DOMAIN</u>
For items 1-3:

0 = Rarely or never

1 = About once a week

2 = More than once a week

3 = About once a day

4 = More than once a day

1. Over the past **four weeks**, how often have you leaked urine?

2. Over the past **four weeks**, how often have you urinated blood?

3. Over the past **four weeks**, how often have you had pain or burning with urination?

4. Which of the following best describes your urinary control during the **last four weeks**?

0 = No urinary control whatsoever

1 = Frequent dribbling

2 = Occasional dribbling

3 = Total control

5. How many pads or adult diapers per day did you usually use to control leakage during the **last four weeks**?

0 = No pads

1 = One pad per day

2 = Two pads per day

3 = Three or more pads per day

For questions 6 through 12, use the scale below:

How big a problem, if any, has each of the following been for you **during the last four weeks?**

0 = No Problem

1 = Very Small Problem

2 = Small Problem

3 = Moderate Problem

4 = Big Problem

6a. Dripping or leaking urine (wetting your pants)

6b. Urine leakage interfering with your sexual activity

7. Pain or burning on urination

8. Bleeding with urination

9. Weak urine stream or incomplete emptying

10. Waking up to urinate

11. Need to urinate frequently during the day

12. Overall, how big a problem has your urinary function been for you **during the last four weeks?**

BOWEL DOMAIN

13. How often have you had rectal urgency (felt like you had to pass stool, but did

not) **during the last four weeks?**

0 = Rarely or never

1 = About once a week

2 = More than once a week

3 = About once a day

4 = More than once a day

14. How often have you had uncontrolled leakage of stool or feces **during the last four weeks?**

0 = Rarely or never

1 = About once a week

2 = More than once a week

3 = About once a day

4 = More than once a day

15. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) **during the last four weeks?**

0 = Never

1 = Rarely

2 = About half the time

3 = Usually

4 = Always

16. How often have you had bloody stools **during the last four weeks?**

0 = Never

1 = Rarely

2 = About half the time

3 = Usually

4 = Always

17. How often have your bowel movements been painful **during the last four weeks?**

0 = Never

1 = Rarely

2 = About half the time

3 = Usually

4 = Always

18. How many bowel movements have you had on a typical day **during the last four weeks?**

0 = Two or less

1 = Three to four

2 = Five or more

19a. How much distress have your bowel movements caused you **during the last four weeks**?

0 = Severe distress

1 = Moderate distress

2 = Little distress

3 = No distress

19b. How often have you had crampy pain in your abdomen, pelvis or rectum **during the last four weeks?**

0 = Rarely or never

1 = About once a week

2 = More than once a week

3 = About once a day

4 = More than once a day

For items 20-26:

How big a problem, if any, has each of the following been for you **during the last four weeks**?

0 = No Problem

1 = Very Small Problem

2 = Small Problem

3 = Moderate Problem

4 = Big Problem

20. Urgency to have a bowel movement
21. Increased frequency of bowel movements
22. Watery bowel movements
23. Losing control of your stools
24. Bloody stools
25. Abdominal, pelvic or rectal pain
26. Overall, how big a problem have your bowel habits been for you **during the last four weeks?**

SEXUAL DOMAIN

For items 27-29: How would you rate each of the following **during the last four weeks**?

0 = Very poor to none

1 = Poor

2 = Fair

3 = Good

4 = Very good

27. Your level of sexual desire

28. Your ability to have an erection

29. Your ability to reach orgasm (climax)

30. How would you describe the usual QUALITY of your erections **during the last four weeks?**

0 = None at all

1 = Not firm enough for any sexual activity

2 = Firm enough for masturbation and foreplay only

3 = Firm enough for intercourse

31. How would you describe the frequency of your erections **during the last four weeks?**

0 = I NEVER had an erection when I wanted one

1 = I had an erection LESS THAN HALF the time I wanted one

2 = I had an erection ABOUT HALF the time I wanted one

3 = I had an erection MORE THAN HALF the time I wanted one

4 = I had an erection WHENEVER I wanted one

32. How often have you awakened in the morning or night with an erection **during the last four weeks?**

0 = Never

1 = Less than once a week

2 = About once a week

3 = Several times a week

4 = Daily

33. **During the last four weeks,** how often did you have <u>any</u> sexual activity?

0 = Not at all

1 = Less than once a week

2 = About once a week

3 = Several times a week

4 = Daily

34. **During the last four weeks**, how often did you have sexual intercourse?

0 = Not at all

1 = Less than once a week

2 = About once a week

3 = Several times a week

4 = Daily

35. Overall, how would you rate your ability to function sexually **during the last four weeks?**

0 = Very poor

1 = Poor

2 = Fair

3 = Good

4 = Very good

For items 36-39:

During the last four weeks, how big a problem, if any, has each of the following been for you?

0 = No Problem

1 = Very Small Problem

2 = Small Problem

3 = Moderate Problem

4 = Big Problem

36. Your level of sexual desire

37. Your ability to have an erection

38. Your ability to reach orgasm (climax)

39. Overall, how big a problem has your sexual function or lack of sexual function been for you?

Appendix E

POWE FATALISM INVENTORY

Please show how much you agree or disagree with these statements by circling the number from 1 (very much in disagreement) to 5 (very much in agreement) which best shows how you feel about each statement.

1 = Very much in disagreement
2 = In disagreement
3 = Neither in agreement or disagreement
4 = In agreement
5 = Very much in agreement

1. I think if someone is meant to have prostate cancer, it doesn't matter what types of food they eat, they will get prostate cancer anyway.	**1**	**2**	**3**	**4**	**5**
2. I think if someone has prostate cancer, it is already too late to get treated for it.	**1**	**2**	**3**	**4**	**5**
3. I think someone can eat fatty foods all their life, and if they are not meant to get prostate cancer, they won't get it.	**1**	**2**	**3**	**4**	**5**
4. I think if someone is meant to get prostate cancer, they will get it no matter what they do.	**1**	**2**	**3**	**4**	**5**
5. I think if someone gets prostate cancer, it was meant to be.	**1**	**2**	**3**	**4**	**5**
6. I think if someone gets prostate cancer, their time to die is soon.	**1**	**2**	**3**	**4**	**5**
7. I think if someone gets prostate cancer, that's the way they were meant to die.	**1**	**2**	**3**	**4**	**5**
8. I think getting checked for prostate cancer makes people scared that they may really have prostate cancer.	**1**	**2**	**3**	**4**	**5**
9. I think if someone is meant to have prostate cancer, they will have prostate cancer.	**1**	**2**	**3**	**4**	**5**
10. I think some people don't want to know if they have prostate cancer because they don't want to know they may be dying from it.	**1**	**2**	**3**	**4**	**5**

11. I think if someone gets prostate cancer, it doesn't matter whether they find it early or late, they will still die from it.	**1**	**2**	**3**	**4**	**5**
12. I think if someone has prostate cancer and gets treatment for it, they will probably still die from the prostate cancer.	**1**	**2**	**3**	**4**	**5**
13. I think if someone was meant to have prostate cancer, it doesn't matter what doctors and nurses tell them to do, they will get prostate cancer anyway.	**1**	**2**	**3**	**4**	**5**
14. I think if someone is meant to have prostate cancer, it doesn't matter if they eat healthy foods, they will still get prostate cancer.	**1**	**2**	**3**	**4**	**5**
15. I think prostate cancer will kill you no matter when it is found and how it is treated.	**1**	**2**	**3**	**4**	**5**

Appendix F

PROSTATE CANCER KNOWLEDGE

Please indicate whether the statements below are true, false, or if you do not know the answer.

1 = True
2 = False
3 = Don't know

1. Prostate cancer is the most common cancer, excluding cancer, in men living in the U.S.	**1**	**2**	**3**
2. White men are more likely to have prostate cancer than are African-American men.	**1**	**2**	**3**
3. Prostate cancer is the eighth leading cause of cancer death in U.S. men	**1**	**2**	**3**
4. One in six men will be diagnosed with prostate cancer	**1**	**2**	**3**
5. African-American men are twice as likely to die of prostate cancer compared to white Men.	**1**	**2**	**3**
6. Prostate cancer is more common in Asia than in North America or Europe.	**1**	**2**	**3**
7. The prostate gland produces sperm.	**1**	**2**	**3**
8. In healthy men, the normal range for Prostate-specific antigen (PSA) is 0.0 to 4.0.	**1**	**2**	**3**
9. A Gleason score indicates how large a prostate cancer tumor is.	**1**	**2**	**3**
10. "Watchful waiting" refers to waiting for the lab to send your PSA results.	**1**	**2**	**3**
11. More than 70% of all prostate cancers are diagnosed in men over the age of 65.	**1**	**2**	**3**
12. After prostate cancer treatment, men are unable to have a sexual orgasm (climax).	**1**	**2**	**3**
13. Having a father or brother with prostate cancer doubles a man's risk of developing prostate cancer.	**1**	**2**	**3**

14. African American men should begin screening for prostate cancer at age 65.	**1**	**2**	**3**
15. Your PSA level can only be taken from a sample of blood.	**1**	**2**	**3**
16. Men who have a history of a prostate infection are more likely to develop prostate cancer than men who have never had an infection.	**1**	**2**	**3**
17. It is possible to have prostate cancer even if a man does not have any symptoms.	**1**	**2**	**3**
18. Prostate cancer is more common in 50-year-old men than in 70-year-old men.	**1**	**2**	**3**
19. Radiation treatment for prostate cancer causes a man's head hair to fall out.	**1**	**2**	**3**
20. Doctors are sure that screening will prevent men from dying of prostate cancer.	**1**	**2**	**3**
21. If a man weighs 180 pounds about 30% percent of his food calories should be from fat.	**1**	**2**	**3**
22. Rectal examination and a PSA test is the best method for detecting prostate cancer.	**1**	**2**	**3**
23. For a man with early stage prostate cancer, watchful waiting may be equal to surgery or radiation treatment.	**1**	**2**	**3**
24. Compared to prostate cancers detected without screening, the prostate cancers detected by screening are more likely to be curable.	**1**	**2**	**3**
25. Normal erections may return in some men with prostate cancer who undergo surgery to remove the prostate.	**1**	**2**	**3**
26. Eating red meat is more likely to increase a man's risk of developing prostate cancer than eating chicken.	**1**	**2**	**3**
27. Eating tomatoes may help prevent the development of prostate cancer.	**1**	**2**	**3**

Appendix G

PROSTATE CANCER KNOWLEDGE SCALE

By: Kilbridge et al. (2009)

1. Men who have a history of a prostate infection are more likely to develop prostate cancer than men who have never had an infection?
    1. True
    2. False*
    3. I do not know

2. It is possible to have prostate cancer even if a man does not have any symptoms?
    1. True*
    2. False
    3. I do not know

3. Prostate cancer is more common in 50-year-old men than in 70-year-old men?
    1. True
    2. False*
    3. I do not know

4. Radiation treatment for prostate cancer causes a man's head hair to fall out?
    1. True
    2. False*
    3. I do not know

5. Will screening prevent men from dying of prostate cancer?
    1. At this time, doctors are unsure*
    2. Definitely yes
    3. Definitely no
    4. I do not know

6. If a man weighs 180 pounds, what percentage of his food calories should be from fat?
    1. 10%
    2. 20%
    3. 30%*
    4. 40%
    5. I do not know

7. Which is the best method for detecting prostate cancer?
    1. A rectal examination
    2. A rectal examination and a prostate ultrasound
    3. A rectal examination and a PSA*

4. A PSA and a prostate ultrasound
5. I do not know

8. Which of the following statements is correct for a man with early stage prostate cancer?

1. Watchful waiting may be equal to surgery or radiation treatment*
2. Surgery or radiation treatment cures very few patients
3. Surgery or radiation treatment cures all patients
4. Surgery causes cancer cells to spread
5. I do not know

9. Compared to prostate cancers detected without screening, the prostate cancers detected by screening are:

1. More likely to be curable*
2. Less likely to be curable
3. Just as likely to be curable
4. I do not know

10. Which of the following statements is correct for a man with prostate cancer who undergoes surgery to remove the prostate?

1. Impotence occurs in all patients
2. Permanent incontinence always occurs
3.Normal erections may return in some men*
4. Additional treatment is never needed
5. I do not know

11. Eating which of the following foods is most likely to increase a man's risk of developing prostate cancer?

1. Red meat*
2. Peanuts
3. Chicken
4. Olive oil
5. I do not know

12. Eating which of the following foods is most likely to help prevent the development of prostate cancer?

1. Broccoli
2. Oranges
3. Tomatoes*
4. Carrots
5. Cauliflower
6. I do not know

KEY: PSA _ prostate-specific antigen (test).
** Correct answer.*