IMPACT OF RECURRENCE ON PROSTATE CANCER SURVIVORS

by

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Abstract

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The present study examined the impact of recurrence on health-related and prostate-specific quality of life, post-traumatic stress disorder symptoms, physiological arousal to stress, and psychological distress by comparing disease-free survivors (N = 46) to survivors who experienced recurrence (N = 18), and healthy controls (N = 18). Participants completed paper and pencil questionnaires and submitted blood samples. Groups did not report differences in health-related quality of life, sexual and urinary function, problems with urinary function, perceived stress, psychological distress, epinephrine levels and post-traumatic stress disorder symptoms. Survivors who experienced recurrence reported less bowel function than disease-free survivors. However, survivors who experienced recurrence reported fewer problems with bowel function than disease-free survivors. Survivors who experienced recurrence reported more problems with sexual function than disease-free survivors. Additionally, diseasefree survivors reported fewer problems than healthy controls. Finally, norepinephrine levels were higher for disease-free survivors than for survivors who experienced recurrence. The current study furthered existing research examining the psychological impact of recurrence. Future directions should focus on potential differences in coping styles among the three groups and examine the effect of post-traumatic growth in survivors of prostate cancer.

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Chapter 1

Prostate Cancer

The single most common cancer among men in the United States, aside from non-melanoma skin cancer, is prostate cancer. In 2008 alone, a total of 214,633 men in the United States were diagnosed with prostate cancer, and of that number, 28,471 men died (U.S. Cancer Statistics Working Group, 2012). Survival of prostate cancer is nearly 100% for men in earlier stages. However, the survival rate drops to 29% when the cancer has spread to distant lymph nodes, bones, or other organs (American Cancer Society, 2012a). On the other hand, the relative survival rate, or the survival rate that factors in that some people will die from other causes, is nearly 100% for five years, 98% for 10 years, and 91% for 15 years. These numbers indicate that a large population of prostate cancer survivors exists.

Early prostate cancer patients usually do not report any symptoms of the disease. Therefore, early prostate cancer is usually identified by a prostate-specific antigen (PSA) blood test or a digital rectal exam (DRE). If the PSA and DRE come back positive, a diagnosis of prostate cancer is usually made with a prostate biopsy in which a small amount of tissue is examined under a microscope. The more the disease progresses, the more symptoms begin to present (American Cancer Society, 2012b). A slow or weakened urinary stream, and/or a need to frequently urinate, are often the first symptoms to appear. In later stages of the disease, symptoms may include hematuria (blood in urine) or impotence. Additionally, patients may experience pain in the hips, back (spine), or other skeletal areas. This is often due to the cancer spreading. Additional side effects such as weakness or numbness in the legs or feet, and loss of bladder or bowel control are known to occur once the cancer has spread to the spine and has begun to press on the spinal nerves (American Cancer Society, 2012b).

Several treatment options for prostate cancer exist. They include surgery, radiation therapy, chemotherapy, hormone therapy and watchful waiting. Surgery (radical prostatectomy) is performed to remove the prostate and all of its surrounding tissue, and radiation therapy uses radiation to destroy or prevent further growth of the cancer cells (Center for Disease Control, 2012). There are two types of radiation therapy: external and internal (brachytherapy). External radiation therapy utilizes a machine outside of the body to deliver radiation, whereas internal radiation therapy utilizes surgically inserted pellets to deliver the radiation. Chemotherapy uses drugs that are injected into the vein or mouth to combat the cancer, while hormone therapy utilizes drugs, surgery or hormones to remove or block sex hormones in order to stop the cancer from spreading. Finally, watchful waiting consists of only monitoring the patients' status with the use of PSA or DRE tests (Center for Disease Control, 2012). Treatment often includes surgery or radiation therapy, for early stage prostate cancer, monitoring the cancer if you are older, and hormone therapy, or chemotherapy if the cancer has spread. After treatment for prostate cancer has concluded, patients are closely monitored by their doctors with routine tests such as a PSA blood test or a DRE to monitor recurrences of the disease. Despite the effectiveness of prostate cancer treatment, surviving cancer does not free the patient of psychological burden. After the conclusion of primary treatment, many survivors report fears of recurrence (Smith & Lesko, 1988).

Introduction

Prostate cancer is the most common form of cancer found in men (U.S. Cancer Statistics Working Group, 2012). Although common among men, due to the recognized effectiveness of various treatments for prostate cancer, survival rates for the disease are nearly 100% (American Cancer Society, 2012a). However, treatments for prostate cancer can be stressful and treatment side effects such as urinary, sexual, and bowel

dysfunction can dramatically alter quality of life and increase distress in this population. Unfortunately, a large number of cancer survivors will develop a recurrence of the disease (Uchio, Aslan, Wells, Calderone, & Concato, 2010). The experience of a recurrence carries additional subsequent treatment, worries concerning the future, and fatigue. These burdens are exacerbated by the continuous monitoring they must undergo by healthcare professionals, and therefore patients can never place their cancer episode into the past (Mahon, Cella, & Donovan, 1990).

Studies that have analyzed cancer survivors have not emphasized the differences that may lie between survivors who have not experienced a recurrence, survivors who have experienced a recurrence, and the healthy population. Research has centered on the differences between cancer survivors who have not experienced a recurrence and the healthy population, and have yet to place emphasis on survivors who have endured a recurrence. Suffering a recurrence might make the experience seem like a "current" threat to patients rather than one that occurred in the past, and may carry with it heavy psychological burden such as post-traumatic stress disorder symptoms and increased distress. Therefore, the current study compared three groups of participants: survivors who have experienced a recurrence, survivors without any recurrences, and healthy participants who had no prior history of cancer. The study aimed to analyze the psychological effect of not only surviving cancer, but the added burden of experiencing recurrences and the effect this had on patient health-related and prostate-specific quality of life, physiological arousal to stress, general distress, and post-traumatic stress disorder symptoms (i.e. avoidant/intrusive thoughts).

Recurrence in cancer

Cancer recurrence in prostate cancer survivors occurs in thirty to forty percent of prostate cancer survivors (rates vary based on treatment type, stage of initial disease,

etc.). The 15-year survival rate of prostate cancer survivors who have not experienced a recurrence is nearly 100%. However, the prostate cancer survival rate of prostate cancer survivors who experienced a recurrence range from twenty-one to forty-two percent (Uchio, Aslan, Wells, Calderone, & Concato, 2010). Despite the gravity of the above statistics, prostate cancer survivors who experienced a recurrence are understudied. Little emphasis has been placed on the psychological effects of cancer recurrence. Surviving cancer is a stressful ordeal in and of itself, and only compounded by having to undergo the process more than once. Previous research has focused upon the psychological effects of surviving cancer, and as such, numerous interventions have been conducted in cancer survivors without recurrences. However, very few studies have examined survivors who experienced recurrence, let alone developed interventions to help this population. Due to the additional unique life events experienced by cancer survivors who experienced recurrence, survivors may experience additional or increased psychological burden when compared to disease-free cancer survivors or healthy populations. By identifying the unique psychological effects that recurrence may have, future interventions may be better equipped to target this population in order to improve patient quality of life, psychological distress, aversive symptoms due to post-traumatic stress disorder, as well as improve coping behaviors. It is important to note that very little research has focused on the psychological effects of recurrence in cancer. This warrants future research in order to better understand the psychological role that recurrence plays on prostate cancer survivors. The current study sought to enhance the paucity of research.

Cancer Survivors and Psychological Concerns of Survivorship

Researchers have often labeled the experience of cancer survivorship as the
"Damocles syndrome". According to the story, Damocles was invited to the king's

banquet for dinner. Naturally, he was very excited to be sitting at his table. However, he quickly noticed that there was a sword, suspended by just one horse hair above his head. If he made any movement toward the food, he risked knocking the sword loose. As much as he wanted to enjoy the feast, he kept worrying about the suspended sword. Cancer survivors might not be so different: after being given a "second chance" at life, many concerns such as impaired social functioning, fear of recurrence, and subsequent treatment, fear of the future, dependence on others, sexual, urinary, and bowel dysfunction, fear of death, trouble sleeping, fatigue, etc. are hanging by a "proverbial" horsehair above their head (Smith & Lesko, 1988).

Therefore, the "Damocles syndrome" may be present in the growing population of cancer survivors. Surviving an event such as cancer may carry significant psychological burden. In addition, patients who have not only survived a cancer experience, but have also experienced a recurrence may be placed under additional burden of constant fear or uneasiness that may be unique to this population. The following sections will examine the effects of survivorship on health-related quality of life, post-traumatic stress disorder, and psychological distress, as well as the psychological effects that recurrence plays on survivors.

Health-related quality of life

Prostate cancer patients may experience impaired health-related quality of life (HRQoL). As noted above, treatments for prostate cancer can cause profound side effects such as impairments to patients' sexual, urinary, and bowel functions (American Cancer Society, 2012b). Such side effects may, in turn, affect patient quality of life despite the severity of disease, with decrements being reported even in early stage patients (Penson, Litwin, & Aaronson 2003). Furthermore, these decrements have also

been reported in men in the watchful waiting groups, indicating that it is not only treatment that can cause these effects (Galbraith, Arechiga, Ramirez, & Pedro, 2005).

Quality of life impairments may persist for prostate cancer survivors as well.

Research examining survivors reported that prostate cancer and its subsequent treatment impaired prostate specific HRQoL, with some studies reporting effects up to eight years following the conclusion of treatment (Eton, & Lepore, 2002; Litwin et al., 1995; Potosky et al., 2004; Stanford et al., 2000; Shrader-Bogen, Kjellberg, McPherson, & Murray, 1997; Miller et al. 2005). Unlike survivors of other types of cancers, quality of life may decrease over time for prostate cancer survivors (Bloom, Petersen, & Kang, 2007; Shag, Ganz, Wing, Sim, & Lee, 1994). Additionally, single, African American and younger men report worse health-related quality of life (Bloom, Petersen, & Kang, 2007).

It is important to note that the previously mentioned studies did not compare prostate cancer survivors with survivors who had experienced recurrences. They only compared survivors against healthy controls. Research comparing differences between the psychological effects of survivorship and cancer recurrence on HRQoL is therefore lacking. Cancer recurrence may have a psychological effect on HRQoL unlike that of disease-free survivorship. The additional burden of cancer recurrence may worsen HRQoL through increased psychological distress, or post-traumatic stress disorder symptoms such as avoidant or intrusive thoughts.

Post-traumatic stress disorder

Prostate cancer survivors may experience symptoms of post-traumatic stress disorder after the completion of primary treatment. Post-traumatic stress disorder is a disorder that usually occurs after an atypical stressful event. It can be diagnosed if a person has experienced an event or events that involve actual or witnessed threatening of death or serious injury with the person reacting in either fear, helplessness, or horror.

A person can continuously re-experience the event by either having recurrent/intrusive recollections of the event, emotional numbing to the event, distress occurring upon reminder of the event with either internal or external cues, a physiological hyper-arousal response to the internal/external cues, and intentionally avoid thoughts, feelings, conversations, recollections, activities, people and/or places attached to the event. They may also have a difficult time trying to fall or stay asleep, experience bursts of anger or difficulty concentrating, among other symptoms (DSM-IV-TR; American Psychological Association, 2000). Each of these symptoms cause major distress.

A potential explanation as to how the disorder and its symptoms may develop in cancer survivors, especially those who have experienced a recurrence, has been proposed. According to Ehlers and Clark's (2000) cognitive model of post-traumatic stress disorder; the disorder may develop when individuals process previous trauma (i.e. cancer) as an immediate threat, or as likely to occur again (i.e. recurrence of cancer). This sense of threat may occur due to negative appraisals of the trauma (i.e. cancer and treatment) and a disturbance of autobiographical memory. Specifically, stress related to cancer may begin with the diagnosis of the disease and continue through aversive treatment followed by body dysfunctions, treatment side effects and even disruptions with social and occupational functioning (negative appraisals of the trauma). This creates a challenge to cancer survivors to identify the exact stressor (impairment of autobiographical memory) that may precipitate post-traumatic stress disorder symptoms, or the disorder itself. Improper coping strategies later prevent any change in the negative appraisals of the trauma. The authors believe that those who have experienced a recurrence may feel that the threat of cancer is not time-limited and therefore an immediate threat. In sum, cancer survivors may be more likely to develop post-traumatic

stress disorder, because the traumatic experiences they endured created a fear that the cancer may return and may be more likely to view cancer recurrence as a current threat.

Other explanations as to why post-traumatic stress disorder or its symptoms may develop in cancer survivors have been offered. Past research has found that post-traumatic stress disorder symptoms have been linked to less intense but persistent events, rather than more intense acute events (Davidson & Baum, 1986). Cancer is a chronic disease which consists of prolonged, multiple, repeated stressful events, not of acute events. Also, the fear of cancer recurrence is a traumatic life event of an internal nature, unlike that of a traumatic event of an external nature. Cancer may be perceived as an inescapable event with certain physical limitations and continuous doctor's visits serving as reminders that the experience may not be over. Studies have shown that post-traumatic stress disorder symptoms may occur for up to one year after the end of treatment; however, the long-term persistence of the disorder or its symptoms over longer time frames have not been thoroughly studied (Deimling, Kahana, Bowman, & Schaefer, 2002). In all, because cancer is such a complex disease, it may place certain populations more at risk for developing post-traumatic stress disorder or its symptoms.

Avoidant and intrusive thoughts are common in cancer populations. Studies have found that approximately 10% of disease-free cancer survivors, including prostate cancer survivors, meet the diagnostic criteria for post-traumatic stress disorder and up to 48% reported symptoms (i.e. avoidant and intrusive thoughts; Alter, Axelrod, Harris, & Grobois, 1996; Holland, & Reznick, 2005; Kangas, Henry, & Bryant, 2002; Mehnert, Lehmann, Graefen, Huland, & Koch, 2009; Black, & White, 2005). Additionally, disease-free cancer survivors reported experiencing other symptoms such as a concern of the illness returning (68.1%), disease recurrence (59.8%), fears regarding the future (57.7%) and sleep difficulties (47.9%; Baker, Denniston, Smith, & West, 2005).

The aforementioned studies only examined disease-free cancer survivors. Although literature is sparse, some research exists examining survivors with recurrence such as Mahon, Cella, and Donovan (1990). The authors found that thoughts of recurrence were reported by eighty five percent of the patients (intrusion symptoms of PTSD). Eighty-two and a half percent of patients reported not wishing to discuss the recurrence (avoidance symptoms of PTSD). Patients also reported impaired social functioning. These thoughts may lead to increased psychological distress.

Psychological Distress

Prostate cancer survivors may experience increased psychological distress.

Psychological distress is the feeling of increased stress, anxiety and depression often in response to a severe stressor such as a medical illness. Prostate cancer survivors endure chronic stressors associated with diagnosis, treatment and consequent side effects, as well as future worries concerning surveillance for recurrence (Stark, & House, 2000). For example, disease-free survivors with high levels of urinary incontinence report higher levels of distress (Dalkin, Wessells, & Cui, 2003). Further, continued testing and monitoring during the survivorship period increases distress (Burish, & Tope, 1992; Glanz & Lerman, 1992). Cancer survivors are more likely to express cancer-related health worries (Benyamini, McClain, Leventhal, & Leventhal, 2003). African American and younger men report more psychological distress due to prostate cancer (Bloom, Petersen, & Kang, 2007). Due to these stressors, prostate cancer survivors experience increased psychological distress as a result of their cancer.

Deimling, Bowman, Sterns, Wagner, and Kahana (2006) developed a model to illustrate how psychological distress (i.e. anxiety and depression) can occur in long-term (5+ years) cancer survivors. According to the model, primary stressors such as personal characteristics (i.e. race), as well as cancer and treatment characteristics (i.e. cancer

type, symptoms during treatment) along with secondary stressors such as current health (i.e. functional difficulties) all influence cancer-related health worries as survivors often interpret inconsequential symptoms as alarming, because they view them as signs of possible recurrence (Holland, & Reznick, 2005). These in turn may translate into psychological distress. To test this model, the role of cancer-related health worries on anxiety and depression in long-term survivors (5+ years) of breast, prostate and colorectal cancer was examined. They found that 39% of prostate cancer patients had worries about the cancer coming back. Thirty-eight percent worried that the symptoms that they experienced indicated a recurrence of cancer. Thirty-six percent worried about developing another type of cancer or of future diagnostic tests. They further found that these rates were similar among all cancers examined. Most interestingly, they found that these cancer-related health worries were a strong predictor of distress.

Distress over fears related to prostate cancer may not subside after the initial treatment as research indicates that prostate cancer-related fears persist two years after the completion of treatment (Mehta, Beck, Pasta, & Litwin, 2003). Worries over fear of recurrence, fear of the future, fear of death, impaired social functioning, trouble sleeping, and the effects of post-treatment symptoms are not just limited to disease-free cancer survivors. Survivors who experienced a recurrence reported increased distress over such worries (Mahon, Cella, & Donovan 1990). Psychological distress for those survivors who experienced recurrence may be higher than for survivors who did not experience such an event. Burgess, Cornelius, Love, Graham, Richards, and Ramirez (2005) followed breast cancer patients for up to five years following their initial diagnosis and found that for patients who experienced recurrence, distress was more prevalent at recurrence than at initial diagnosis.

Purpose and Hypotheses of Current Study

Past research had not focused on the impact of cancer recurrence on prostate cancer patients. With such a large population of survivors, it was essential to analyze whether survivors who have experienced a recurrence exhibited more psychological burden than survivors who never experienced recurrence.

The current study aimed to examine the psychological impact of recurrence on health-related quality of life, physiological arousal to stress, post-traumatic stress disorder symptoms, and psychological distress among samples of prostate cancer survivors who had experienced a recurrence, disease-free survivors and healthy control participants. Specifically, it was hypothesized that:

H₁: Patients in the recurrent group would report lower levels of health-related quality of life (physical and mental health) than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report lower levels of health-related quality of life (physical and mental health) than the healthy controls.

H₂: Patients in the recurrent group would report lower levels of urinary, sexual, and bowel function than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report lower levels of urinary, sexual, and bowel function than the healthy controls.

H₃: Patients in the recurrent group would report more problems with their urinary, sexual, and bowel functions than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report higher levels of bother with their urinary, sexual, and bowel functions than the healthy controls.

H₄: Patients in the recurrent group would report higher levels of general distress (perceived stress and psychological distress) than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report higher levels of general distress (perceived stress and psychological distress) than the healthy controls.

H₅: Patients in the recurrent group would report higher levels of intrusive and avoidant symptoms of post-traumatic stress disorder than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report higher levels of intrusive and avoidant symptoms of post- traumatic stress disorder than the healthy controls.

H₆: Patients in the recurrent group would report higher platelet catecholamine levels than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report higher platelet catecholamine levels than the healthy controls.

Chapter 2

Methods

Participants

Participants were 82 (76 = European American, 6 = African American) men divided into three groups: recurrent, non-recurrent, and the healthy patient control group. Patients in the recurrent group (N = 18) had experienced recurrence in their disease within the past year or were currently undergoing treatment for their recurrence, while patients in the non-recurrent group (N = 46) had no disease-related events. Patients in the healthy patient control group (N = 18) consisted of healthy patients with no prior diagnosis of cancer. Patients in the recurrent and non-recurrent groups were treated for prostate cancer at the University of Pittsburgh Cancer Institute (UPCI) between 1990 and 1993 who survived five to ten years past treatment for localized prostate cancer.

Demographic and medical variables of the three groups can be found in Table 2-1.

Subsequent chi- square and analysis of variance tests did not reveal any statistically significant demographic differences between the three groups. Time since initial diagnosis and PSA level at initial diagnosis were significantly different among groups.

Table 2.1 Demographic and Medical Variables for Recurrent, Non-Recurrent, and Healthy Control Groups

Variable	Recurrent	Non-recurrent	Healthy Control	F/ χ2	Significance
	(N = 18)	(N=46)	(N = 18)	value	
Age, M (SD)	72.5	68.96	66.72	2.68	.07
Education, N (%)					
Less than high school	2 (11.1%)	6 (13%)	1 (5.6%)		
High school graduate	3 (16.7%)	12 (26.1%)	2 (11.1%)	5.68	.68
Some college	3 (16.7%)	9 (19.6%)	5 (27.8%)		
College graduate	3 (16.7%)	15 (10.9%)	5 (27.8%)		
Post-graduate training	7 (38.9%)	13 (28.3%)	5 (27.8%)		
Employment, N (%)					
Full-time	3 (16.7%)	9 (19.68%)	5 (27.8%)		
Part-time	0 (0%)	4 (8.7%)	0 (0%)	4.25	.64
Retired	12 (66.7%)	30 (65.2 %)	12 (66.7%)		
Not employed	1 (5.6%)	1 (2.2%)	1(5.6%)		
Religion, N (%)					
Protestant	8 (44.4%)	16 (34.8)	7 (38.9%)		
Catholic	9 (50%)	23 (50%)	4 (22.2%)	14.71	.06
Jewish	0 (0%)	2 (4.3%)	3 (16.7%)		
Atheist/Agnostic	0 (0%)	0 (0%)	2 (11.1%)		
Other	1 (5.6%)	4 (8.7%)	2 (11.1%)		
Race, N (%)					
European American	16 (88.9%)	44 (95.7%)	16 (88.9%)	1.36	.51
African American	2 (11.1%)	2 (4.3%)	2 (11.1%)		

Table 2.1 - Continued

Variable	Recurrent	Non-recurrent	Healthy Control	F/ χ2	Significance
	(N = 18)	(N=46)	(N = 18)	value	
Children, N (%)	15 (83.3%)	43 (93.5%)	17 (94.4%)	1.96	.37
Marital Status, N (%)					
Married	14 (77.8%)	38 (82.6%)	14 (77.8%)		
Widowed	2 (11.1%)	5 (10.9%)	2 (11.1%)	6.33	.61
Divorced	1 (5.6%)	2 (4.3%)	0 (0%)		
Single (never married)	1 (5.6%)	1 (2.2%)	2 (11.1%)		
Time Since Initial Diagnosis	8.27 years	6.21 years	Not Applicable	40.00	<.001
	(SD = 1.43)	(SD = .93)			
PSA Level at Initial Diagnosis	21.29	10.35	Not Applicable	10.24	.002
	(SD = 15.34)	(SD = 8.99)			
Gleason Scores at Original Diagnosis	5.09	4.89	Not Applicable	.11	.742
	(SD = 1.70)	(SD = 1.74)			
Stage at Original Diagnosis					
T1	0 (0%)	3 (6.5%)	Not Applicable	1.01	.314
T2	11 (61.1%)	28 (60.86%)	Not Applicable		
Т3	4 (22.2%)	7 (15.21%)	Not Applicable		
Treatment Type					
Surgery	17 (94.4%)	45 (97.8%)	0 (0%)	.47	.49
Radiation Therapy	2(11.1%)	2 (4.3%)	0 (0%)	.99	.32
Chemotherapy	0 (0%)	0 (0%)	0 (0%)		
Hormone Therapy	2(11.1%)	4 (8.7%)	0 (0%)	.08	.77
Watchful Waiting	0 (0%)	0 (0%)	0 (0%)		
Family History of Cancer	5 (27.8%)	10 (21.7%)	2 (11.1%)	.78	.46

Procedures

Data were collected between 1998 and 2001. Initial contact was made either by the medical staff from the University of Pittsburgh Cancer Institute Cancer Program or through the physicians who treated each patient. The first phone call made was to inform the cancer survivors that a study examining the quality of life among prostate cancer survivors was being conducted and whether they would be interested in receiving another call about participating in the study. When this initial phone call was made, they were assured that they were not obligated to participate in this study and that participation was voluntary. Then, if they agreed to the second phone call, potential participants were contacted by the project researchers.

Participants were seen in the Behavioral Medicine Laboratory of the University of Pittsburgh Cancer Institute (UPCI). Participants attended three separate appointments over a one year interval (six months apart). The initial appointment lasted approximately two hours. All subsequent sessions lasted 90 minutes. During the initial appointment, participants completed the informed consent and were explained the objectives of the study. Then participants completed the structured clinical interview for DSM IV (SCID; First, Spitzer, Gibbon, & Williams, 1995). For all three sessions, participants answered a series of paper and pencil questionnaires to measure assessments of health-related quality of life, event-related distress, and psychological distress. Participants also had a blood sample (30cc) taken upon arrival at the laboratory. Participants were paid \$25 per visit for participating in the study.

Measures

Demographics

Staging information, treatment technique, and risk factors such as age, family history of cancer, race, and other background information were gathered from medical records or were attained through participant response.

Event-related distress

The Impact of Events Scale (IES; Horowitz, Wilner, & Alvarez, 1979) was a measure of stress reactions in the past week after a traumatic event. It consisted of 15-items. Items were rated on a 4-point Likert scale (0 = not at all, 1 = rarely, 3 = sometimes, 5 = often). The IES assessed two responses to stressful events: intrusion (reexperiencing images of a stressor, incontrollable thought, ideas, images, feelings or bad dreams related to event) and avoidance (consciously recognized avoidance of certain ideas, feelings or situations). Seven items represented the intrusion subscale, while eight assessed avoidance. All items were also summed to compute a total IES score. Scores ranged from 0 to 75 with higher scores indicating more distress. The scale consisted of items such as "I thought about it when I didn't mean to" or "I tried to remove it from memory". Both the intrusion and avoidance scales had good reliability (α = .78 and α = .85, respectively). The scale can be found in Appendix A.

General Distress

General distress was measured using the Perceived Stress Scale (PSS; Cohen, Kamarak, & Mermelstein, 1983) and Baum symptom checklist. The PSS measured the degree to which situations in one's life were appraised as stressful in the past week. It consisted of 14 items. Items were rated on a five-point Likert scale with responses ranging from 0 (never) to 4 (very often). Scores ranged from 0 to 56 with higher sores

indicating more stress. The scale consisted of items such as "In the last week, how often have you felt that you were unable to control the important things in your life?" or "In the last week, how often have you found that you could not cope with all the things that you had to do?". The scale had good reliability (α = .84) and can be found in Appendix B.

The Baum symptom checklist was a measure of psychological distress in the past week. It consisted of 98 items rated on a 5-point Likert scale with higher scores indicating higher levels of psychological distress. Every item was rated on two scales: frequency of symptoms and how bothersome they were to the respondent. Examples of items included "feeling sad" or "feeling tense". The scale had good reliability (α = .96). The scale can be located in Appendix C.

Physiological arousal to stress

Blood samples were collected to measure platelet catecholamine levels. They were measured by high performance liquid chromatography. High performance liquid chromatography exposes the blood samples to high pressure in order to separate the catecholamines present. This amount was then compared to known standards. Platelet catecholamine levels have been used as sensitive and robust biological measurements of stress to measure of stress-related arousal over the past ten to twelve day period (Cohen, Kessler, & Gordon, 1997). The catecholamines epinephrine and norepinephrine were analyzed.

Quality of life

Prostate cancer specific health-related quality of life was measured using the UCLA Prostate Cancer Index (PCI; Litwin, Hays, & Fink, Ganz, Leake, & Brook, 1998). The scale measured six separate domains: urinary function, sexual bother, bowel function, problems with urinary function, problems with sexual function and problems with bowel function. It consisted of twenty items. The urinary, bowel and sexual function

scales measured incontinence, proctitis (inflammation that may cause discomfort, bleeding, or a discharge of mucus or pus) and sexual difficulties, respectively. On the other hand, the scales that assessed problems associated with urinary, sexual, and bowel function measured the level of trouble the patient had with the dysfunctions. Each scale was computed by summing the scores to responses with higher scores representing more favorable health. The score was then transformed to a 0-100 scale, with higher scores indicating more favorable health. The scale consisted of items such as, "How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks?" or "Over the past 4 weeks, how often have you leaked urine?" The scale had good reliability (α = .77). The scale can be located in Appendix D.

Health-related quality of life, not specific to prostate cancer, was measured using the Medical Outcome Study 36-Item Short Form Health Survey (SF-36; Ware, Snow, Kosinski, & Gandek, 1993). The SF-36 consisted of 36 items and assessed general medical illness quality of life in eight domains: physical functioning, physical impediments to role functioning, pain, general health perceptions, vitality, social functioning, and emotional impediments to role functioning and mental health. These were grouped into two summary component scores, physical and mental health, that were used in the analyses. Higher scores represented more favorable health. The scale consisted of such items such as, "During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health" or "During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?" The scales had good reliability (a's = .85 - .87). The scale can be located in Appendix E.

Chapter 3

Results

Prior to analyses, all variables were assessed for univariate outliers and proper distribution. The analyses were conducted using SPSS 21 Statistics software. A square transformation was performed to reduce negative skewness in problems with urinary function. A log function was performed in order to reduce positive skewness in problems with bowel function. Age, education, marital status, employment, religion, race, having children, cancer stage, initial treatment type (surgery, chemotherapy, radiation therapy, chemotherapy, hormone therapy, watchful waiting), time since initial diagnosis, PSA levels, and Gleason scores were considered as potential covariates. Although initially PSA levels and time since diagnosis differed amongst groups (see Table 2-1), they were not used as covariates in the analyses. This is because subsequent analyses of variance tests assessing the relationship between PSA levels/time since diagnosis and all of the dependent variables did not come out as significant. Additionally, prior literature has found that PSA levels and time since diagnosis are not good predictors of health-related and prostate-specific quality of life (Descazeaud, Zerbib, Hofer, Chaskaloic, Debre, & Peymaure, 2005). However, based on prior literature, age and whether patients initially received surgery were chosen as covariates to be used in all analyses. Prior literature has noted that younger men and men who received surgery as a primary treatment option reported poorer outcomes in psychological outcomes such as health-related quality of life (Bloom, Petersen, & Kang, 2007; Descazeaud, Zerbib, Hofer, Chaskaloic, Debre, & Peymaure, 2005).

First, attrition rates for each dependent variable at the three time points were examined (see Table 3-1). While attrition was low for a longitudinal study, there were concerns that the sample size was underpowered to examine a full factorial model.

However, all hypotheses were initially tested using a 3 (group) X 3 (time) repeated measures multivariate analysis of covariance, but none of the effects were significant. This may have been due to insufficient power. Given that the hypotheses of interest concerned main effects of group and no effects of time or group by time were expected. the decision was made to re-analyze all of the hypotheses using only data from the first assessment. The analyses presented here were multivariate analyses of covariance comparing the three groups while taking into account the two covariates. Dependent variables to be analyzed together were grouped based on similarity as per recommendations by Tabachnick and Fidell (2007). Therefore, the first hypothesis was tested using a multivariate analysis of covariance with the dependent variables physical and mental health-related quality of life. The second hypothesis was tested using a multivariate analysis of covariance with the dependent variables of urinary, bowel, and sexual function. The third hypothesis was tested using a multivariate analysis of covariance with the dependent variables problems with urinary, bowel, and sexual function. The fourth and fifth hypotheses were tested using a multivariate analysis of covariance with the dependent variables perceived stress, psychological distress, and avoidant and intrusive symptoms of post-traumatic stress disorder. The sixth hypothesis was tested using a multivariate analysis of covariance with the dependent variables epinephrine and norepinephrine. In order to account for unequal group sizes, bootstrapping was used to test all hypotheses. Bonferroni corrections were used to adjust for Type I error.

Table 3.1 Attrition Rates of Participants for Three Time Points

Variable	Time 1 N (%)	Time 2 N (%)	Time 3 N (%)	Total Attrition for All 3 Time Points N (%)
Health-Related				
Ouality of Life SF-36-physical component	82 (100%)	82 (100%)	78 (95.1%)	78 (95.1%)
SF-36-mental component	82 (100%)	82 (100%)	78 (95.1%)	
Prostate-Specific				
Quality of Life				
Urinary Function	82 (100%)	78 (95.1%)	77 (93.9%)	
Bowel Function	82 (100%)	79 (96.3%)	77 (93.9%)	67 (81.7%)
Sexual Function	77 (93.9%)	76 (92.6%)	75 (91.4%)	
Problems With	82 (100%)	78 (95.1%)	78 (95.1%)	
Urinary Function		, ,	, , ,	
Problems With	80 (97.5%)	78 (95.1%)	76 (92.6%)	64 (78%)
Bowel Function				
Problems with Sexual	74 (90.2%)	73 (89%)	73 (89%)	
Function				

Table 3.1 - Continued

Variable	Time 1 N (%)	Time 2 N (%)	Time 3 N (%)	Total Attrition for All 3 Time Points N (%)
General and Event- Related Distress				
Perceived Stress	78 (95.1%)	79 (96.3%)	75 (91.4%)	
Psychological Distress	81 (98.7%)	79 (96.3%)	79 (96.3%)	59 (70 79/)
Avoidant Symptoms of Post-Traumatic Stress Disorder	75 (91.4%)	77 (93.9%)	75 (91.4%)	- 58 (70.7%)
Intrusion Symptoms of Post-Traumatic Stress Disorder	79 (96.3%)	79 (96.3%)	77 (93.9%)	
Physiological				
Arousal to Stress				
Norepinephrine	53 (64.6%)	56 (68.2%)	59 (71.9%)	34 (41.4%)
Epinephrine	53 (64.6%)	56 (68.2%)	59 (71.9%)	

Quality of Life

A multivariate analysis of covariance was conducted to test the first hypothesis, which stated that patients in the recurrent group would report lower levels of health-related quality of life (physical and mental health) than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report lower levels of health-related quality of life (physical and mental health) than the healthy controls. A multivariate main effect of group was not found, F_{mult} (4, 154) = .583, p = .681, partial η^2 = .02. Group differences were not reported in mental and physical health-related quality of life.

A multivariate analysis of covariance was conducted to test the second hypothesis, which stated that patients in the recurrent group would report lower levels of urinary, sexual, and bowel function than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report lower levels of urinary, sexual, and bowel function than the healthy controls. A multivariate main effect of group was found, F_{mult} (6, 140) = 2.95, p = .010, partial η^2 = .11. Participants did not report differences in sexual and urinary function, F (2, 77) = 1.01, p = .371, partial η^2 = .03; F (2, 77) = .25, p = .780, partial η^2 = .07, respectively. However, participants reported differences in bowel function, F (2, 77) = 7.96, p = .001, partial η^2 = .18. Post-hoc analyses revealed that the recurrent group (M = 83.62, SE = 3.01) reported less bowel function than the non-recurrent group (M = 95.13, SE = 2.36). Differences were not observed between the non-recurrent and healthy control groups (M = 82.93, SE = 6.15) and between the recurrent and the healthy control groups.

A multivariate analysis of covariance was conducted to test the third hypothesis, which stated that patients in the recurrent group would report more problems with their urinary, sexual, and bowel functions than the patients in the non-recurrent group.

Additionally, patients in the non-recurrent group would report more problems with their urinary, sexual, and bowel functions than the healthy controls. A multivariate main effect of group was found, F_{mult} (6, 132) = 4.20, p = .001, partial η^2 = .16. Participants reported differences in problems associated with bowel function, F(2, 73) = 7.02, p = .002, partial η^2 = .17. Post-hoc analyses revealed that the recurrent group (M = 4.25, SE = .09) reported fewer problems with bowel function that the non-recurrent group (M = 4.57, SE = .07). No group differences were observed between the non-recurrent and the healthy control groups (M = 4.36, SE = .17) and between the recurrent and healthy control groups. Participants also reported differences in problems associated with sexual function, F(2, 73) = 6.14, p = .004, partial $n^2 = .15$. Post-hoc analyses revealed that the recurrent group (M = 60.85, SE = 11.16) reported more problems with sexual function than the non-recurrent group (M = 30.77, SE = 8.89). The non-recurrent group reported fewer problems than the healthy control group (M = 102.57, SE = 21.81). Differences were not observed between the recurrent and healthy control groups. Participants did not report differences in problems associated with urinary function, F(2, 73) = .00, p =.999, partial $n^2 = .00$.

General Distress and Post-Traumatic Stress Disorder Symptoms

A multivariate analysis of covariance was conducted to test the fourth and fifth hypotheses. The fourth hypothesis stated that patients in the recurrent group would report higher levels of general distress (perceived stress and psychological distress) than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report higher levels of general distress (perceived stress and psychological distress) than the healthy controls. The fifth hypothesis stated that patients in the recurrent group would report higher levels of intrusive and avoidant symptoms of post-traumatic stress disorder than the patients in the non-recurrent group. Additionally,

patients in the non-recurrent group would report higher levels of intrusive and avoidance symptoms of post- traumatic stress disorder than the healthy controls. A multivariate main effect of group was not found, F_{mult} (8, 124) = .73, p = .662, partial η^2 = .05. Groups did not differ in levels of perceived stress, psychological distress, and avoidant and intrusive symptoms of post-traumatic stress disorder.

Physiological Arousal to Stress

A multivariate analysis of covariance was conducted to test the sixth hypothesis, which stated that patients in the recurrent group would report higher platelet catecholamine levels (norepinephrine and epinephrine) than the patients in the non-recurrent group. Additionally, patients in the non-recurrent group would report higher platelet catecholamine levels (norepinephrine and epinephrine) than the healthy controls. A multivariate main effect of group was found, F_{mult} (4, 94) = 2.79, p = .031, partial η^2 = .11. A univariate analysis of covariance revealed group differences in norepinephrine levels, F (2, 53) = 9.30, p = .030, partial η^2 = .14. Subsequent post-hoc analyses revealed that recurrent group (M = 2.89, SE = .53) observed lower norepinephrine levels than the non-recurrent group (M = 4.26, SE = .52). Group differences were not observed between the recurrent and the healthy control groups (M = 1.77, SE = 1.38) and between the non-recurrent and healthy control groups. A univariate analysis of covariance did not reveal group differences in epinephrine levels F (2, 53) = .02, p = .34, partial η^2 = .04. Groups did not differ in epinephrine levels.

Chapter 4

Discussion

The current study aimed to examine the psychological impact of recurrence on health-related quality of life, physiological arousal to stress, post-traumatic stress disorder symptoms, and psychological distress among samples of prostate cancer survivors who had experienced recurrence, disease-free survivors and healthy control participants. However, results did not support all of the hypotheses. Group differences were not observed in health-related quality of life, sexual and urinary function, problems with urinary function, perceived stress, psychological distress, post-traumatic stress disorder symptoms, and epinephrine levels. However, the recurrent group reported less bowel function as expected but, surprisingly, fewer problems with bowel function than did the non-recurrent group. There were no other group differences in frequency or problems associated with bowel function. As predicted, the recurrent group reported more problems with sexual function than did the non-recurrent group. However, the nonrecurrent group reported fewer problems than did the healthy controls. Differences in problems with sexual function between the recurrent group and the healthy controls were not observed. Finally, contrary to expectations, norepinephrine levels were higher for the non-recurrent than for the recurrent group. Group differences were not observed between the recurrent and healthy control and non-recurrent and healthy control.

The first hypothesis was not supported. Group differences in health-related quality of life were not observed. This is contrary to past research that indicated survivors of cancer reported poorer health-related quality of life (Bloom, Petersen, Kang, 2007). However, other studies have noted better quality of life in survivors of prostate cancer (Shag, Ganz, Wing, Sim, Lee, 1994). Perhaps group differences were not observed due to improved coping techniques employed by both of the survivor groups. However, given

that past research is mixed in regards to reported differences in health-related quality of life, future research is warranted to further investigate this construct and the factors that may affect it (i.e. coping).

Although past research indicated that survivors of cancer reported poorer prostate-specific quality of life, the second and third hypotheses were only partially supported (Bloom, Petersen, Kang, 2007). Specifically, although group differences were not observed in sexual and urinary function, group differences were observed in bowel function, as well as problems with sexual and bowel functions. These results indicate that urinary function and the problems reported with urinary function were not altered following survival of cancer, nor did the problems return after a recurrence had transpired. Bowel function was impaired more for the recurrent than the non-recurrent group, a potential complication due to the recurrence of cancer. However, bowel function did not differ between the recurrent and healthy control and the non-recurrent and healthy control groups. Despite the recurrent group reporting greater impairment in bowel function than the non-recurrent group, the recurrent group reported fewer problems associated with bowel function than the non-recurrent group. These findings may potentially be attributed to an increased focus on the recurrence and the treatment in the recurrent group rather than focusing specifically on the problems caused by bowel dysfunction. Patients in the non-recurrent group may have been more focused on symptoms of bowel dysfunction because of an increased fear of future health worries. However, despite group differences not being reported with sexual function, the recurrent group reported more problems with sexual function than the non-recurrent group. This finding is supported by previous literature which found that problems with sexual function initially decrease after treatment (Litwin, Melmed, & Nakazon, 2001). Given that the recurrent group was either undergoing treatment or had recently finished treatment, these

finding were expected. Contrary to expectation, the non-recurrent group reported fewer problems with sexual function than the healthy controls. Research has found that older men, with no prior history of prostate cancer, still report problems with sexual function, even though they do not report problems with urinary or bowel function (Litwin, 1999). The non-recurrent group might have scored lower because they were being compared to a group that already reported problems with sexual function.

The fourth hypothesis was not supported. Specifically, group differences in distress were not observed. This finding was contrary to past research which indicated that cancer survivors were more likely to express cancer-related health worries than participants from healthy populations (Benyamini, McClain, Leventhal, & Leventhal, 2003). In addition, Deimling, Bowman, Sterns, Wagner, and Kahana's (2006) model of distress predicted that those with prior history of cancer and those who had experienced cancer more recently (the recurrent group) were more likely to report increased distress. Perhaps group differences were not observed because of different coping techniques that both groups of survivors may have adapted in the past. Therefore, if cancer survivors (recurrent and non-recurrent) learned better coping techniques through their cancer experience, their distress levels may not differ from the healthy populations, which may not employ those techniques as effectively.

Although past research indicated that posttraumatic stress disorder systems were prevalent among cancer populations, including prostate cancer patients, the fifth hypothesis was not supported (Alter, Axelrod, Harris, & Grobois, 1996; Holland, & Reznick, 2005; Kangas, Henry, & Bryant, 2002; Mehnert, Lehmann, Graefen, Huland, & Koch, 2009; Black, & White, 2005). Specifically, group differences were not observed in post-traumatic stress disorder symptoms. This finding was contrary to what was expected because past research indicated that post-traumatic stress disorder develops in those

who are faced with a chronic rather than acute stress (Davidson & Baum, 1986). In addition, Ehler's and Clark's (2000) model of post-traumatic stress disorder indicated that patients who develop post-traumatic stress disorder do so because they do not view the cancer episode as a time-limited event. All of this would suggest that group differences would be observed between the three groups. Perhaps group differences were not observed because prostate cancer is a slowly progressing disease and therefore may not have affected patients to the degree that a more aggressive life-threatening disease would.

Norepinephrine levels are a good physiological indicator of stress (Trevino, Uhelski, Dougall, & Baum, 2012). Although group differences were not observed in levels of perceived stress, higher norepinephrine levels were reported in the non-recurrent than the recurrent groups leading to the assumption than the non-recurrent group had a higher physiological response to stress than the recurrent group. It was originally hypothesized that the recurrent group would report higher levels of norepinephrine due to the increased stress response of undergoing additional treatment for a recurrence (H₅). Patients' initial stress response when first informed of recurrence may have subsided and recurrent patients were more focused on survival than worrying about the future and other stressful events. Mahon, Cella and Donovan (1990) found impairments in social functioning and increased stress in their patients because these were patients who had been newly diagnosed with a recurrence and not those who were further along in the process. In contrast, the current study consisted of patients who were already undergoing treatment for their recurrence or had recently completed it.

It was previously hypothesized that group differences would be observed in epinephrine levels, as epinephrine is another physiological indicator of stress (H₅; (Trevino, Uhelski, Dougall, & Baum, 2012). During a stress response the body produces

various quantities of norepinephrine and epinephrine. However, norepinephrine is more prevalent in the blood stream than epinephrine (Trevino, Uhelski, Dougall, & Baum, 2012). Therefore, epinephrine levels may not have been detected as much as norepinephrine levels.

Taken together these findings suggest that patients with recurrent prostate cancer are not very different from disease-free survivors or healthy controls. Differences were primarily attributable to prostate-related physical complaints. However, it is important to caution that this study was limited by several factors. The study sample consisted of unequal group sizes. To correct for this limitation, bootstrapping was performed for all of the analyses. Additionally, the current study was not able to observe group differences over time possibly due to the study being underpowered. Future studies should recruit a greater sample size in order to increase power. Despite this limitation, the current study was able to observe the main effects. Also, patients in the recurrent and non-recurrent group were treated with surgery, radiation therapy and hormone therapy. No group members were treated using chemotherapy or were under watchful waiting conditions. Future studies should focus on recruiting patients who have undergone all treatment types. Patients in the recurrent group were either undergoing treatment for their recurrence or had recently completed treatment. The study might have yielded better results if the recurrent group had consisted of either patients currently undergoing treatment for recurrence or patients who had just completed their treatment. Another limitation of the current study was that ninety-two percent of participants were European American. Future studies should explore other races/ethnicities to identify and examine any disparities in the results. The final limitation identified in the study was the inability to compare scores to baseline scores at initial diagnosis/treatment. If data were collected prior to initial treatment, this may ensure that deviations are analyzed within the context of any impairment present at baseline. Furthermore, the collection of a larger sample size to account for attrition rates in order to monitor the longitudinal effects is warranted and would greatly benefit future studies.

It is important to note that the current study furthered existing research examining the psychological impact of recurrence. Past research examined the differences between recurrent patients and healthy controls or between survivors without recurrence and healthy controls. The current study was able to compare all three groups together and, therefore, was able to provide results that help to better differentiate the psychological impact between the one-time experience of cancer and the experience of recurrence. Future directions should focus on potential differences in coping styles among the three groups. It is possible that varying coping styles may have a differing psychological impact on cancer survivorship and recurrence. Therefore, differing coping styles may prove to be a better predictor of psychological outcomes than the number of times one has experienced cancer. Another potential factor that might impact psychological outcomes is the development of post-traumatic growth, or the development of positive psychological effects in response to a traumatic event, following a cancer episode. Post-traumatic growth was not measured in this study, but future research should focus on this area. It is possible that surviving cancer "empowers" rather than "breaks down" a survivor, enabling better psychological outcomes. Nevertheless, it is essential to further study this population and explore the psychological impact of recurrence on patients with prostate cancer. This research may lead to advances in treatment to not only improve quality of life but to enhance the lives of patients on a multitude of levels.

Appendix A

Impact of Events Scale

Below is a list of comments made by people after stressful life events. Please check each item, indicating how frequently these comments were true for you *DURING THE PAST SEVEN*DAYS. If they did not occur during that time, please mark the "not at all" column.

Not at All Rarely Sometimes Often

- 1. I thought about it when I didn't mean to.
- 2. I avoided letting myself get upset when I thought about

it or was reminded of it.

- 3. I tried to remove it from memory.
- I had trouble falling asleep or staying asleep,
 because of pictures or thoughts about it that came

into my mind.

- 5. I had waves of strong feelings about it.
- 6. I had dreams about it.
- 7. I stayed away from reminders of it.
- 8. I felt as if it hadn't happened or it wasn't real.
- 9. I tried not to talk about it.
- 10. Pictures about it popped into my mind.
- 11. Other things kept making me think about it.
- 12. I was aware that I still had a lot of feelings about
- it, but I didn't deal with them.
- 13.1 tried not to think about it.
- 14. Any reminder brought back feelings about it.
- 15. My feelings about it were kind of numb.

Appendix B

Perceived Stress Scale

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate. For each question choose from the following alternatives: 0. never 1. almost never 2. sometimes 3. fairly often 4. very often

- 1. In the last month, how often have you been upset because of something that happened unexpectedly?
- 2. In the last month, how often have you felt that you were unable to control the important things in your life?
 - 3. In the last month, how often have you felt nervous and "stressed"?
 - 4. In the last month, how often have you dealt successfully with irritating life hassles?
- 5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?
- 6. In the last month, how often have you felt confident about your ability to handle your personal problems?
 - 7. In the last month, how often have you felt that things were going your way?
- 8. In the last month, how often have you found that you could not cope with all the things that you had to do?
 - 9. In the last month, how often have you been able to control irritations in your life?
 - 10. In the last month, how often have you felt that you were on top of things?
- 11. In the last month, how often have you been angered because of things that happened that were outside of your control?
- 12. In the last month, how often have you found yourself thinking about things that you have to accomplish?

- 13. In the last month, how often have you been able to control the way you spend your time?
- 14. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?

Appendix C

Baum Symptom Checklist

Please indicate how often you experienced the following and the degree to which these experiences were bothersome in the past week. For each item please indicate how frequently you felt this way (1=not at all, 5=all the time) and then how bothersome or negative this experience was (1=not bothersome, 5=very bothersome) by placing a check mark () in the corresponding box.

		How often?	How bothersome?
		1 2 3 4 5	1 2 3 4 5
1.	Feeling sad	<u> </u>	<u> </u>
2.	Having headaches	<u> </u>	1 1 1 1 1 1
3.	Feeling tense	<u> </u>	<u> </u>
4.	Feeling like something bad is		
	about to happen	<u> </u>	<u> </u>
5.	Being very alert	<u> </u>	11111
6.	Having trouble getting things		
	done	<u> </u>	11111
7.	Not being able to concentrate	<u> </u>	11111
8.	Feeling irritable	<u> </u>	11111
9.	Being impatient	<u> </u>	<u> </u>
10.	Feeling nervous	<u> </u>	<u> </u>
11.	Worrying about something	<u> </u>	11111
12.	Always being on your guard	<u> </u>	11111
13.	Feeling like you have little		
	energy	<u> </u>	<u> </u>
14.	Not being able to "psych" yours	self	
	up	<u> </u>	<u> </u>

15.	Being easily distracted	1 1 1 1 1	<u> </u>
16.	Being aware of less of what is		
	going on around you	<u> </u>	11111
17.	Being easily angered	<u> </u>	11111
18.	Having back pain	<u> </u>	1 1 1 1 1
19.	Having stomach, GI pain	<u> </u>	1 1 1 1 1
20.	Having trouble sleeping	<u> </u>	1 1 1 1 1
21.	Having to watch out for trouble	e	
	or danger	<u> </u>	1 1 1 1 1
22.	Feeling "bad vibes"	<u> </u>	11111
23.	Feeling lazy or slow	<u> </u>	1 1 1 1 1
24.	Angered by minor irritants	<u> </u>	11111
25.	Waking up at night	<u> </u>	11111
26.	Ignoring a lot of what is going		
	on around you	<u> </u>	11111
27.	Feeling shaky or unsure of		
	yourself	<u> </u>	<u> </u>
28.	Feeling tired	<u> </u>	11111
29.	Having trouble getting back to		
	sleep if awakened	<u> </u>	<u> </u>
30.	Trouble remembering things	<u> </u>	11111
31.	Changes in eating habits	<u> </u>	<u> </u>
32.	Not getting enough sleep	<u> </u>	<u> </u>
33.	Crying more than usual	<u> </u>	11111
34.	Blaming yourself for things	<u> </u>	11111
35.	Having too much to do	1 1 1 1 1	<u> </u>

36.	Not having control of things	1 1 1 1 1 1	1 1 1 1 1
37.	Feeling lonely	1 1 1 1 1 1	1 1 1 1 1 1
38.	Feeling like nothing is		
	interesting or worth doing	1 1 1 1 1	11111
39.	Restless sleep	11111	11111
40.	Being upset	1 1 1 1 1	11111
41.	Wishing you could take		
	something back	11111	11111
42.	Having trouble concentrating	1 1 1 1 1 1	11111
43.	Being short of breath	11111	11111
44.	Feeling faint	1 1 1 1 1 1	1 1 1 1 1 1
45.	Avoiding certain people or		
	places	1 1 1 1 1	11111
46.	Feeling like you have too much	1	
	energy	11111	11111
47.	Being overwhelmed by how		
	much there is to do	1 1 1 1 1	<u> </u>
48.	Not being able to avoid things	11111	11111
49.	Losing control over things	<u> </u>	1 1 1 1 1 1

Appendix D

Prostate Cancer Index

Sexual function

How would you rate each of the following during the last 4 weeks?

- 1. Your level of sexual desire? Very poor; Poor; Fair; Good; Very Good
- 2. Your ability to have an erection? Very poor; Poor; Fair; Good; Very Good
- 3. Your ability to reach orgasm (climax)? Very poor; Poor; Fair; Good; Very Good
- 4. How would you describe the usual QUALITY of your erections? None at all; Not firm enough for any sexual activity; Firm enough for masturbation and foreplay only; Firm enough for intercourse
- 5. How would you describe the FREQUENCY of your erections? I NEVER had an erection when I wanted one; I had an erection LESS THAN HALF the time I wanted one; I had an erection ABOUT HALF the time I wanted one; I had an erection MORE THAN HALF the time I wanted one; I had an erection WHENEVER I wanted one
- 6. How often have you awakened in the morning or night with an erection? Never; Seldom (less than 25% of the time); Not often (less than half the time); Often (more than half the time); Very often (more than 75% of the time)
- 7. During the last 4 weeks, did you have vaginal or anal intercourse? No; Yes, Once; Yes, More than Once
- 8. Overall, how would you rate your ability to function sexually during the last 4 weeks? Very poor; Poor; Fair; Good; Very good

Sexual bother

1. Overall, how big a problem has getting and maintaining an erection been for you during the last 4 weeks? No problem; Very small problem; Small problem; Moderate problem; Big problem

Urinary function

- 1. Over the past 4 weeks, how often have you leaked urine? Every day; About once a week; Less than once a week; Not at all
- 2. Which of the following best describes your urinary control during the last 4 weeks? No control whatsoever; Frequent dribbling; Occasional dribbling; Total control
- 3. How many pads or adult diapers per day did you usually use to control leakage during the last 4 weeks? 3 or more pads per day; 1-2 pads per day; No pads How big a problem, if any, has each of the following been for you during the last 4 weeks?
- 4. Dripping urine or wetting your pants No problem; Very small problem; Small problem; Moderate problem; Big problem
- 5. Urine leakage interfering with your sexual activity No problem; Very small problem; Small problem; Moderate problem; Big problem

Urinary bother

1. Overall, how big a problem has your urinary function been for you during the last 4 weeks' No problem; Very small problem; Small problem; Moderate problem; Big problem

Bowel function

- 1. How often have you had rectal urgency (felt like I had to pass stool, but did not) during the last 4 weeks? More than once a day; About once a day; More than once a week; About once a week; Rarely or never
- 2. How often have you had stools (bowel movements) that were loose or liquid (no form, watery, mushy) during the last 4 weeks? Never; Rarely; About half the time; Usually; Always
- 3. How much distress have your bowel movements caused you during the last 4 weeks? Severe distress; Moderate distress; Little distress; No distress

4. How often have you had crampy pain in your abdomen or pelvis during the last 4 weeks?

Several times a day; About once a day; Several times a week; About once a week; About once this month; Rarely or never

Bowel bother

1. Overall, how big a problem have your bowel habits been for you during the last 4 weeks? No problem; Very small problem; Small problem; Big Problem

Appendix E

Medical Outcome Study 36-Item Short Form Health Survey

- 1. In general, would you say your health is: Excellent, Very Good, Good, Fair, Poor
- 2. Compared to one year ago, how would you rate your health in general now? Much better now than one year ago, Somewhat better now than one year ago, About the same as one year ago, Somewhat worse now than one year ago, Much worse now than one year ago

The following items are about activities you might do during a typical day. Does your health now limit you in these activities? Is so, how much? Response choices are: Yes, limited a lot; Yes, limited a little; No, not limited at all

- 3. Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports
- 4. Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf
- 5. Lifting or carrying groceries
- 6. Climbing several flights of stairs
- 7. Climbing one flight of stairs
- 8. Bending, kneeling, or stooping
- 9. Walking more than a mile
- 10. Walking several blocks
- 11. Walking one block
- 12. Bathing or dressing yourself

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? Response choices are yes or no.

- 13. Cut down on the amount of time you spent on work or other activities
- 14. Accomplished less than you would like
- 15. Were limited in the kind of work or other activities.
- 16. Had difficulty performing the work or other activities (for example, it took extra effort)

During the past 4 weeks have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious). Response choices are yes or no.

- 17. Cut down on the amount of time you spent on work or other activities
- 18. Accomplished less than you would like
- 19. Didn't do work or other activities as carefully as usual
- 20. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups? Not at all, Slightly, Moderately, Quite a bit, Extremely
- 21. How much bodily pain have you had during the past 4 weeks? None, Very mild, Mild, Moderate, Severe, Very severe
- 22. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? Not at all, A little bit, Moderately, Quite a bit, Extremely

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks. Response choices include: All of the time, Most of the time, A good bit of the time, Some of the time, A little of the time, None of the time

- 23. Did you feel full of pep?
- 24. Have you been a very nervous person?
- 25. Have you felt so down in the dumps that nothing could cheer you up?
- 26. Have you felt calm and peaceful?
- 27. Did you have a lot of energy?

- 28. Have you felt downhearted and blue?
- 29. Did you feel worn out?
- 30. Have you been a happy person?
- 31. Did you feel tired?
- 32. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)? All of the time, Most of the time, Some of the time, A little of the time, None of the time

How TRUE or FALSE is each of the following statements for you? Response choices include:

Definitely true, Mostly true, Don't know, Mostly false, Definitely false

- 33. I seem to get sick a little easier than other people.
- 34. I am as healthy as anybody I know.
- 35. I expect my health to get worse.
- 36. My health is excellent.

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Gabriela Orsak received her Bachelor of Arts in Psychology from West Virginia University in May 2010. She is currently seeking her Master of Science in Psychology at the University of Texas at Arlington. Her research interests include examining the psychological factors that affect non-adherence and quality of life in chronic disease populations.

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