MEN WITH PROSTATE CANCER:

PSYCHOLOGICAL, SYMPTOM, AND DECISION-RELATED DISTRESS ACROSS TIME

Submitted by

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Abstract

Men with prostate cancer can encounter many challenges, including coping with the cancer diagnosis, making treatment decisions, and living with side effects of treatment, all of which can contribute to various experiences of distress. The current study aimed to explore, longitudinally, the patterns of psychological distress, symptom distress, and decision-related distress reported by 141 men with prostate cancer. Based on participants' responses to self-report questionnaires, regression analyses were undertaken to examine physical symptom and decision making predictors of depression, anxiety, and trauma at three time points. Physical symptom predictors of psychological distress varied over time, although fatigue was the most commonly occurring unique predictor across all types of psychological distress and all time points. Age was also an important aspect of these outcomes, with some psychological and symptom variables varying across age at Times 1 and 2 but not at Time 3. When the data were examined across time, no significant differences were found for the psychological, physical symptom, or decision making variables. Coping strategies were also used to predict depression, anxiety, and trauma, with self-blame being a significant predictor across all three types of psychological distress. Furthermore, resilience, which was operationalised as a positive personality characteristic that enhances individual adaptation to life stressors, predicted depression and trauma but not anxiety. Implications for clinical practice and optimal care of men with prostate cancer are discussed, focusing on the need to recognise and manage psychological and symptom distress in these men from very early in the disease trajectory. Furthermore, the need to address decision making issues around treatment and symptom management to minimise decision-related distress are also considered and recommendations for both research and practice are made.

Statement of Authorship

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis submitted for the award of any other degree or diploma.

No other person's work has been used without due acknowledgement in the main text of the thesis.

The thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

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Background and Overview

Prostate cancer is the most common cancer in Australian men and is the second most common cause of cancer deaths in men. In Australia the incidence of prostate cancer is reported as 105 cases per 100,000 males (Australian Institute of Health and Welfare (AIHW), 2011). However, prostate cancer research is under-represented in the empirical literature in comparison to other major cancer types (e.g., Couper et al., 2009). This disparity in oncology research is surprising given the many challenging issues men diagnosed with prostate cancer face.

The lack of certainty about the most effective treatment for prostate cancer together with the adverse side effects of treatment, presents men with a difficult predicament. It is therefore not surprising that research to date has found that some men with prostate cancer experience distress, which can stem from the diagnosis, the treatment decision making process, and/or side effects of treatment. When men are diagnosed with prostate cancer, they must decide whether or not to pursue treatment at the time of diagnosis. Currently, there is great debate about differentiating between patients who will require definitive treatment early enough for cure and those who can safely delay treatment to avoid or delay potential treatment side effects (Davison, Oliffe, Pickles, & Mroz, 2009). The issue at the heart of this debate, of whether to treat immediately or wait to intervene, has major implications for the well-being of men with prostate cancer. All types of treatment for prostate cancer have the capacity to result in side effects, such as incontinence and impotence, which can give rise to symptom distress. In some cases, this symptom distress may be linked with psychological distress and in other cases the cancer experience itself may be psychologically distressing and contribute to symptoms of depression, anxiety, or trauma.

The existing literature reveals many gaps and unexplored relationships in the area of distress in men with prostate cancer. While research has examined psychological

distress in men with prostate cancer, there is conflicting evidence about the levels of depression, anxiety, and trauma that they experience. Additionally, although many studies have importantly investigated quality of life in men with prostate cancer, they have failed to specifically tap into various types of psychological distress. Furthermore, studies to date have explored the experience of physical symptoms in men with prostate cancer and have found urinary, bowel, and sexual dysfunction, with varying levels across treatment types. However, the majority of these studies have failed to assess the levels of distress associated with these physical symptoms in their own right. The current study aimed to add to the existing knowledge of psychological distress as it presents in men with prostate cancer by examining factors that are associated with psychological distress, such as physical symptoms and decisional conflict, regret, and satisfaction. It also aimed to explore distress over the cancer trajectory, an aspect many previous studies have neglected to include. It is crucial to assess men longitudinally to ascertain whether distress is stable over time or whether there are changes over the trajectory.

It is clear that men with prostate cancer are likely to encounter some degree of distress in their cancer trajectory, whether it is related to diagnosis, treatment decision making and/or side effects of treatment. According to the stress coping model (Lazarus & Folkman, 1984), how each individual appraises his situation is important in determining how he will cope and adjust to the experience of cancer.

Stress Coping Model

Transactional stress coping models (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Lazarus, 1990; Lazarus & Folkman, 1984) propose that the reaction to stress is not universal but is individually determined. According to this approach, personal experience, value and belief systems, and coping strategies can influence the way in which an individual cognitively appraises the experience of stress,

which in turn impacts on psychological and physical adjustment and health outcomes (Bauer-Wu & Farran, 2005). Such models have been applied to research on physical illness, including cancer. In the context of physical illness, the appraisal and adjustment process is seemingly influenced by patients' age and developmental stage at the time of diagnosis, that is, where the patient is biologically, personally, and socially in his or her life (Moos & Schaefer, 1984; Rowland, 1989).

According to the transactional model of stress and coping by Lazarus and Folkman, (1984) outcomes that take place in reaction to a stressor are mediated by the individual's cognitive appraisal of the stressor and his/her coping resources and strategies. Stress is defined as the relationship between the individual and the environment that is appraised as challenging or exceeding his/her resources and endangering well-being. In the appraisal process, individuals assess the effect of an encounter with the environment on their well-being. There are three types of cognitive appraisal in the model (Lazarus & Folkman, 1984). Primary appraisal is the initial judgment that an encounter is irrelevant, benign-positive, or stressful. Secondary appraisal is a judgment about viability and effectiveness of coping. Reappraisal is a changed appraisal on the basis of new information from the environment, the person, or both. If an event is appraised as threatening or harmful, the model predicts that the individual will employ coping strategies. Coping is defined as the cognitive and behavioural efforts, following cognitive appraisal, to manage particular continually changing external or internal demands, or both, that are appraised as challenging beyond the resources of the person to execute. Within the transactional process of coping there are many mutually dependent feedback and feedforward loops, whereby coping is a mediator that prevents or buffers against any negative influence of the stressor on the individual (Heim, 1991). As such, when an event is appraised as irrelevant or benign-

positive, no coping response is stimulated but when an event is appraised as stressful, resources are mobilised to cope with the situation (Lazarus & Folkman, 1984).

The processes of appraisal and coping described above are pertinent to individuals with cancer. For these individuals specifically, appraisal enables them to evaluate their diagnoses and the possible consequences of treatment and thereby initiate their coping response (Ahmad, Musil, Zauszniewski, & Resnick, 2005). Being confronted with cancer and the associated treatment and uncertainty, can have an overwhelming and long-lasting impact. Importantly, while some individuals cope rather well and come out of their illness experience, others experience feelings of demoralisation and subsequent psychological difficulties (Clarke, 2002; Moos & Schaeffer, 1984).

Indeed, in the area of oncology, research has shown that the impact of cancer varies and for some individuals the effects are fairly inconsequential whereas for others these effects are severely debilitating and may occur both in the preliminary period following diagnosis as well as many years subsequently (Roesch et al., 2005). In research specific to prostate cancer, it has been suggested that the coping strategies one uses or perceptions of the illness that one holds, may predict which individuals with prostate cancer have better or worse psychological and physical adjustment during their cancer experience (Roesch et al., 2005). As such, it is clear that ascertaining the psychosocial factors that contribute to both positive and negative psychological and physical outcomes is crucial. Various studies have assessed coping in men with prostate cancer and this research will be discussed below.

Coping with Prostate Cancer

A diagnosis of cancer brings a wide range of circumstances with which to cope, including painful or frightening symptoms, ambiguity about prognosis, and side effects of treatments. Situational factors such as the site of cancer, stage of the disease, time

since diagnosis, and whether the person is having current treatment, may all impact on coping behaviour in individuals with cancer (Dunkel-Schetter, Feinstein, Taylor, & Falke, 1992). While an adaptive coping strategy for physical difficulties may be problem-focused, the optimal strategies for dealing with ambiguity about the future may involve emotion-regulating strategies (Dunkel-Schetter et al., 1992). In their meta-analysis on coping with prostate cancer, Roesch et al. (2005) found that men with prostate cancer who utilised problem-focused and emotion-focused coping were healthier psychologically and physically than those who used more avoidant coping. However, the effect sizes for problem-focused coping and emotion-focused coping were more modest than those for approach coping. For approach coping, these effect sizes were especially robust for self-esteem, positive affect, depression, and anxiety. On the contrary, men with prostate cancer who used avoidance coping experienced increased negative psychological adjustment and physical health. These findings suggest that active approaches to coping with prostate cancer are valuable psychologically, physically, and are positively related to a return to pre-cancer activities (Roesch et al., 2005). The various coping strategies men with prostate cancer use will be explored in the current study.

Researchers have also examined individual coping strategies. Some studies (Ptacek, Pierce, Ptacek, & Nogel, 1999; see also Bjorck, Hopp, & Jones, 1999) have found that coping strategies such as blaming oneself, engaging in wishful thinking, and avoidance in general were all related to negative psychological adjustment. Interestingly, Perczek, Burke, Carver, Krongrad, and Terris (2002) found that avoidant coping was predictive of poor adaptation but found no relationship between reduced distress and active coping styles. Also examining coping with prostate cancer was Davison et al. (2009). It was apparent from anecdotes from the study that most men tried not to “think about” or “dwell on” having prostate cancer between Prostate

Specific Antigen (PSA) testing and appointments with their specialists. The men reported that travel plans and leisure activities were a distraction and "life went on". Most men reported that they continued to lead their lives 'as normal' or attempted to minimise their cancer status. It was found that men did not like talking about their cancer saying it was a "private matter" or "no big deal". However, most did talk to their wives around the time of their follow-up appointments and PSA tests (Davison et al., 2009). The question arises, are these men in denial or perhaps are they displaying resilience? The construct of resilience is discussed below.

Resilience and Cancer Coping

Despite experiencing catastrophic events at times, many cancer survivors exhibit incredible resilience in the face of illness (Rowland & Baker, 2005). While resilience was initially a construct mostly explored in the area of trauma within developmental psychology, more recently the construct has been utilised as a variable to predict coping with illness and life threats and has been shown to be important in coping and adaptation (Farber, Schwartz, Schaper, Moonen, & McDaniel, 2000). It is important to bear in mind that the resilience literature is largely limited in its focus on children and the components of resilience in older adults may not be the same as those for children and adolescents (Pentz, 2005).

Resilience has been defined in various ways including the ability to successfully cope with change or misfortune (Wagnild & Young, 1993). Resilience has been described as relating to a "dynamic process encompassing positive adaptation within the context of significant adversity" (Luthar, Cicchetti, & Becker, 2000 p. 543). This construct of resilience includes exposure to a severe threat or significant adversity, demonstrating positive adaptation despite such threats. Another definition viewed resilience as the "maintenance, recovery, or improvement in mental and physical health following change…Resilience is an outcome of an individual's resources operating as

protective factors at the sociodemographic, psychological, social, and biological levels" (Bar-Tur & Levy-Shiff, 2000, p. 263). Alternatively, Felten (2000) defined resilience as "the ability to achieve, retain, and/or regain a level of physical and/or emotional health after devastating illness or loss" (p. 102). This definition was considered the most appropriate for this study as it includes the important factors from the other definitions outlined above. Furthermore, Felten derived their definition from data collected from older adults, adding to its construct validity.

Relating this notion of resilience to the area of psycho-oncology, some researchers have studied resilience-related variables to describe cancer survivors (Cook Gotay, Isaacs, & Pagano, 2004; Parry, 2003; Stewart, Wong, Duff, Melancon, & Cheung, 2001; Wenzel et al., 2002). They mostly found that these patients had higher resilience levels than controls. Cook Gotay et al. (2004) suggested that surviving the experience of any cancer diagnosis may play a part in the development of resilience and a sense of meaning of life. While the above research is specific to cancer populations, research on resilience in the context of cancer remains understudied. The current study has endeavoured to add to this limited body of research by exploring resilience in a prostate cancer population. Researchers and clinicians alike must recognise the diversity that exists in how men with prostate cancer adapt to their experience to distinguish between those who are resilient and equipped to positively adapt and those who struggle to cope. The exploration of coping is critical because the way in which men cope with their cancer experience can have a significant impact on their psychological well-being as discussed previously. Investigating the ways in which men cope with their cancer can inform the design of interventions to assist these men, especially those at high risk of developing psychological distress and adjustment difficulties.

Organisation of the Thesis

Chapter 1 examines the various treatment types for prostate cancer and their implications. Chapter 2 reviews the psychological literature in men with prostate cancer. Chapter 3 examines the literature on the physical symptoms under examination, including those related to prostate cancer and its treatment specifically, as well as more general cancer-related symptoms of pain and fatigue. Chapter 4 outlines the literature on decision making in prostate cancer, encompassing research on decisional conflict, decisional regret, and decisional satisfaction. This is followed by the aims and expectations of the current study. Chapter 5 provides a description of the method, including the participants, the materials used and the procedures implemented. The psychometric properties of the measures used in the study are described. In Chapter 6, the results of the study are presented, including the results of data at all three time points as well as analysis of the data longitudinally. Finally, in Chapter 7 the results are discussed with reference to existing empirical research and the relevant theoretical background. The limitations of these findings are discussed together with suggestions for future research. The chapter concludes with the implications of this research for clinical practice.

Treatment of Prostate Cancer

In understanding the impact of prostate cancer in Australia it is important to consider its prevalence. One in seven Australian men will develop prostate cancer by age 75 and one in four by age 85. With regards to age at diagnosis, while younger men are less likely to be diagnosed with prostate cancer, they are more likely to die prematurely from it (AIHW, 2010). Furthermore, as will be discussed later on, age is an important factor in the prostate cancer experience in terms of both psychological distress and physical symptom experience and distress. The relationship between age and prostate cancer experience is examined in the current study.

While distress may occur in men of any age when they are diagnosed with prostate cancer, the treatment they choose can have a great impact on their symptom and psychological distress levels. As previously mentioned distress can stem from treatment side effects and this in turn may impact on coping during the cancer experience in the context of the stress coping model which was previously discussed. To better understand the complexity of treatment decisions for men with prostate cancer, each treatment type along with its potential complications will be outlined below.

Various treatment options exist for men diagnosed with localised prostate cancer. These include active surveillance/watchful waiting (which relies on close monitoring of the disease), prostatectomy (which involves removal of some or the entire prostate via surgical operation), or radiotherapy (the application of external-beam radiation or internal-beam radiation, known as brachytherapy, to irradiate the tumour) (Incrocci, 2006). Treatment for advanced prostate cancer often involves hormone therapy, known as androgen deprivation therapy (ADT) (Salminen, Portin, & Nurmi, 2007). Each treatment for prostate cancer comes with its own consequences which may be physical such as urinary, bowel, and sexual dysfunction, and/or psychological in nature. The discussion of each treatment on its own is paramount given that it is the

anticipation of side effects that affects initial decisions and it is the appraisal of actual side effects that might impact on decisional regret later. Research has demonstrated that some men with prostate cancer experience decision-related distress given the complex nature of treatment decision making (e.g., Gwede et al., 2005; Steginga, Turner, & Donovan, 2008) and this issue will be addressed in a later chapter.

Two approaches to what could be called more conservative treatment techniques are often conflated. Watchful waiting involves conservative management and is a palliative approach, typically used for older or physically unfit men with limited life expectancy. This approach follows patients until the cancer reaches an incurable state, at which time treatment is palliative (Parker, 2004). On the other hand, active surveillance, which is expectant treatment and management, is a proactive approach with curative intent, where active treatment is deferred until the cancer shows signs of significant growth (Carter et al., 2007; Cooperberg, Lubeck, Meng, Mehta, & Carroll, 2004; Parker, 2004). Whilst the distinction has been made here between watchful waiting and active surveillance, the distinction is not always made in practice or in the literature and men with prostate cancer will talk about the two approaches interchangeably. As such, future references in this review will be according to the literature which is being discussed, whether that be under the term watchful waiting or active surveillance.

Definitive treatment of localised prostate cancer may not be indicated in all cases. While the incidence of prostate cancer is high, many cases are non-fatal and often progress very slowly. Men who decide not to endure immediate therapy may choose to have continued follow-up under a program of active surveillance (Thompson et al., 2007). According to a review by Dall'era et al. (2008), watchful waiting has been underutilised in some countries as a choice for older men with localised prostate cancer. Research in the United States by Cooperberg, Broering, Kantoff, and Carroll (2007) found that only 10% of men with low-risk disease elect watchful waiting as an initial

management plan. It is commonly thought that men treated with active surveillance are at risk for disease progression (Carter et al., 2007). However, it is possible to delay definitive treatment options without decreasing the chance for cure (Carter et al., 2007). Active surveillance may be related to psychological difficulties, such as patients feeling anxiety and distress while living with 'untreated' cancer (Wallace, 2003). This issue of active surveillance-related anxiety will be discussed further in the chapter on psychological distress.

Surgery for prostate cancer usually involves a radical prostatectomy. Advanced surgical techniques, especially those that are nerve-sparing, have decreased the side effects of incontinence and impotence in recent years (Walsh, DeWeese, & Eisenberger, 2007). Nonetheless, many men still experience those side effects and these can be very psychologically distressing (Hervouet et al., 2005; Visser et al., 2003). Generally, radical prostatectomy is not offered to men over the age of 70 due to the perioperative mortality risk; however this phenomenon may change as surgical techniques advance (Mohile, Lachs, & Dale, 2008).

External-beam radiation is the most frequently used treatment for the majority of older men with localised prostate cancer (Cooperberg et al., 2004). Technical advances have meant that higher radiation doses can be given with less toxicity and improved cancer control (Walsh et al., 2007). Observational studies have demonstrated that external-beam radiation outcomes are equivalent to those of radical prostatectomy (Kupelian, Elshaikh, Reddy, Zippe, & Klein, 2002). External-beam radiation is minimally invasive and is linked to reduced risk of acute toxicities when compared to radical prostatectomy. Common side effects of external-beam radiation include nocturia, urinary frequency, impotence, and radiation proctitis (Mohile et al., 2008). An alternate form of radiotherapy is brachytherapy which refers to the placement of radioactive seeds inside or near the tumour. Brachytherapy generally allows a higher

dose of radiation to be given than with external-beam radiation (Mohile et al., 2008). It is usually patients with low-risk disease who are given brachytherapy sometimes in combination with short-term hormone therapy. As brachytherapy is a relatively novel technique, minimal data are available on its long-term efficacy (Mohile et al., 2008).

The use of androgen deprivation therapy (ADT), otherwise known as hormone therapy, has significantly increased over the last 10 years to treat advanced prostate cancer (Cooperberg et al., 2007; Cooperberg et al., 2004). ADT aims at ceasing the production of male hormones, such as testosterone, which feed the growth of prostate cells, particularly cancer cells (Salminen et al., 2007). Concern has been raised about the increased use of ADT for localised disease. The reason for this concern is that there is a rising incidence of localised disease implying that perhaps many men are being over treated (Mohile et al., 2008). Side effects of hormonal therapy include decreased libido, sexual dysfunction, breast enlargement, and hot flushes (Hervouet et al., 2005; Visser et al., 2003). In addition, there is research to suggest a link between ADT and depression (Pirl, Siegel, Goode, & Smith, 2002), which will be discussed further in the chapter on psychological distress.

Treatment decisions are further complicated by the fact that it is still unclear which treatment is the most efficacious (Eton & Lepore, 2002). For patients with low-risk prostate cancer, equivocal survival rates are reported for the various treatment options (Hack et al., 2010). As previously mentioned, for each of the treatment options available, well-documented side effects exist, including urinary, bowel, and sexual dysfunction, and each option is associated with psychological and/or symptom distress in men with prostate cancer (Harden et al., 2002; Helgason et al., 1996; Helgason, Dickman, Adolfsson, & Steineck, 2001; Litwin, Lubeck, Spitalny, Henning, & Carroll, 1995; Roth et al., 1998; Thornton, Perez, & Meyerowitz, 2004).

Given the abovementioned potential gains but also negative outcomes of treatment for prostate cancer, the decision making process about treatment can be difficult. It has been suggested that facilitating men to participate in the treatment decision making, consistent with a patient-centred care philosophy, can assist in the decision process and minimise levels of associated distress (Arora, Weaver, Clayman, Oakley-Girvan, & Potosky, 2009; Davison & Goldenberg, 2003). This will be discussed in greater detail in the chapter on treatment decision making. However, an overriding aspect to the care of men with prostate cancer is how the potential for psychological distress is managed.

Psychological Distress

This chapter aims to outline psychological distress as explored in the prostate cancer literature. A common issue existing in medical populations is that individuals experience troublesome and distressing symptoms but fail to meet the criteria for a psychiatric disorder. These are considered subsyndromal symptoms and are very important in medical patients, including those with cancer (Roth et al., 1998). Indeed, difficulties remain in teasing out 'subclinical' from 'clinical' distress. It is particularly difficult to say definitely that for example depression in medical populations, in this case cancer, is equivalent to a depressive disorder in Diagnostic and Statistical Manual-IV-Text Revised (DSM-IV-TR), despite some researchers and clinicians doing so (De Jonge, 2011).

Due to the plethora of studies on general distress and the more clinical focus of the various constructs of psychological distress in the current study, only studies that have examined depression, anxiety, and trauma specifically in men with prostate cancer will be discussed, rather than those that have used overall measures of psychological distress. Furthermore, due to the abundant number of studies in the area, only the most recent and relevant studies have been included in the review below. In addition, in the review of the literature, at times the measures used will be mentioned as this is an important part of an evaluation of published literature in this area, given that the measurement tool can have a major impact on the results obtained.

Depression

Depression and cancer.

Depression can influence the course of cancer, morbidity, hospital stays, treatment compliance, efficacy, and possibly prognosis (Pasquini & Biondi, 2007). As such, improving screening and treatment of this psychosocial complication of cancer is paramount in oncology care (Reich, 2008). Past researchers have found a wide variation

in terms of the prevalence and predictors of depression amongst cancer populations, which may reflect differing settings, cancer sites, or staging at diagnosis; use of different research measures, cut-off scores, and diagnostic criteria (Passik et al., 2000), which will be noted in the following review where pertinent.

Sellick and Crooks (1999) have highlighted the fact that the depression classification system means that many sub-clinical cases will be overlooked as individuals may exhibit depressive symptoms but not fit criteria for Major Depressive Disorder or Dysthymic Disorder. Controversy remains about the optimal diagnostic criteria for depression in the medical setting, such as oncology, and many challenges exist regarding the assessment and management of depression in individuals with a cancer diagnosis (Pasquini & Biondi, 2007). Clinical presentations of depression in cancer populations are varied and it is often difficult to differentiate between biological or physical symptoms induced by the depression itself from symptoms of the illness or side effects of cancer treatment. That is, many depression symptoms such as fatigue, weight loss, loss of appetite and sleep disruption, closely parallel symptoms of cancer and/or its treatment. It has been suggested that the prevalence of depression in cancer patients is often underestimated as a result (Pasquini & Biondi, 2007).

Some have argued (e.g., Raison & Miller, 2003) that it is necessary to differentiate the somatic symptoms of cancer and those due to treatment from DSM-IV-TR criteria for depression, while others (e.g., Massie & Holland, 1990) maintain that in such a medical population certain depressive features are of greater importance. These features include sadness, anhedonia, hopelessness, helplessness, low self-esteem, guilt feelings, and suicidal ideation. In other words, some recommend differentiating the somatic and psychological features of depressive phenomenology. However, in cancer populations, it is crucial that a distinction is made between normal degrees of sadness associated with a diagnosis and abnormal levels of depressive symptomatology (Massie

& Holland, 1990). This is of utmost importance as depression not only influences quality of life but also the ability to tolerate and adhere to treatment, and thereby ultimately the course of illness (Hermann et al., 1998; Sellick & Crooks, 1999). A more in-depth discussion of depression in prostate cancer will follow.

Depression and prostate cancer.

Studies have examined the prevalence rates of depression in men with prostate cancer, with the majority of studies finding low levels of depression but some other studies reporting greater rates of depression. In Bisson et al. (2002), Cliff and Macdonagh (2000), Hinz et al. (2009), and Lintz et al. (2003), only a few men scored in the clinically significant range for depression on the Hospital Anxiety and Depression Scale (HADS; Snaith, 2003). Another study which used clinical interview to assess for depression, considered to be the gold standard for accurate diagnosis, found a rate of 5.6% for major depression in their sample of men with prostate cancer (Couper et al., 2006).

In contrast, an elevated incidence of depression was found by Monahan et al. (2007) in their study of 105 men newly treated with radical prostatectomy, external beam radiation or brachytherapy. They found that 14% of their sample met criteria for clinical depression as measured by the Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977). The authors suggested that this elevated rate of clinical depression related to the timing at which depression was measured. Depressive symptoms were measured shortly after (within 30 days) treatment and as such the stress of treatment and its side effects may have inflated the level of clinical depression seen in this study. While the above discrepancy in the reported incidence and levels of depression in men with prostate cancer may be partly due to the variability in the measures used to assess depression, it may also be due to the other methodological and sample issues described above.

Therefore, as outlined above, research to date has generally found low rates of depression in men with prostate cancer, however, select studies have found higher rates. As such, the current study aims to assess levels of depression in men with prostate cancer in order to add to the existing knowledge and to gain a clearer understanding as to how many men with prostate cancer experience difficulties with depression.

Factors affecting depression.

Men most at risk for depressive symptoms include those with advanced disease, prominent cancer symptoms and side effects of treatment, and a history of clinical depression according to a review by Bennett and Badger (2005). Furthermore, men with co-morbidities have also been reported to have a higher risk of developing depression (Dirksen, Epstein, & Hoyt 2009). While some risk factors for depression have been identified, Bennet and Badger also referred to some protective factors which include being older, being married, having high social support, being optimistic, and having less impairment in physical functioning (Bennett & Badger, 2005).

While, as previously mentioned, depression rates in the disease tend to be low, Bennett and Badger (2005) found that prostate cancer pain appeared to be strongly connected with depressive symptoms, whereas fatigue as a result of treatment had not been consistently linked to increasing depression. Furthermore, advanced disease is a factor for depression in men with prostate cancer, whereby men with advanced disease are at a higher risk for depression than those with localised disease (Lintz et al., 2003). In their study of men with prostate cancer, Dirksen et al. (2009) using a small sample of 51 men, found that 51% of men had a clinically significant level of depressive symptoms. This range is at the higher end of depressive levels previously reported for men with prostate cancer (e.g., Bisson et al., 2003; Cliff & Macdonagh, 2000; Lintz et al., 2003). Dirksen et al. have suggested that the reason for this difference may have been due to the large number of men with advanced disease in their study. In addition,

the small sample size employed by Dirksen et al. should be kept in mind when considering their results. This notion of higher levels of depression in men with advanced disease is supported by Lintz et al. (2003) who found that men with advanced prostate cancer were significantly more depressed than those with early-stage disease.

In contrast, Rosenfeld, Roth, Gandhi, and Penson (2004) found no association between the HADS depression score and stage of disease. Their sample consisted of 385 men with prostate cancer including 186 men with organ confined disease, 92 with locally advanced disease, and 63 with metastatic prostate cancer. The authors proposed that the lack of association between depression and stage of disease in their study may be due to the fact that while men with prostate cancer may undergo a deterioration in emotional functioning as their disease progresses they may not necessarily experience significant symptoms of depression such as those assessed by rating scales such as the HADS. Furthermore, given that Dirksen et al. (2009) and Rosenfeld et al. (2004) had significantly different proportions of men with metastatic disease, it is not surprising that their findings are considerably different.

As noted above, another risk factor for depression in men with prostate cancer is a prior history of depression. Pirl et al. (2002) found that a premorbid history of depression was associated with a diagnosis of current depression in a sample of men undergoing ADT. There was a prevalence rate of 83.3% of current Major Depression in men with who had a history of depression. Indeed, all patients who received a Structured Clinical Interview for DSM Disorders (SCID)-based diagnosis of Major Depression had a history of depression and no patients without a history of depression received a diagnosis of Major Depression. Further support for the notion of a history of depression as a risk factor for future depression in prostate cancer, was higher mean Beck Depression Inventory (BDI) scores in men with a history of depression in comparison to those without a history in the same study. This evidence of previous

depression as a risk factor for depression during prostate cancer is particularly important for treating clinicians to take into consideration when assessing and managing their patients.

One very significant factor given minimal attention in the literature is the association between prostate cancer treatment type and levels of depression. While a number of studies have focused on the relationship between hormone therapy and depression, which will be discussed subsequently, very few studies have looked at the comparison of depression levels across other treatment types. One study that examined treatment type and depression found that men who received radiotherapy were more likely to report clinical depression than those who did not receive radiotherapy at the outset (Hervouet et al., 2005). Comparing depression levels across treatment groups is crucial given the unique profile of each treatment and their associated consequences. If indeed research were to find variations in depression in different treatment groups, this would be vital for targeting psychological screening and interventions in these men. Furthermore, these variations would also be able to be drawn on when giving men advice during the treatment decision making process. Therefore, as is evident from the review above, various factors influence depression levels in men with prostate cancer and it is important to bear these factors in mind when examining the literature on prevalence in such populations, when conducting research in this area, and especially importantly in clinical practice.

ADT and depression.

Decreased testosterone levels have been associated with decreases in muscle mass, strength, bone mass, and sexual function and increases in body fat, fatigue, and depressed mood (Bremner, 2010). From studies on depression and low testosterone in non-cancer patients (e.g., Shores, Moceri, Sloan, Matsumoto, & Kivlahan, 2005), reports of increased psychological symptoms in men receiving ADT have begun to

emerge (Pirl, et al., 2002). These findings highlight the importance of studying depression in men receiving ADT for prostate cancer. As will be seen below, research to date has not found higher depression levels in men on ADT, which is surprising given the anecdotal reports and the probable impact of hormone manipulation.

Research that examined the effects of ADT on depression in men with prostate cancer found that at the initiation of ADT, 3% of men met the cut-off for probable cases of depression (Stone, Hardy, Huddart, A'Hern, & Richards, 2000). Further research found that 87% of a sample of men with prostate cancer did not report significant depressive symptoms, 13% reported mild to moderate depression, and no patients reported moderate to severe depression. The authors found Major Depressive Disorder at a prevalence rate of 12.8% (Pirl et al., 2002). When considering the findings of the above study, it should be kept in mind that the study only reported the rate of depression in men on ADT with no comparison to men with prostate cancer not receiving ADT. Additionally, Pirl, Greer, Goode, and Smith (2008) found that hormone therapy did not appear to cause clinically significant changes in depression between pre-treatment baseline, 6 months, and 12 months in a sample of men with locally advanced prostate cancer.

The abovementioned studies have potential weaknesses, with small samples in terms of the numbers of participants. While Salminen et al. (2007) used a larger sample of men with prostate cancer in examining the impact of ADT on distress; the number of men in their sample receiving ADT was small and while they reported associations between hormone treatment and all distress variables, it was unclear whether this was specific to depression. As such, as can be seen from the research above on depression and ADT in men with prostate cancer, high levels of depression have thus far not been found.

Fatigue, pain, and depression.

The relationships between fatigue and depression and pain and depression are commonly described in the broader literature, as well as in prostate cancer populations (e.g, Heim & Oei, 1993; Pirl et al., 2002). Fatigue has been found to be significantly associated with psychological symptoms including depression (Pirl et al., 2002; Stone et al., 2000). However, as previously noted, fatigue and major depression have many overlapping characteristics and can be difficult to differentiate in individuals with cancer (Pasquini & Biondi, 2007). The difficulty exists in that individuals with cancer-related fatigue can be incorrectly diagnosed with depression due to the presence of low energy levels, sleep disturbances, and poor concentration. As Pirl et al. (2002) noted, depression and fatigue were measured retrospectively and while fatigue seemed to increase following the commencement of hormone therapy, depression did not. Importantly, this study's data provides evidence of an association but not causality.

Like with fatigue and depression, there is a well established relationship between pain and depression. Minimal research has been conducted assessing the relationship between pain and depression in men with prostate cancer. However, one study by Heim and Oei (1993) found that men with prostate cancer who reported pain were significantly more likely to exhibit depressive symptoms. The lack of research on the link between pain and depression is surprising given it is a well established relationship in other medical populations. It is of particular importance to examine this association in men with advanced stage prostate cancer where pain and depression are more likely to be present. Pain and fatigue in men with prostate cancer in the context of physical symptoms will be discussed in a later chapter looking at physical symptom experiences.

Treatment for depression.

Systematic reviews have been conducted by Rodin et al. (2007) and Williams and Dale (2006) on depression treatment in cancer patients. Rodin et al. reported that

only modest evidence exists for the benefit of pharmacological and psychosocial interventions, with neither modality more efficacious than the other and significant side effects occurring with pharmacological treatments. They also suggested that withdrawal rates from study interventions tend to be high with both types of treatments as well as placebo groups. Williams and Dale reported that while few in number, studies on pharmacological interventions for depression in cancer patients have provided some evidence that antidepressant medication is effective. The authors also reported that there are limited trial data on the efficacy of psychotherapeutic treatments for depression and depressive symptoms in cancer patients but that cognitive behavioural therapy seems to be effective in decreasing depressive symptoms in cancer patients.

Further research is needed to examine the effectiveness of strategies for treating depression in cancer populations and would benefit from multisite research to achieve larger sample sizes of patients with specific types of cancer. Consideration of the different side-effect profiles of various antidepressant medications and the relative benefit of psychosocial, pharmacological, and combined interventions also warrants investigation (Rodin et al., 2007).

Anxiety

Anxiety and cancer.

Cancer is a threatening event and it is not surprising that many people experience anxiety in response to that threat. While anxiety is a common response to threat, in certain situations it can become maladaptive. The difficulty is judging at what point the anxiety is disproportionate to the cancer ‘threat’. Anxiety levels should be considered in the context of the proximity of the threat, whereby some level of anxiety is normal after receiving a diagnosis, but as the extent of the real threat varies through the cancer trajectory, so do levels of anxiety. While thoughts about recurrence and death are natural for a period after diagnosis or relapse, this is not the case during long periods

of remission. However, determining when anxiety becomes maladaptive in the oncology setting is complex (Stark & House, 2000).

It has been suggested that in the oncology setting, unacceptable intolerable symptoms and disturbance to functioning are useful in distinguishing pathological from normal anxiety. Intrusive and unpleasant anxious thoughts, often involving recurrence of disease, death, or disability can result in significant disturbances to concentration, decision making, sleep, and social functioning (Stark & House, 2000). Behaviours as a result of these cognitions may include avoidance, repetitive checking of health, and seeking reassurance for transient physical symptoms, which can be disturbing for individuals and their families (Stark & House, 2000). While it is true that cancer is a threat to one's health and to life, for most patients it is not the cause of disabling anxiety. However, if the anxiety is heightened it is important to explore the interpretations and meanings attached to events for that individual, such as treatment procedures (Stark & House, 2000), as was outlined previously in the section on the stress coping model.

Anxiety and prostate cancer.

In terms of identifying those individuals having difficulties with anxiety, screening has been used in an attempt to improve detection and thereby management of the anxiety. Many screening questionnaires exist and measures such as the HADS and various quality of life measures have been used. The studies that will be discussed below have all used a specific anxiety measure, rather than an overall quality of life measure or worry assessment. Hence, they provide a more reliable and well validated assessment of anxiety symptoms. In their study of 121 men with prostate cancer, Roth et al. (1998) found that 32.6% scored at or above the anxiety cut-off score of 7 on the HADS, reflecting over a third of the sample had troublesome anxiety symptoms. Later research by Bisson et al. (2002) in a sample of 88 men newly diagnosed with prostate cancer, found that 18% of patients had anxiety symptoms as measured by the HADS.

Furthermore, Lintz et al. (2003) examined anxiety in 210 men with localised and advanced prostate cancer and found that four patients scored in the moderate to severe range of anxiety, 26 in the mild range, and 180 scored lower in the normal range. No difference in anxiety levels was found according to cancer stage. However, an age difference was found whereby men under 65 years old reported higher anxiety scores than those over 65. The authors suggested that younger patients' higher levels of anxiety may have been related to their greater psychological distress associated with sexual dysfunction. Similarly to Lintz et al., Rosenfeld et al. (2004) found that prostate cancer stage was unrelated to anxiety scores as measured by the HADS. As stated for depression, the authors suggested that men with prostate cancer may not experience significant symptoms of anxiety such as those examined by rating scales such as the HADS and that psychological/emotional domains of health-related quality of life are to some extent less susceptible to the impact of disease progression relative to the physical and functional domains. As pointed out by Rosenfeld et al. there could have been confounding variables such as time since last treatment received, and sexual or bowel functioning which could have significantly impacted on the study results. These possible confounding factors could have a great effect on anxiety levels and therefore should be considered in future research on anxiety in men with prostate cancer.

ADT and anxiety.

Research has found that prostate cancer-specific anxiety predicted early ADT initiation for older men who experienced biochemical recurrence, even when other clinical factors were controlled for (Dale et al., 2009). The predictive value for commencing ADT was disease specific, with significance not extending to the HADS anxiety score, suggesting that it was anxiety about prostate cancer that affected behaviour. While there was a correlation between general anxiety and prostate cancer-specific anxiety, it was only the prostate cancer-specific anxiety that predicted the

choice to commence ADT earlier. It is interesting to note that doctors rated patient anxiety as fairly low on their list of important factors in decision making regarding starting ADT. The authors questioned why anxiety was such a robust predictor in the early initiation of ADT if physicians do not consider this factor strongly. They suggested that patients may relay their prostate cancer-specific anxiety to their doctors and their desire to commence ADT early and subsequently the doctor commences ADT in a process of shared decision making with the patient (Dale et al., 2009). If indeed anxiety leads to earlier commencement of ADT, a treatment with many side effects and a negative impact on quality of life, anxiety would be a natural target of intervention for those patients in whom commencement of ADT is premature (Dale et al., 2009).

Active surveillance and anxiety.

In active surveillance, patients are closely monitored using PSA testing and at times repeat prostate biopsies. The aim of active surveillance is to decrease the burden of treatment side effects without compromising survival but research in this area is not definitive (Parker, 2004). Apart from the current uncertainties around the medical facets of active surveillance, this strategy may be linked to psychological difficulties such as illness-related uncertainty (Bailey, Wallace, & Mishel, 2007; Latini et al., 2007; Wallace, 2003). To date, mixed results have been found in research on anxiety levels in men with prostate cancer who opt for active surveillance. Low anxiety levels in men on active surveillance were found by van den Bergh et al. (2010). They also found that anxiety at nine months after diagnosis was mainly predicted by scores at the start of the study. The authors reported favourable anxiety scores when compared with reference values and groups of patients with prostate cancer who chose other treatment types. However, the authors focused on a select group of men who had already chosen active surveillance as the initial treatment type and the authors suggested that these men may have made this decision as they experienced low levels of anxiety, thereby potentially

biasing the results. Therefore, the results of the study cannot be generalised to men with early prostate cancer before they have decided on their treatment choice. Further research on active surveillance and anxiety found that men on active surveillance who were still investigating new treatment options reported higher anxiety levels (Davison et al., 2009). Anxiety was also triggered by stories in the media that emerged about new treatments and stories about people who died from prostate cancer, subsequent to which the men worried about whether their cancer had grown or metastasised and the accuracy of test results from their PSA tests and biopsies (Davison et al., 2009).

While the relationship between active surveillance and psychological distress is an area of ongoing investigation, it is important to acknowledge that increased psychological distress, including anxiety, may result in men changing from active surveillance to radical treatment when this is not indicated from a medical viewpoint (Latini et al., 2007), such as discussed above in relation to the early initiation of ADT. In summary, as postulated by Tosoian et al. (2011), active surveillance with curative intent seems to be a sensible alternative to immediate intervention for older men who have been carefully chosen. Limiting active surveillance to men with the lowest risk category of prostate cancer may decrease the occurrence of adverse outcomes.

PSA anxiety.

A further dimension of anxiety in men with prostate cancer discussed in the literature is anxiety about PSA levels. Measuring PSA can be used for screening men with no symptoms, detecting relapse after treatment for localised prostate cancer, and monitoring the response to treatment (Lofters, Juffs, Pond, & Tannock, 2002). Understandably, anxiety surrounding PSA tests is considerable until the men receive their results. PSA results are often closely examined by men and their families so that even minute changes within the normal range may result in unnecessary worry (Roth et al., 1998).

Research on men with metastatic prostate cancer has found that most men reported some level of anxiety prior to receiving the results of their PSA tests, with a third of men in the study reporting moderate to severe anxiety about their PSA levels (Lofters et al., 2002). The majority of patients reported increased PSA levels as evidence that their disease was worsening and almost half recorded it as the only evidence that their disease was worsening. Physical symptoms like pain and urinary difficulties were noted much less frequently. Further results revealed that the men's anxiety score on the HADS strongly correlated with anxiety about PSA. The findings also showed that there were greater levels of PSA anxiety in men with less than a post-secondary education, non-English speakers, younger men, and those with hormone resistant disease. It is interesting to note that few patients voluntarily acknowledged that their PSA levels was the factor that caused them the most anxiety despite the results indicating that PSA measurement correlated strongly with anxiety.

The fundamental issue in PSA anxiety as pointed out by Lofters et al.'s (2002) study, is that many men with prostate cancer classify changes in the state of their cancer by the numerical value of a blood test and in fact for some patients the decrease in PSA level becomes a more important treatment goal than symptom improvement. This issue raises ethical concerns around PSA testing. As postulated by Lofters et al., PSA testing could be stopped given the principle in medicine to avoid tests if the results would not change management and in particular if they would trigger anxiety in the patient. However, this strategy would be unlikely to succeed as more than half of the men in the study would feel that their doctor had given up on them if they ceased PSA testing. The results from this study should be interpreted with caution given the multiple analyses and small sample size. In summary, the issue of PSA testing remains contentious.

Treatment for anxiety.

Many research papers on psychological distress in cancer, report findings for both the treatment of anxiety and depression without differentiating between the two conditions, reflecting the depression and anxiety combined state some researchers report on. This presents a difficulty given the current research differentiates between these two types of psychological distress. Nonetheless, in one review of management of distress in cancer patients, Holland and Alici (2010) have explained that treatment of anxiety in cancer patients is dependent on the aetiology and timing of symptom onset. Medications and non-pharmacological management have been used to treat anxiety in cancer patients. Various behavioural techniques such as progressive muscle relaxation and guided imagery have been successfully employed in treating anxiety disorders in cancer patients (Breitbart, Lederberg, Rueda-Lara, & Alici, 2009; Holland & Alici, 2010).

Trauma

While less research has been done on trauma in cancer than depression and anxiety, debate continues as to whether cancer should be deemed a traumatic experience given the extent to which cancer corresponds to a psychosocial or biomedical model of trauma. A similar debate exists regarding other extreme experiences that do not clearly fit a biomedical model of Post Traumatic Stress Disorder (PTSD) which, despite its worth in acute traumatic events such as motor vehicle accidents or violent assaults, offers various shortcomings when used with chronic and complex phenomena such as cancer (Sumalla, Ochoa, & Blanco, 2009). In their paper on Posttraumatic Growth (PTG) in cancer, Sumalla et al. (2009) outlined the differences between cancer diagnosis and treatment and other acute adverse events. Firstly, they discussed the difficulty in singling out a single traumatic stressor within the cancer experience. While some traumatic events can be typified as simple and discrete in nature, during a cancer experience, the stressors may be related to the diagnosis, its severity and prognosis, the

aggressiveness of treatments, changes in body image, a reduction in the level of functional autonomy or role changes. As such, in cancer, it is typically very challenging to pinpoint the exact stressor or group of stressors. The authors also discussed the internal source of the stressor, whereby the acute traumatic event is most commonly external to the individual, however, cancer has an internal nature and origin. It was suggested that this internal nature may also play an important role in shifting assumptions about the individual's self (Sumalla et al., 2009). Yet another issue in this debate raised by Sumalla et al. was that of temporal dimensions. Contrary to acute traumas, in which the recurrence of symptoms is related to a past traumatic event, in oncology the majority of the intrusive cognitions advance worries related to the individual's future health and those of their closest family members. The nature of the trauma in cancer populations is about the future, whereas for most other traumas it is about the past (Sumalla et al., 2009).

Furthermore, Sumalla et al. (2009) pointed to temporal delimitation of the stressors. With cancer it is difficult to determine the onset and termination of the traumatic event. Contrary to an acute trauma with a visibly defined onset and conclusion, cancer is more like a long obstacle race. Finally, the authors discussed perceived control. With cancer, individuals experience a certain level of control over their treatment and its outcomes. This is contrary to the unanticipated and uncontrollable nature of an acute trauma. For instance, Komura and Hegarty (2006) have claimed that many of the positive changes described by patients diagnosed with cancer can be directly associated with a greater sense of perceived control over their lives and selves. This perception is a typical characteristic of traumas associated with illness and, logically, the phenomena of posttraumatic growth associated with falling ill can be affected by this distinguishing factor.

Whether PTSD exists in all cancer populations remains a controversy. However, the discussion below will focus on the experience of trauma and its symptoms in men with prostate cancer. While this discussion will not focus on PTSD per se, reviewing some of the criteria of PTSD in the DSM-IV-TR provides a broad description of trauma and the typical responses it engenders. To satisfy criteria for PTSD, one must have been exposed to, or witnessed a traumatic event that involved actual or threatened death, or a threat to the physical integrity of oneself or others, and which invoked intense fear, helplessness or horror in the recipient. The DSM-IV-TR requires that the individual experiences either intrusive memories, nightmares, a sense of reliving the traumatic event, or psychological and physiological distress when reminded of the event. It also requires at least three of the following: avoidance of thoughts, feelings or reminders of the trauma, inability to recall aspects of the trauma, withdrawal from others, emotional numbing, or a sense of foreshortened future. The DSM-IV-TR stipulates the presence of at least two of the following symptoms: insomnia, irritability, concentration difficulties, hypervigilance, or exaggerated startle response.

Previous research has found that cancer patients experience negative intrusive cognitions, which are subsequently linked to significant levels of distress (Kangas, Henry, & Bryant, 2002). The majority of studies examining intrusive thoughts in cancer patients have used the Impact of Events Scale (IES), which was developed to measure subjective distress related to a traumatic event. While intrusive thoughts and memories have been assessed in cancer patients, investigations have characteristically involved female patients (Whitaker, Brewin, & Watson, 2008). It is likely that women's experience of trauma is different than that of men and therefore data from studies using women cannot be generalised to samples of men such as those with prostate cancer. As such, the studies discussed below specifically involve this understudied population of men with prostate cancer.

Early research found no significant difference in scores on intrusion between those men who were having no treatment, those having radical prostatectomy and radiation therapy only, and those having hormone therapy (Kornblith, Herr, Ofman, Scher, & Holland, 1994). Another study which was conducted by Herr and O'Sullivan (2000) found that although not statistically significant, there were higher levels of psychological distress, as measured by the Intrusion subscale of the IES, among men with locally advanced prostate cancer. Further research was conducted by Whitaker et al. (2008) who found a mean score on the IES was 17.76, which was below the midpoint of possible scores. Intrusive cognitions were also assessed by structured interview and 23% of patients in their study reported intrusive cognitions. Furthermore, 74% of intrusive cognitions were related to the person's own cancer experience, and 15% were concerning a relative's illness, injury, or death. As such, in total, 82% of intrusions that were reported were specifically about cancer. The results indicated that the existence of intrusive cognitions was not related to cancer stage and the authors suggested that it may be that cancer-specific intrusions denote more general subjective threats of the disease rather than prognosis-specific threats. Furthermore, the authors reported that intrusive memories were reported as vivid and that when they were experienced the patients felt the event was reoccurring. Patients in the study reported that they 'somewhat' re-experienced emotions the same as or very similar to those during the actual event, while re-experiencing the physical sensations was uncommon (Whitaker et al., 2008). Therefore, while research to date indicates that some men experience intrusive cognitions in response to their cancer experience, the putative 'trauma', further research is needed to explore this phenomenon.

Age and Psychological Distress

Given the current research is about men with prostate cancer, which is classically a disease of older men, it is imperative to consider the relationship between

aging and psychological distress. Indeed, the incidence of prostate cancer increases significantly in men over the age of 75. However, it is important to bear in mind that there has been an increase in the number of younger men being diagnosed with prostate cancer (Diefenbach, Mohamed, Horwitz, & Pollack, 2008). As such, many men are currently living with the disease and the outcomes of its treatment for much longer. For the elderly though, there are various physical and social factors that may complicate a cancer diagnosis, making it more difficult to cope, consider different treatment options, and deal with the side effects of these treatments (Nelson et al., 2009). With prostate cancer, the diagnosis calls for these men to concurrently adapt to changes brought about by the cancer in addition to other normative changes specific to their age (Harden et al., 2008).

As such, despite this greater vulnerability to distress in older men, research has shown that younger adults with cancer are at a higher risk of psychological distress than their older counterparts (Blank & Bellizzi, 2008). Blank and Bellizzi (2008) have suggested that age may serve as a protective factor against cancer-related psychological distress. For younger men, the impact of a prostate cancer diagnosis and treatment may be more distressing than for their older counterparts as it occurs during earlier stages of their life cycle when they are still working, rearing children, and supporting their families (Diefenbach et al., 2008; Dirksen et al., 2009). As postulated by Leventhal and Prochaska (1986), older men may attribute their physical problems such as impotence and incontinence to old age and therefore be more accepting of deterioration in health as an unavoidable result of aging. Furthermore, Diefenbach et al. (2008) suggested that older men may engage in social comparative processes by comparing their health state to others and reaching the conclusion that they are better off than at least some of their peers. As such, the effect of a prostate cancer diagnosis and side effects from treatment

may have less impact on the older men's quality of life and adjustment as compared to younger men.

Whilst Harden et al. (2008) did not directly assess distress as operationalised in the current study by depression, anxiety, and trauma, they did examine quality of life. There are a vast number of studies on quality of life in prostate cancer; however most were deemed extraneous to discuss in the context of the current research. Regarding the study by Harden et al., it was deemed important due to its exploration of age which is pertinent to the research at hand as will be discussed further on. Harden et al. divided their sample into three age groups: middle age (50-64), young old (65-74), and old old (75-84). Their results indicated that the young old men had superior mental health quality of life than the middle age men. The authors postulate that developmentally, the young-old group have achieved many of their life goals, reached retirement, and still experienced relatively good overall health prior to diagnosis. As such, it may be that the reduced quality of life in men in the middle age group stems from disruption to their daily lives including work and social activities. Interestingly, the mental health quality of life in the old old men was significantly lower than the young old group. This is dissimilar to other research which has found that older individuals experience less psychological distress than younger counterparts when diagnosed with cancer (Blank & Bellizzi, 2008).

In addition, Harden et al. (2008) explored illness appraisal which was previously discussed in the introduction in the context of the stress coping model. They found that men in the young old group had a less negative illness appraisal than the other two age groups. This is to say that men in the young old group found their diagnoses less threatening than those in the middle age and the old old groups. This is consistent with research by Bowman, Deimling, Smerglia, Sage, and Kahana (2003), who found that younger age was associated with more stressful cancer experience appraisals. Since it is

expected that the middle age men are more likely to be employed, it is likely their financial situation may be negatively impacted by their prostate cancer treatment more so than the young old men, as they endure disruption to their work schedule. The old old men may already be enduring stress related to ageing and other co-morbid health problems so that the prostate cancer diagnosis and its treatment are seen as one more stress to deal with, resulting in a more benign appraisal of the cancer.

Further exploration of age and psychological distress was conducted by Bisson et al. (2002) who found that younger age was mildly predictive of poorer psychological functioning. In fact, while younger men were faring worse in psychological functioning than older men, this effect only accounted for 10% of the total variance in the Impact of Events Scale-Revised score. The authors reported that the results of their linear regression analysis did not facilitate them being able to predict those who would develop psychological difficulties after diagnosis. Additionally, in a study by Nelson et al. (2009) ageing was related to lower anxiety scores but higher depression scores in a study of 716 men with prostate cancer. These results support a pattern suggestive of decreased anxiety with age and increased depressive symptoms with age. While the strength of the relationships in the study was small, age remained a significant predictor of anxiety and depression after controlling for variables such as functional well-being, thereby lending support to the significance of the above findings. The authors postulated that for older cancer patients, a decreasing emphasis on an externally focused perspective may explain the decrease in anxiety, yet the inward focus and less interaction with the outside world may leave older cancer patients alone in coping with a cancer diagnosis, fear of recurrence, deciding on cancer treatments, and managing the side effects of treatment. The general results for older cancer patients may be greater susceptibility to depressive symptoms than in younger cancer patients. Therefore, as can be seen from the discussion above, variations exist in the effects of age on

psychological distress, and as such are an important factor under examination in the current study.

Psychological Distress Across Time

Studies examining the temporal course of psychological distress in men with prostate cancer are scarce. Nordin, Berglund, Glimelius, and Sjödén (2001) assessed psychological distress over time and found that the levels of depression and anxiety at diagnosis were the best predictors of depression and anxiety 6 months later. Bisson et al. (2002) also examined depression and anxiety in 88 men with prostate cancer and revealed a reduction in mean anxiety from 5.1 to 4.4 within a 2-week interval, while depression increased from 1.8 to 2.5. A study by Salminen et al. (2003) using the BDI in men undergoing ADT found little difference in depression levels at baseline, 6 months, and 12 months. Therefore, it is evident that further research is needed on studying psychological distress in men with prostate cancer longitudinally and hence this is a focus of the current study.

In summary, a variety of types of psychological distress may be present in men with prostate cancer, including depression, anxiety, and trauma, all of which are explored in the present study. Early identification of distress in men with prostate cancer will enable educational and supportive interventions to be put in to place in order to reduce the impact of the illness and the chance of more serious psychological problems (Roth et al., 1998). The psychological experience of men with prostate cancer can be affected by the physical symptoms they may experience as a result of treatment. Those symptoms can in turn impact on their psychological well-being and therefore will be discussed subsequently.

Physical Symptom Experience

The physical symptoms that men may experience as a result of prostate cancer treatment can have an impact on their overall well-being. Therefore, the physical symptoms will be reviewed here as an aim of the current study is to examine how these physical symptoms impact on psychological distress. As previously mentioned, the various treatments for prostate cancer are not without adverse physical consequences (Hervouet et al., 2005). For example, many patients who undergo radical prostatectomy experience total erectile dysfunction while some experience permanent incontinence. Those who have radiotherapy are also at risk for erectile dysfunction as well as urinary and bowel problems. For patients with more advanced disease, palliative treatment can result in complications such as decreased libido, erectile dysfunction, and hot flushes (Visser et al., 2003). These abovementioned potential treatment complications can have a profound effect on quality of life (Gomella, Johannes, & Trabulsi, 2009).

The impact of prostate cancer treatment on sexual function has been extensively explored in the literature. In fact, erectile dysfunction is the most commonly reported long-term side effect from prostate cancer treatment (Bokhour, Clark, Inui, Silliman, & Talcott, 2001). Following treatment, men wonder if erectile dysfunction is long-lasting, and when or if they will be able to engage in sex in the future (Roth, Weinberger, & Nelson, 2008). In recent years, surgeons and radiation therapists have attempted to modify treatments for men with prostate cancer to minimise sexual morbidity. Schover et al. (2002) have postulated that men newly diagnosed with prostate cancer often have unrealistic expectations of sexual outcomes and that realistically most survivors experience severe and lasting sexual dysfunction and dissatisfaction. Nonetheless, changes in sexual function are a likely source of significant distress in men with prostate cancer. As such, it would be expected that the literature would explore this distress. However, many studies have neglected to do so and have purely reported sexual

function symptoms. The current study aims to address this problem by examining not only the symptoms but also the distress related to these symptoms.

As a result of the large number of studies in this area of treatment side effects, only the most relevant and recent ones will be discussed here. Currently, while there is a plethora of studies on the side effects of treatment, there is no review of these studies, which is a significant deficiency in today's literature. A further shortcoming of the existing literature is the lack of focus on distress stemming from physical symptoms. The distress resulting from urinary, sexual, and bowel consequences is a central focus of the current study. While some studies on side effects have examined individual symptoms, others have looked at multiple symptoms or symptoms across treatment type. The following review will outline the side effects according to studies on each treatment type.

Radical Prostatectomy

Temporal changes in urinary and sexual function up to 5 years post-radical prostatectomy were examined by Penson et al. (2005) in a sample of 1,288 men. With urinary symptoms, they found that at baseline 3.4% of men reported frequent urinary leakage or no control. This percent peaked 6 months post-diagnosis with 25% of men reporting frequent leakage or no control. By 24 months, 10.4%, of men reported this much leakage although it increased to 13.9% 60 months post-diagnosis. While there was a minor deterioration in some urinary symptoms from years 2 to 5, the frequency of incontinence, number of urinary pads used and extent of urinary frequency remained fairly stable. Slightly more men reported moderate to great bother from urinary incontinence at 60 months. Overall scores in the urinary function domain reached their lowest point at 6 months post-diagnosis but gradually increased through 24 months with minimal change at 60 months.

For sexual function at baseline, 81% of men reported erections firm enough for intercourse; however at 6 months post-diagnosis this dropped to only 9%, with this number increasing to 22% by 24 months following diagnosis and 28% at 60 months. A similar trend was found for difficulties in maintaining an erection. While erectile function improved minimally between 24 and 60 months, men reported only a small corresponding change in sexual activity. At 24 months, 44% of men reported no sexual activity and by 60 months this figure was up marginally to 46% of men. The percentage of men reporting that sexual function was a moderate or great problem decreased from 54% at 24 months to 46% at 60 months. Overall scores in the sexual function domain showed that the lowest point was at 6 months post-diagnosis, followed by a continual improvement through 60 months. Age was an important predictor of sexual function outcomes (Penson et al., 2005).

Further research on urinary and sexual symptoms following prostatectomy found a statistically significant decrease in urinary function, urinary bother, sexual function, and sexual bother 1 year following surgery (Shikanov et al., 2008). A higher baseline score was predictive of a higher post-surgery score. Severe deterioration at 1 year in urinary function, urinary bother, sexual function, and sexual bother was observed in 15%, 33%, 35%, and 31% of men, respectively. In addition, 6% of men had significant recovery in urinary function and 22% in urinary bother. For sexual function and bother, 3% and 9% of men, respectively, exhibited significant score improvement. Baseline urinary function and bother were the only significant predictors of a severe deterioration in urinary function. Preoperative urinary function and bother were the only significant predictors of severe deterioration in urinary bother. The extent of nerve preservation did not affect the urinary function or bother outcome. For a severe worsening in sexual function, the baseline sexual function score, baseline sexual bother score, and nerve sparing technique were significant predictors. Severe decrease in sexual bother was

predicted by the baseline sexual function score, the baseline sexual bother score, and nerve sparing technique (Shikanov et al., 2008).

Post-Operative Radiotherapy

In a study of men undergoing postoperative radiotherapy, Sia et al. (2010) found that 60.4% of men in their sample reported urinary incontinence, while 26.2% reported more than three episodes of incontinence per day, which was considerably more than reported at baseline, when 73% of men reported good bladder control. The authors questioned whether this figure was representative of a real change or an under-reporting of symptoms at baseline. However, the number of men reporting the use of incontinence pads was comparable pre- and post-radiotherapy, suggesting that the addition of radiotherapy did not raise the rate of severe incontinence in these men. Very few men reported moderate or severe bother from their urinary dysfunction and only 2.4% of men reported moderate to severe disruption from incontinence. The authors indicated that it is unclear why there is a disassociation between reported frequency and the consequent disruption of incontinence. They suggested that the apparent inconsistency may correspond to an accommodation of urinary dysfunction over time, or that treatment expectations were properly addressed in the beginning (Sia et al., 2010). This may also be an example of 'response shift' where individuals 'adjust' to the new reality. The idea of response shift will be explored in the discussion chapter.

Sia et al. (2010) also found that men reported changes in bowel function. Liquid or loose bowel movements were the most common complaint reported by 8.4% of men with associated loss of control seen in 5.4% of men. Moderate to severe disruption from some aspect of bowel dysfunction was found in 5.4% of the sample and the most frequent causes were rectal urgency (5%) and loss of control (5.4%). Sia et al. (2010) is one of very few studies to have examined men's response to sexual dysfunction as a result of prostate cancer treatment. They found dissatisfaction with sexual function was

the most unfavourable outcome with only 2.5% of men being extremely happy or satisfied with their level of sexual functioning. Extreme unhappiness was reported by 42.7% of men, which is consistent with the result that 55.6% preserved a moderate to very high level of sexual interest but 88.3% faced impaired function. The current study endeavoured to add to this data by examining distress as it relates to sexual function in men with prostate cancer.

Brachytherapy

A study by Eckman, Ying, Hertzfeld, Kumar, and Barrett (2010) examined 394 men with newly diagnosed early stage prostate cancer who underwent brachytherapy. Urinary symptoms commenced abruptly in the first 3 months following brachytherapy, reduced quickly over the next 9 months, and then reduced more gradually thereafter, suggesting initial acute injury. With bowel function, diarrhoea, constipation, and pain with defecation remained fairly flat while rectal bleeding peaked at 18 months, which is suggestive of more chronic injury. Sexual dysfunction was evident as both acute and chronic responses to treatment; it increased sharply at approximately 6 months and continued to increase although more gradually throughout the follow-up period.

Across Treatments

Several studies have compared physical symptoms across treatment types. Early research examining urinary, bowel, and sexual function was conducted by Fowler, Barry, Lu-Yao, Wasson, and Bin (1996). They compared a sample of 621 men who had undergone radiation therapy with a group of 373 men from previous research who had undergone surgery. Regarding urinary function, more than 60% of men who had radiotherapy reported no dripping or leaking urine post-treatment, which was less than for men who had undergone surgery. Only 7% of the former were using pads to deal with wetness while 32% of men who had surgery were using pads. In relation to bowel function, problems were reported more by the radiation therapy group than the surgery

group. Radiation patients reported significantly more difficulties when asked to rate how much of a problem they were currently having with pain or discomfort with bowel movements and with frequent bowel movements. The difference was most striking in regard to frequent bowel movements, for which only 56% of men in the radiation therapy group reported no problem compared to 85% of men in the surgery group. For men both older and younger than 70 at the time of treatment, differences in the impact of surgery and radiation on sexual function were evident and highly statistically significant. Even among the older population treated with radiation, about 25% said they had erections firm enough for intercourse prior to the survey, whereas this was the case only for 10% of the surgery group. The men were also asked about the degree to which problems with sexual functioning was a concern for them. No statistically significant differences were found between the surgery and radiation samples in either age group (Fowler et al., 1996).

Also examining physical symptoms in men who had undergone radical prostatectomy or external beam radiation therapy, was Potosky et al. (2004). They examined 1591 men with prostate cancer and found that approximately 14%-16% of the radical prostatectomy group and 4% of the external beam radiation therapy group were incontinent at 5 years. Bowel urgency was more prevalent in the external beam radiation therapy group. Furthermore, at 5 years following diagnosis, overall sexual function had deteriorated to about the same level in both groups. However, at this time, erectile dysfunction was more common in the radical prostatectomy group than the external beam radiation therapy group. Data from another study which employed a sample of 111 men with localised prostate cancer, found that for men who had radical prostatectomy, urinary symptoms and bother were worse 2 months after treatment and got better at 12 months. This was also true for sexual bother and symptoms. Bowel symptoms and bother did not alter over time. For men who received radiotherapy,

urinary bother and symptoms were worst at 2 months and improved at 12 months. Sexual bother was worse 2 months following treatment. Bowel symptoms and bother changed with time, getting worse at 2 months and getting better at 12 months. For men who opted for watchful waiting, physical functioning did not change over time (Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2004).

In a study of 1236 men with localised prostate cancer who had also undergone radical prostatectomy or radiation therapy, Schover et al. (2002) found that at the time of diagnosis 64% of their sample was potent. The desire to preserve erectile function did not influence 49% of the sample in their choice of treatment but it was a minor influence for 27% and a major influence for 24%. Only 14% of the sample reported that their erections stayed the same or improved following treatment while erections became somewhat worse for 21% and much worse for 65%. The proportion of men with erection difficulties who rated themselves as moderately to extremely distressed about them was 61%, with 60% rating themselves distressed to a similar degree about desire problems and 64% of men reporting distress about orgasm difficulties. Across treatment types, nerve-sparing radical prostatectomy was to some extent better than other treatments with regard to rates of full recovery of erections and superior results with medical treatments for erectile dysfunction. Overall, the authors found that a majority of men in their study remained sexually dysfunctional and dissatisfied at an average of more than four years following treatment for localised prostate cancer.

A number of studies have explored the physical symptoms, including urinary, bowel, and sexual symptoms in samples of men who had been treated with radical prostatectomy, external beam radiation, or brachytherapy. Research by Hervouet et al. (2005) found significant differences across treatment types for all physical symptoms examined. Men who underwent radical prostatectomy reported lower levels of urinary problems in comparison to those who had external beam radiation therapy or

brachytherapy. They also reported lower levels of bowel and hormone-related symptoms compared to those who underwent external beam radiation therapy, after controlling for covariates. In contrast, the radical prostatectomy group reported higher levels of sexual problems compared to men who underwent brachytherapy. They also found that men who received brachytherapy were less likely to report clinical levels of sexual problems than those who did not receive this treatment, while men who had radical prostatectomy were more likely to report clinical levels of sexual problems.

A similar study was conducted by Sanda et al. (2008) who examined outcomes for 1201 men with prostate cancer treated via radical prostatectomy, brachytherapy, or external beam radiation therapy. They found that the brachytherapy group reported experiencing enduring urinary irritation, bowel and sexual symptoms, and transient difficulties with hormonal function. Unfavourable effects of prostatectomy on sexual function were mitigated by nerve sparing techniques. Following prostatectomy, urinary incontinence was detected, but urinary irritation and obstruction had improved. Furthermore, Ferrer et al. (2008) conducted a longitudinal study and found that radical prostatectomy had a substantial negative impact on sexual functioning and urinary continence, while radiotherapy had a moderate negative effect on bowel functioning and a small negative effect on sexual functioning. For brachytherapy, the only negative outcome was a moderate increase in urinary irritation. Litwin, Sadetsky, Pasta, and Lubeck (2004) examined bowel function and found men who had surgery, external beam radiation, or brachytherapy had different longitudinal profiles of bowel function and bother for the first two years following treatment. Bowel function and bother were worse after external beam radiation but they were also problematic after brachytherapy. Men who had surgery experienced transient impairment in bowel functioning.

Talcott et al. (2003) also examined a sample of men who had undergone external beam radiation therapy, radical prostatectomy, or brachytherapy. Prior to treatment,

urinary incontinence was uncommon, and did not significantly differ between the treatment groups. Following external beam radiation therapy and brachytherapy, incontinence did not significantly change, but this symptom rose sharply following radical prostatectomy, with similar changes found in bother scores. By 12 months, men who had undergone radical prostatectomy had improvements in their mean scores; however the improvement did not continue after that. At 24 months, 57% of men who had surgery reported incontinence within the past 7 days, 17% reported incontinence at least daily, and 20% reported using pads. Radiation therapy, particularly brachytherapy, briefly increased urinary obstruction and irritation. The mean dysfunction score of the brachytherapy group increased at 3 months, with a smaller rise for the external beam radiation therapy group (Talcott et al., 2003).

Bowel dysfunction was also negligible prior to treatment. However, at 3 months, soon after the completion of external beam radiation therapy, bowel problems had increased. The number of men reporting at least occasional diarrhoea increased from 17% to 43%, and 13% reported diarrhoea at least several times a week. Bowel problem scores improved at 12 and 24 months although not back to baseline levels. Among men who had undergone external beam radiation therapy, the frequency of diarrhoea had returned to baseline by the 24 month follow-up, bowel urgency did not improve after 3 months, and the reported prevalence of rectal bleeding increased steadily from 5% at pre-treatment to 25% at 24 months (Talcott et al., 2003).

In the sexual domain, pre-treatment sexual dysfunction was lowest among men who had surgery, although that of men in the brachytherapy group was almost as good. However, sexual dysfunction had dramatically increased when first assessed at 3 months following radical prostatectomy. During this preliminary period, external beam radiation therapy and brachytherapy patients' sexual function diminished modestly. Modest improvement by men in the radical prostatectomy group together with the

continuing increase in other groups' dysfunctions decreased the relative radical prostatectomy disadvantage at 24 months. It was not surprising that men who underwent nerve sparing surgery had superior pre-treatment sexual function and it continued to be modestly better at 24 months. At 3 months, only 17% of men in the radical prostatectomy group reported any erections in the past 4 weeks, and only 8% reported an erection firm enough for penetration, but scores increased to 41% and 20% respectively, by 24 months following surgery. The ability to have an orgasm, was disproportionately preserved, being reported in 46% of surgery patients at 3 months and 57% at 24 months. In spite of older age, greater co-morbidity, and inferior pre-treatment sexual function, men in the external beam radiation therapy group had sexual dysfunction similar to that of the surgery group at 24 months following treatment. All treatment groups had increased sexual dysfunction at 24 months (Talcott et al., 2003).

Other research has explored physical symptoms in men who had endured radical prostatectomy, brachytherapy, combined external beam radiation and brachytherapy, or hormone therapy. Research by Huang, Sadetsky, and Penson (2010) explored side effects of treatment in 1,269 men with localised prostate cancer. They found deterioration in urinary function immediately after treatment in the radical prostatectomy, brachytherapy, and combined external beam radiation therapy and brachytherapy groups. The preliminary worsening was greatest in men who were in the radical prostatectomy group but subsequent recovery was also the greatest among this group. After two years, there was little change in the surgery and radiotherapy groups. A slight gradual decrease was observed in the ADT group. Regarding urinary bother, decreases from baseline were found in the first year in all surgery and radiotherapy groups, followed by recovery between the first and second years. A slight gradual decrease was again observed in the ADT group from baseline to year four (Huang et al., 2010).

With regards to bowel function and bother, men who underwent radical prostatectomy had little change from baseline throughout follow-up. On the other hand, men who had any type of radiation therapy experienced slight deterioration during year 1, followed by recovery almost reaching baseline levels. Men who had received ADT also reported a decrease in bowel function and bowel bother until 2 years with no changes after 2 years. Bowel bother results were similar to the abovementioned bowel function findings (Huang et al., 2010). Findings in the sexual function domain revealed substantial deterioration of sexual function in all groups immediately following treatment with the greatest decline for the radical prostatectomy group. This group experienced some improvement after year 1 while all other groups experienced little or no improvement following the initial decline. Sexual bother trends with time across all treatment groups were similar to sexual function but improvement in the radical prostatectomy group was more marked. Clear improvement was observed from years 1 to 2 with continued but slight improvement from years 2 to 4 (Huang, et al., 2010).

In a study comparing symptoms in men treated with radical prostatectomy or watchful waiting, Steineck et al. (2002) found that urinary leakage was more prevalent among those in the radical prostatectomy group and that 27% of men in that group and 18% in the watchful waiting group stated they were moderately or greatly distressed by their urinary problems. There was little difference in bowel function between the two groups and 3% of the radical prostatectomy group and 6% of the watchful waiting group were distressed by their bowel symptoms. In the sexual function domain, the frequency of sexual thoughts was similar in the two groups, while the prevalence of satisfactory erectile function was higher in the watchful waiting group. Somewhat fewer men in the radical prostatectomy group indicated that their sexual function was important compared to the watchful waiting group. This is suggestive of ‘revisionism’, in that the fear of a symptom is more extreme than the actuality of it. Among men in the radical

prostatectomy group, 56% were distressed to a moderate or great degree by deterioration in sexual function, in comparison to 40% in the watchful waiting group (Steineck et al., 2002).

Different treatment groups were compared in a study by Malcolm et al. (2010) who used a sample of men who had undergone brachytherapy, cryotherapy (the freezing of prostate cancer cells), or radical prostatectomy. They found that overall urinary function and bother scores were higher after brachytherapy and cryotherapy compared to prostatectomy. Men who received brachytherapy and cryotherapy had a 3-fold higher rate of return to baseline urinary function when compared to men who underwent prostatectomy. Sexual function and bother scores were highest following brachytherapy, with a 5-fold higher rate of return to baseline function in comparison to cryotherapy and brachytherapy. All treatments were associated with fairly transient and less marked impact on bowel function and bother than the other side effects.

In comparing one group who had radical prostatectomy plus observation and another group who had radical prostatectomy and adjuvant radiation therapy, Moinpour et al. (2008) found problems in bowel function for the radical prostatectomy plus radiation therapy arm for the first two years and more frequent urination over the 5 year period. It was not surprising that there was no significant difference in erectile dysfunction between the two arms given both had undergone surgery, which is known to result in sexual dysfunction for many men.

Finally, in a study of 875 men with prostate cancer, Fransson et al. (2009) examined urinary, bowel, and sexual symptoms in men receiving hormone therapy alone and men receiving hormone therapy and radiotherapy. For urinary symptoms, mean overall bother increased from baseline to the end of radiotherapy in men in the combined treatment group. Mean overall urinary bother nearly restored to baseline scores 3 months following radiotherapy. The hormone only treatment group had

reduced urinary bother from baseline at 3 months following treatment commencement and at the 6 month follow-up. No statistically significant differences were found in overall distress levels from urinary symptoms. Urinary leakage was worse in the combined treatment group than in the hormone only treatment group. Urinary leakage and nocturia increased between baseline and 4-year follow-up in both groups. Overall urinary bother was the only item of all urinary symptoms which recorded a small clinically significant difference between the two groups at the 4-year follow-up. Urinary leakage was the only urinary symptom in the combined treatment group to show a clinically significant change between baseline and 4 years (Fransson et al., 2009).

For bowel symptoms, mean overall bother was high at the conclusion of radiotherapy compared with baseline in men in the combined treatment group. Symptoms improved subsequently but remained high in comparison with baseline at the 4-year follow-up. Bowel bother was also heightened in the hormone only group at 3 months when compared to baseline. Bowel bother returned to near baseline scores after 6 months. Men in the combined treatment group reported more bowel symptoms than those in the hormone only treatment group. Bowel symptoms also increased between baseline and 4 years, particularly in the combined treatment group. Overall bother from all bowel symptoms was slightly increased in the hormone only treatment group from baseline to 4 years. Bowel bother was not significantly increased over time in the hormone only treatment group. More men in the combined treatment group reported moderate or severe bowel symptom bother than in the hormone only treatment group. Only small clinically significant differences were found in bowel symptoms between the two groups at 4 years (Fransson et al., 2009).

For sexual function, mean overall bother increased from baseline in the hormone only group at 3 months and for the combined treatment group at the beginning of radiotherapy. Mean erectile function deteriorated in the hormone only group at 3

months and in the combined treatment group at the start of radiotherapy. Overall bother from sexual function was high at 4 years in both treatment groups. Although the bother was minimally higher in the combined treatment group, when examining change over time, both groups reported large clinically significant changes. Moderate or severe sexual bother was reported by more men in the combined treatment group than in the hormone only group. In the combined treatment group, more men were unable to attain an erection firm enough for intercourse when compared to the hormone only group. At baseline 47% of men in the hormone only group reported an erection firm enough for intercourse compared to 51% in the combined treatment group. At 4 years, 37% of the hormone only group and 18% of the combined treatment group reported an erection adequate for intercourse (Fransson et al., 2009).

Therefore, it is clear from the above review of the physical symptom literature, that a great proportion of men who undergo prostate cancer treatment experience at least some side effects. While the above literature has reported only minimally on the distress associated with these symptoms, it is clear from the nature of the symptoms, such as erectile dysfunction, that men may find these difficult to deal with and that they may be a source of distress. As such, the current study aims to assess symptom distress and to examine whether these physical symptoms are predictive of psychological distress in men with prostate cancer.

Symptom Distress

While some of the abovementioned studies have examined physical symptom distress, overall very few studies have directly assessed distress stemming from prostate cancer treatment side effects. However, an early study by Helgason et al. (1996) assessed distress from physical symptoms in 431 men with prostate cancer who had undergone various treatments and 435 randomly selected men of a similar age. The prostate cancer patients were more likely to report overall low frequency and/or

intensity in all aspects of sexual function. The majority of men, irrespective of group membership, were distressed by their diminishing sexual capacity. More men with prostate cancer than in the reference group were severely distressed as a result of deterioration in sexual function. The willingness to trade off (hypothetically speaking) an intact sexual function for long-term survival varied significantly among men in the reference group. Urinary and bowel symptoms were less prevalent than deteriorating sexual function in both groups. Few men seemed to be severely distressed by urinary or bowel symptoms. The authors concluded that a decline in sexual function was the most common cause of disease-specific distress in their sample of men with prostate cancer (Helgason et al., 1996).

Symptom Distress and Age

Prostate cancer is characteristically a disease of older men, with the incidence increasing dramatically in men in their seventies. However, this is not to say that younger men do not receive diagnoses of prostate cancer. Indeed, there is a 1 in 39 chance for man in his forties or fifties to be diagnosed with prostate cancer, with this chance increasing to 1 in 15 for men in their sixties and 1 in 7 for men in their seventies (Jemal et al., 2008). As such, the number of men living with the disease and with the outcomes of treatment is growing in our aging population.

Little research to date has examined symptom distress across age. One study by Harden et al. (2008) examined symptom distress as part of assessing physical quality of life in men with prostate cancer according to age cohort: middle age (50-64), young old (65-74), and old old (75-84). Findings from the study indicated that patients in the young-old group experienced superior outcomes in several domains than did the other two age cohorts. They explored symptom distress in men who had undergone hormone therapy and found that symptom distress was more of a problem in men in the middle age group than men in the young-old group. Examples of the side effects experienced

include hot flashes and loss of libido (Harden et al., 2008). No significant difference was found among the three age cohorts for distress in regard to urinary or sexual symptoms. However, the variance in scores for each group in the EPIC (Expanded Prostate Cancer Index Composite: Wei, Dunn, Litwin, Sandler, & Sanda, 2000) sexual component was high, showing that within each group some of the men did suffer a high level of bother and diminished function than the mean scores would suggest. Indeed, previous research has shown that treatment for prostate cancer impacts on urinary and sexual function and this is further affected by older age (e.g., Hu et al., 2004). As mentioned above, the existing literature is deficient on data on the impact of age on symptom distress. It is possible that similar to psychological distress, symptom distress varies across age groups. This potential difference across age groups is an important factor in management and intervention from a clinical viewpoint. As such, the current study aims to add to the limited knowledge of symptom distress across age in an attempt to ascertain which age groups are more likely to experience symptom-related distress, and thereby provide data which can inform clinical practice.

Fatigue

Fatigue is a pervasive problem and one that is commonly reported by cancer patients (Brown & Kroenke, 2009; Mendoza et al., 1999). The impact of cancer-related fatigue on one's ability to function is significant and as such this symptom is among the most distressing reported by cancer patients (Hoffman, Ryan, Figueroa-Moseley, Jean-Pierre, & Morrow, 2007). The causes of cancer-related fatigue are poorly understood but the experience of fatigue is linked with psychological and symptom distress as well as reductions in functional status (Brown & Kroenke, 2009; Hoffman et al., 2007; Mendoza et al., 1999). Psychological symptoms, particularly depression, and to a lesser degree, anxiety, have been found to have high correlations with cancer-related fatigue (Brown & Kroenke, 2009). Understanding the nature of the relationship between fatigue

and psychological symptoms has proven hard to pin down. Does a patient become depressed or anxious due to the effects of fatigue or is it the opposite? On the other hand, is there a bidirectional relationship between fatigue and distress, with each impacting on each other? Are there external factors that independently bring about both fatigue and depression or anxiety (Brown & Kroenke, 2009)? Whilst the answers to these questions are still unknown, they are important considerations when contemplating fatigue in cancer patients, including men with prostate cancer. This is particularly important given that symptoms of fatigue are especially upsetting for men who had in the past led active and independent lives (Roth et al., 2008).

Research has found a significant increase in subjective fatigue in patients with prostate cancer after treatment with luteinising hormone releasing hormone (LHRH) (Stone et al., 2000). The authors concluded that the aetiology of fatigue in men undergoing hormone therapy remains unknown and further research is warranted. Other research has examined fatigue in men undergoing radiation therapy and found that men who underwent external beam radiation therapy were more likely to report fatigue than those who did not receive external beam radiation therapy initially (Hervouet et al., 2005). A notable limitation of the above study was its cross sectional design which limited the assessment of fatigue over time. In another study on radiation therapy and fatigue, it was found that the severity of both evening and morning fatigue increased during radiotherapy and then decreased after treatment (Miaskowski et al., 2008). Fransson (2010) explored fatigue in men who had undergone external beam radiation therapy. The results indicated that pre-treatment fatigue was absent in 59% of men, while 66% had fatigue 5 years following treatment. Severe pre-treatment fatigue was reported by 2% of men. Severe fatigue at 5 years following treatment was reported by 4% of men.

Further research on fatigue in prostate cancer was conducted by Krydalen, Dahl, Hernes, Cvancarova, and Fossa (2010) and Krydalen, Dahl, Hernes, Hem, and Fossa (2010). In Krydalen, Dahl, Hernes, Cvancarova et al.'s 2010 study, men were observed for a median of 18 months from the commencement of radiotherapy. Approximately 40% of the 1 year or greater prostate cancer survivors from the group on continued hormone therapy reported chronic fatigue, in comparison to approximately a quarter of men from the group who discontinued hormone therapy. The prevalence of chronic fatigue in the latter group was similar to that of the hormone-naive radiotherapy control group and males from the general population. For the group who discontinued hormone therapy, men aged 65 years or below were at an increased risk of chronic fatigue. In their 2010 study, Kyrdalen, Dahl, Hernes, Hem, et al., explored fatigue in hormone-naïve men with prostate cancer. Their sample consisted of 337 men who had undergone radical prostatectomy and 184 men who had undergone radiotherapy treatment. The overall prevalence of chronic fatigue was 26.1% after radiotherapy and 13.4% after radical prostatectomy, with the most difference emerging in survivors with the longest observation times. After a median of 23 months a significantly lower proportion of men reported chronic fatigue after radical prostatectomy in comparison to those who underwent radiotherapy. Younger age at diagnosis, presence of pain, post-treatment co-morbidity and urinary and bowel dysfunction were significantly associated with chronic fatigue in the multivariate analysis. These observations have added to the existing research that fatigue is a significant problem after prostate cancer treatment even in patients without ADT (Kyrdalen, Dahl, Hernes, Hem, et al., 2010). Given the high prevalence of fatigue in cancer patients and the detrimental effect on quality of life, it is an important symptom to consider in management (Brown & Kroenke, 2009). Much of the literature has neglected to assess the impact of fatigue on psychological distress. As such, a goal of the current study is to examine the relationships between fatigue and

depression, anxiety, and trauma and to see whether fatigue predicts psychological distress in a prostate cancer population.

Pain

Limited research exists on the experience of pain for men with prostate cancer. Pain resulting from bone metastases is common in men with advanced prostate cancer. It has been suggested that older men may be hesitant to take pain medication or dosages sufficient to alleviate their pain. It is unclear as to what extent this relates to a fear of potential side effects such as constipation and fatigue, or to a macho attitude of feeling required to endure the pain (Roth et al., 2008). Examining pain in a sample of elderly cancer patients, including men with prostate cancer, Given, Given, Azzouz, Kozachik, and Stommel (2001) found that prostate cancer patients tended to report less pain and fatigue than breast cancer patients. It was not possible to determine the relationship between gender and reports of pain and fatigue in this study. Overall, the literature on pain in men with prostate cancer has for the most part failed to examine the experience of pain over the cancer trajectory. Therefore, the current study will assess pain over time in an attempt to determine not only for what proportion of men pain is a problem, but importantly, for those who do experience pain whether it is stable or variable across time. This data may then be able to guide pain management interventions.

Summary

As was noted previously, much research has disregarded symptom distress and has focused on the actual symptoms instead. This is true for all the symptoms discussed above, in particular the prostate cancer specific ones. Such a phenomenon is indeed puzzling given the importance of the distress these symptoms may bring on. This reflects the more traditional approach in which broad quality of life issues were assessed but now we are asking more sophisticated questions. Further research is needed to address this significant deficiency in existing research. In addition, many studies have

failed to assess symptoms longitudinally, which is crucial given the changes that may occur over the prostate cancer trajectory.

Therefore, from the discussion above it is clear that there are many potential physical side effects from prostate cancer treatments as well as pain and fatigue which occur in many cancer populations. These consequences need to be considered in terms of the distress they may bring about and also their influence on the decision making process, which will be discussed in the next chapter.

Decision Making

The diagnosis and management of prostate cancer is complex (Mohile et al., 2008). As previously mentioned, deciding on a treatment modality for prostate cancer is challenging, complicated, and distressing due to the lack of consensus among medical professionals regarding the most effective treatment option (Cox & Amling, 2008; Lin, Aaronson, Knight, Carroll, & Dudley, 2009). There is a deficiency of comparative data from controlled studies and varying clinical views about the benefits and harms of each treatment option, making the treatment choice for men with prostate cancer particularly difficult (Ramsey et al., 2009). In recent times, there has been movement towards shared decision making, whereby patients are more involved in the decision making processes about their treatment (Edwards, Evans, & Elwyn, 2003). In today's culture, this philosophy of patient-centred care is highly valued. The application of this notion of shared decision making as it relates to prostate cancer will be discussed further below.

Newly diagnosed men with prostate cancer choosing a treatment are met with a multitude of factors to consider including limited evidence concerning efficacy; the risk of potential side effects; recommendations from physicians, family members or friends; economic consequences; previous medical care experiences; and emotions about a diagnosis of cancer (Zeliadt et al., 2006). Some men wish to optimise their chance for 'total cure' and are willing to endure the potential occurrence of negative 'trade offs' such as urinary, bowel, and sexual dysfunction. Other men prefer to maintain their urinary, bowel, and sexual function and make treatment decisions which may increase their risk of cancer recurrence (Pickett, Brunner, Joseph, & Burggraf, 2000).

Many studies have explored different aspects of the treatment decision making process. Some of these include factors affecting the choice of treatment, men's role in decision making, and information needs. One of the most significant issues facing men with prostate cancer is decision-related distress. This distress may be related to the

stress experienced during the decision making process about treatment or even as decisional regret at a later point in time. Not surprisingly this distress can have a significant impact on the well-being of these men. The various aspects of decision making and decision-related distress will be discussed below.

Choosing Treatments

Once a diagnosis of prostate cancer has been made, clinical judgement has been the foundation for treatment decision making by the treatment team (Diblasio & Kattan, 2003). However, it is important to recognise that clinical judgement at times is beset by bias and preferences to recommend particular treatment methods over those with potentially superior results (Diblasio & Kattan, 2003). Indeed, studies have demonstrated that most patients with prostate cancer do not receive the information necessary to make a fully informed decision. As a result, patients often depend on physician opinion, anecdotes, and the opinion of other individuals (Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2002; Davison et al., 2009). Some research has found that it is physician speciality that is the strongest predictor of treatment choice and not patient preference as a result of specialists overwhelmingly advocating the treatment they provide (Diefenbach et al., 2002; Fowler et al., 2000; Sommers et al., 2008). If men with prostate cancer are not sufficiently informed, it is possible they will receive treatment that is not consistent with their values and preferences (Elstein, Chapman, & Knight, 2005).

Several studies have examined factors that impact on men choosing a particular treatment. Research has found that factors associated with treatment choice included age and Gleason score (an index of disease severity); older patients were less likely to choose radical prostatectomy and those with a Gleason score of equal to or greater than 7 were more likely to choose radical prostatectomy (Gwede et al., 2005). They found that patients differed in their beliefs of the effectiveness of treatment options, whereby

patients opting for prostatectomy more strongly believed that prostatectomy was a good option to treat their cancer than those opting for brachytherapy. Specifically, the prostatectomy group had stronger beliefs that the treatment they chose was the best opportunity for cure, while the brachytherapy group had stronger beliefs that the treatment they chose was less invasive, would result in fewer side effects, was least painful, and was convenient (Gwede et al., 2005). Interestingly, Gwede et al. (2005) found an age-effect, whereby older men were less likely than younger men to choose prostatectomy.

Perceptions of seriousness of the cancer have also been exposed as a factor in treatment choice whereby perceptions of seriousness were linked with men choosing surgery (Diefenbach et al., 2002). While men who chose prostatectomy had significantly lower PSA levels at diagnosis compared with those who opted for external beam radiation therapy, they perceived their cancer as more serious and chose surgery. Men who chose surgery believed that prostatectomy had a significantly higher chance of cure than the nonsurgical options. In contrast, men who chose external beam radiation therapy or brachytherapy believed that the treatment they chose would be less effective as a cure than comparable men who elected for prostatectomy (Diefenbach et al., 2002).

In other research on the factors involved in the decision making process, a study of 102 men with prostate cancer found that 70% of men in their sample did not cite a physician recommendation as a central factor in their treatment choice, despite 74% being recommended a specific treatment (Holmboe & Concato, 2000). Most men referred to factors such as evidence for a particular treatment, likelihood of side effects, and intrinsic characteristics of treatments such as invasiveness and length of recovery. Only 13% of men used a risk-benefit analysis to select their treatment. Another study on factors involved in decision making was conducted by Wallace and Storms (2007) using focus groups. Data from the focus groups indicated that men considered their age, the

stage and aggressiveness of the cancer, their lifestyle, treatment side effects, and the demonstrated effectiveness when choosing prostate cancer treatment. The side effects reported most feared by men in the study included impotence and incontinence and men were also worried about treatment success and life expectancy.

There have been several studies that have specifically focused on the factors involved in choosing watchful waiting. Watchful waiting is regarded as a treatment option that is appropriate for some men, particularly if they are at relatively low risk of dying from their disease. This would apply if they have low-risk disease which is defined as a Gleason score of less than or equal to 6, a PSA reading of less than or equal to 10, and stage TI or T2a prostate cancer, or if they have serious co-morbid disease (Thompson et al., 2007). In their study of men with localised prostate cancer Holmboe and Concato (2000) found that the most commonly cited reason for not choosing watchful waiting was the men's need to 'do something' about their cancer. Men also reported physician recommendation as the basis for declining watchful waiting. Another study on watchful waiting by Koppie et al. (2000) found that men who chose watchful waiting were more likely to be older, have lower baseline PSA levels, and more favourable disease characteristics than those who elected for definitive therapy.

Also examining the decision of watchful waiting was Bailey et al. (2007) in a qualitative study of 10 men with prostate cancer. A number of men regarded their decision to watch and wait as an opportunity to effectively manage their uncertainty through work, self-care, keeping options open, and the use of alternative medications and prayer. These men expounded various reasons to explain why watchful waiting was the best choice for them and used these to manage their decision uncertainty. Men used information about poor outcomes from prostate cancer treatment and lives impacted by aggressive surgical interventions to strengthen their confidence in their watchful waiting decision. In a study examining decisional control in patients who chose active

surveillance, Davison et al. (2009) found that men made this treatment choice because their medical professionals deemed it the best approach. The majority of men in the study believed they had assumed ownership of treatment decision after taking into account their doctor's opinion. Indeed, the role men have in the decision making process is important for their well-being and can affect their levels of decision-related distress.

Men's Role in Decision Making

As previously mentioned, in health care today, individuals expect and are asked to be involved in their medical decisions more than ever in the past with the emphasis on the shared decision making paradigm. Many individuals no longer view themselves as passive recipients of care but rather they expect to be involved in all decisions that affect them. The shared medical decision making paradigm encourages informed patients being included in treatment decision making with their physician (Davison & Goldenberg, 2003). However, it is possible that when first diagnosed, some men with prostate cancer lack adequate knowledge or understanding of their illness to be active participants in the decision making process. Using shared decision making in the context of prostate cancer is challenging given the plethora of treatment options available and the lack of clear differences in survival outcome. As such, preferences for participation in shared decision making in men with prostate cancer continue to be examined in the literature (Arora et al., 2009; Irani, 2010; Tariman, Berry, Cochrane, Dorrenbos, & Schepp, 2009).

An issue that has yet to be adequately explored in the literature is the relative contribution of patient factors, such as age and education, contextual factors, such as the nature and strength of the patient-physician relationship, and disease and treatment factors, such as disease stage and treatment side effects on the role taken in decision making. Hack et al. (2010) have suggested that a passive decision style may be

'imposed' on the patient by features of the medical context, such as the communication style of the health professional, which can diminish a patient's perceived capacity to adequately influence decisions impacting on his medical treatment, thereby possibly increasing distress levels. Alternatively, a passive decision style may not increase distress but it can increase other reactions, like dependency on the treating professionals. As such, the psychological components can be quite complex, depending on the personality of the patient and treating professionals. Below is an account of studies that have examined the role taken by men with prostate cancer in treatment decision making.

When considering the following research on the roles taken by men in their treatment decisions, it is important to bear in mind that what men consider 'passive' may vary quite markedly. Some men consider themselves to be collaborating but from the outsider's view they are taking a very passive role. In a study of 74 men with prostate cancer by Davison and Goldenberg (2003), the majority of men had a preference to play either an active (51%) or collaborative (42%) role in decision making with their doctor. Nonetheless, a significantly higher rate of men reported taking on a more active role in decision making than originally planned. The authors suggested that the most plausible explanation for this change was that information provided in the context of a counselling session reduced levels of psychological distress which enabled the men to take more control in the decision making process. However, these findings must be viewed in light of the small sample used. Similar results were found by Gwede et al. (2005) who found that the majority of patients in their sample preferred to have an active role in treatment decision making (63%) while fewer preferred a collaborative (29%) and only a minority a passive (8%) role. They found no significant differences by treatment group in decision making preference. Further consistent results were found by Davison, Parker, and Goldenberg (2004) in that 43% of their sample preferred an active

role, while 47% preferred a collaborative role and only 10% preferred a passive role. Similar results have been reported with Australian men. In another study by Steginga and Occhipinti (2004) it was found that most men (68%) indicated that they would prefer to share the decision about treatment between themselves and their doctors. No men indicated they would prefer the doctor decide alone, 9% preferred the doctor to mainly make the decision, 18% preferred that they as the patient mainly made the decision, and 5% preferred to make the decision on their own.

Related research by Sinfield, Baker, Agarwal, and Tarrant (2008) in 35 men with prostate cancer found that some specialists made the treatment decision without explanation or discussion of other treatments with patients, and at times patients reported that they did not have adequate knowledge to ask questions. Other specialists handed the decision over to the patient, which for some patients was unsettling. While the sample size was small, the findings indicated that not all patients were satisfied with these directive and non-directive methods to treatment decision making as there was a lack of tailoring it to their needs and wishes. Anecdotes from the study revealed that one patient stated he would have preferred a more collaborative approach and another who went on to regret his treatment decision (Sinfield et al., 2008).

The implications for men participating in decision making are proposed by Arora et al. (2009) who have suggested that a more participatory physician style may be related to superior mental health by increasing survivors' participation self-efficacy and thereby their perceptions of personal control as well as their levels of trust which in turn decrease perceptions of uncertainty. As fittingly stated by Sartor (2008), "it is not simply about making decisions that we might choose if given the same diagnosis; it is about educating the patient so that he can be empowered to make his own decisions among reasonable alternatives" (p.64). This statement clearly articulates the crucial role of collaborative decision making, which is so fundamental in the process of prostate

cancer treatment decision making. Also critical to the decision making is the information men receive about the various treatments and side effects.

Information Needs

While men's goals and values are central in their consideration of prostate cancer treatment, they need information about the available treatments and their anticipated outcomes. A study by Feldman-Stewart, Brennenstuhl, Brundage, and Siemens (2009) found that many men in their study with early stage prostate cancer wanted a lot of information about their condition and about treatment options. Nonetheless, there was a wide range within the group both in terms of the amount and details that were considered important by the men. While prostate cancer patients have access to a wide range of information sources about treatment options, minimal research has been conducted to evaluate the sources they use and the impact the sources have on treatment choice. Ramsey et al. (2009) found that although patients on average referred to nearly five information sources, 71% reported they were contemplating or intending only one treatment option, mainly surgery, or external beam radiation therapy. Further analyses revealed that younger age at diagnosis was positively related with consulting more information sources. Ramsey et al. postulated that younger men were more comfortable using the Internet, which could refer them to more sources of information if they wished. Men who were less educated referred to fewer sources, which may have been a result of them being restricted by their knowledge or access to certain sources of information such as the Internet. Further results found that men who were aged 60 and below and those men with more lower Gleason scores contemplated fewer treatments. Minimal relationships were found between the information source referred to and the number of treatments being contemplated, with the exclusion of men who looked at information on the Internet and who contemplated more options. Some information sources were significantly related to considering specific treatments; however the

degree of impact was generally much lower than age, co-morbidity and Gleason score. While this data offers some insight into the information sources being used by men with prostate cancer, the response rate was 57% and it is possible that those who responded to the survey may have been different than the non-responders in some way. This possibility needs to be considered in future research, perhaps identifying the characteristics of the non-responders.

The results of other research on information seeking behaviour in men with prostate cancer suggested that doctors and the information they provide play a significant role in the men's decision making process (Diefenbach et al., 2002). It was found that many men sought multiple treatment opinions, which they claimed displayed the men as active information seekers who try to obtain treatment from doctors of various specialities. The authors also suggest that it is possible that men elect to seek various opinions because they do not receive the necessary information from one source. Indeed, research by Sinfield et al. (2008), found that some men reported that explanations and information such as treatment options and side effects were not provided by their specialists. The men indicated that the urology nurse played an important role in meeting these information needs and some men also indicated that they subsequently accessed the internet for information.

Specifically with regards to the choice of active surveillance, research has found that men being advised to undertake active surveillance by their doctors may lead to an avoidance of seeking information about other treatment options. Indeed, Davison et al. (2009) found that men in their sample on active surveillance tended to trust their specialists to suggest the best treatment option for them. The men did not actively seek information as they were told by their doctor that their prostate cancer was low-risk and did not need treatment. For those who did seek information, the Internet and written information were the most commonly used sources of information; about one third of

patients stated that they communicated a need for information during their treatment consultation. The chances of developing side effects quoted on the internet impacted on some men's decision to pass up active treatment. Indeed, some men avoided treatment due to concerns of potential impotence and incontinence. Therefore, it is evident that the information that men are or are not provided with does impact on their treatment choice.

Decision-Related Distress

Irrespective of the treatment men with prostate cancer choose, the decision making process is difficult and distressing for many (Gwede et al., 2005). It has been suggested that men with a greater understanding of treatment options and potential side effects would not experience as much distress about treatment consequences, as compared to those men with less understanding of treatment options (Christie, Meyerowitz, Giedzinksa-Simons, Gross, & Agus, 2008). This further emphasises the importance of the dissemination of information to men who are deciding on prostate cancer treatment, as discussed previously. Furthermore, discussing treatment options with others has been found to impact on distress levels. Christie et al. (2008) suggested that data from their study indicated that discussing treatment options with others prior to commencing treatment, significantly contributed to improvements in affect at 1 and 6 months following initial treatment.

Research has found that decision-related distress varies across treatment types. In a sample of 654 men with prostate cancer Diefenbach et al. (2002) found that patients experienced moderate levels of distress during the decision making process. They examined decision-related distress by treatment type and found that compared to men who opted for prostatectomy, those who chose non-surgical treatment were significantly less distressed and were significantly less worried about the treatment decision. Despite the men experiencing decision-related distress, the men reported no regrets about their treatment decisions and maintained that they would make the same choice again.

Furthermore, Gwede et al. (2005) found that 45% of men with prostate cancer in their study reported distress during decision making. Similarly, following a treatment decision but prior to undergoing treatment, most men in Steginga et al.'s (2004) longitudinal study, reported clinically high decision-related distress, and for many this emotional reaction persisted during and after treatment. Specifically, at diagnosis, 63% of men had high decision-related distress, and for 42% of men this continued at 12 months after treatment. Moreover, Steginga and Occhipinti (2006) found a significant relationship between time since diagnosis and decision-related distress, with men closer to diagnosis describing more decision-related distress prior to treatment. Two months following treatment, urinary and sexual symptoms were positively associated with decision-related distress. Furthermore, decision-related distress prior to treatment was significantly related to decision-related distress at 2 and 12 months post-treatment (Steginga & Occhipinti, 2006).

As mentioned above, all treatment modalities have potential distressing side effects. Indeed, when deciding on prostate cancer treatment men face an important consideration of the apparent "trade-off" between survival and intact sexual functioning. Men have described the hardship of consenting to a treatment depriving them of their sexuality and feeling like they had to choose between life and sexual functioning (Berterö, 2001; Helgason et al., 1996). Furthermore, despite men in Helgason et al.'s (1996) study reporting their willingness to trade sexual function for the chance for cure, sexual dysfunction continued over time and was greatly distressing for these men. Similarly, men in a study by Gray, Fitch, Phillips, Labrecque, and Klotz (1999) maintained fears about potential sexual dysfunction following surgery for prostate cancer, but generally described them as secondary to getting well. Therefore, it is evident that distress regarding potential treatment side effects is apparent at the time of decision making.

Decisional conflict.

Decisional conflict is a state of uncertainty about a course of action (O'Connor, 1995). This type of uncertainty is more likely to arise when a person is faced with decisions involving risk or uncertainty of outcome, when high stake choices with substantial possible gains and losses are considered, where there is a need to make value tradeoffs in choosing a course of action, or when anticipated regret over the positive aspects of rejected options is likely (O'Connor, 1995).

This construct of decisional conflict was explored in 111 men with prostate cancer by Steginga et al. (2004) who found that undecided men reported greater overall decisional conflict compared with decided men. No statistically significant differences were found in decisional conflict among the various treatment groups, which included radical prostatectomy, external beam radiation therapy, and watchful waiting, across time. At baseline, men reported high levels of decisional conflict which declined following treatment. Prior to treatment, 63% of men had high decisional conflict, falling to 38% at 2 months after treatment and 44% at 12 months. However, this decreased conflict did not occur across all three revised Decisional Conflict Scale (DCS; O'Connor, 1995) subscales used in the study. While decisional uncertainty declined after treatment, prostate cancer uncertainty remained high. Scores on the perceived effective decision making subscale indicated that men were very satisfied with their final treatment choice, and this satisfaction did not fluctuate across time (Steginga et al., 2004).

Examining decisional conflict in a sample of men in a prospective protocol-based active surveillance program van den Bergh et al. (2009) found that lower scores on the DCS were linked with low scores on depression, generic anxiety, and prostate cancer-specific anxiety. Furthermore, their data revealed that men who viewed their doctor as playing the most important role in the shared decision making process were

also those who had more doubts regarding their choice for active surveillance. The authors postulated that this finding suggested that men who view themselves as having had actively participated in the decision making process have fewer doubts regarding their treatment decision.

Also using the DCS, Steginga and Occhipinti (2006) assessed decision-related distress in 111 men with localised prostate cancer. They found a significant correlation between time since diagnosis and decision-related distress at Time 1 (after diagnosis, before treatment) only, with men who were closer to diagnosis being those who reported higher levels of decision-related distress. At Time 2 (2 months after treatment or the decision to watch and wait), urinary and sexual symptoms were positively correlated with decision-related distress. Furthermore, decision-related distress at the time of diagnosis was significantly correlated with decision-related distress at Time 2 and 3 (12 months after treatment or the decision to watch and wait). Therefore, it is clear that decision-related distress as measured by decisional conflict does occur in some men with prostate cancer, although further research is needed to elucidate this occurrence.

Decisional regret.

Regret of a treatment decision can be defined as negative cognitions and affect elicited by thinking about a past treatment choice (Connolly & Reb, 2005). It often entails comparing the status quo after the decision has been implemented with a hypothetical situation that may have occurred if a different treatment choice had been made (Connolly & Reb, 2005). Different researchers have defined regret in very different ways. Most of the definitions of regret recognise that regret " (a) is aversive and is avoided if possible; (b) involves an intimate interplay of thought and feeling; (c) is at least somewhat distinct from other specific emotions, such as disappointment, and from general negative affect; and (d) involves a comparison of some event or process

with another, better event or a process that “might have been” ” (Connolly & Reb, 2005, p. S29).

In theorising about decisional regret, Connolly and Zeelenberg (2002) proposed the decision justification theory. The central notion is that when individuals confront a poor decision outcome, they ask themselves if the decision that led up to the outcome was justified. Regret is felt when the decision was somewhat or completely unjustified and then intensity of the regret is determined by the seriousness of the outcome (Connolly & Reb, 2005; Connolly and Zeelenberg, 2002). Decisional regret is an important aspect of decision making regarding how men live with their prostate cancer treatment decisions. Unfortunately, it is for the most part neglected in the literature with only several studies examining this issue in early stage disease and even fewer with advanced prostate cancer patients. However, the limited existing evidence demonstrates that cancer patients can experience considerable regret, and hence distress, from their decisions (Clark, Wray, & Ashton, 2001; Connolly & Reb, 2005).

Research on decisional regret in men with prostate cancer has found that 16% of men treated for early prostate cancer experienced at least some regret about their treatment decision and this was not dependent on the chosen treatment modality (Clark et al., 2003; Hu, Kwan, Saigal, & Litwin, 2003). These authors also found that 67% of regretful men would opt for a different treatment while 79% of non-regretful men would not opt for an alternative treatment, thereby resulting in an overall concordance rate of 77%. Both studies found sexual function to predict regret, whereby men with greater sexual dysfunction were more likely to express regret regarding their treatment decision. In line with the research by Clark et al. (2003) and Hu et al. (2003), Davison & Goldenberg (2003) found that the treatment modality had no impact on decisional regret. In a study by Brehaut et al. (2003), it was found that higher levels of regret were

significantly associated with greater levels of decisional conflict and lower levels of decisional satisfaction.

The studies described above examined decisional regret at one point in time. Diefenbach and Mohamed (2007) explored regret longitudinally, by assessing men at baseline and then at 6 and 12 months after baseline assessment. At the 6 and 12 month assessments, overall low levels of regret were found. A modest negative association was found between age and decisional regret, indicating that younger men tended to report higher levels of regret than their older counterparts. Findings from their study also revealed that regret increased significantly over time. A significant interaction between treatment and time was found as well as a main effect of treatment with the surgery group reporting more regret compared to the external beam radiation therapy and brachytherapy groups.

Diefenbach and Mohamed (2007) also examined the relationship between regret and physical symptoms. No significant association was found between regret and sexual dysfunction; however, both cross-sectional and longitudinal correlations between sexual bother and regret were found at 6 and 12 month assessments. Significant time effects were found for sexual dysfunction and sexual bother, denoting significant increases in those domains between baseline and both follow-up assessments. With regards to urinary function, significant cross-sectional and longitudinal associations were found between regret, urinary dysfunction, urinary bother, and activity limitations due to urinary dysfunction. This was found at various points in time signifying that higher levels of regret were related to great bother and activity limitations due to urinary dysfunction. These correlations of regret and urinary variables are consistent with the findings of Hu et al. (2003) and Clark et al. (2001). Significant time effects were found for urinary dysfunction, bother, and activity limitation due to urinary dysfunction with

patients reporting a significant increase in the three areas between baseline and follow-up assessments.

Cross-sectional predictors of decisional regret were explored at the 6 and 12 month follow-up. At 6 months results exhibited significant effects of sexual and urinary bother, and activity limitations due to urinary dysfunction on regret. However, no significant effect was found for urinary dysfunction. At the 12 month follow-up, there were significant effects of treatment modality, sexual bother, and activity limitations due to urinary dysfunction. A decrease in the effect of urinary bother on regret was found compared to the findings at 6 months (Diefenbach & Mohamed, 2007).

While overall levels of regret were low in Diefenach and Mohamed's (2007) study, unlike other studies regret differed by treatment modality, whereby the surgery group reported the highest levels of regret. The authors suggested that this difference may be due to the length of time since definitive treatment. The long period of time between diagnosis/treatment and assessment in other regret studies may have allowed time for recovery processes to cushion the effect of treatment side effects on decisional regret. Men in Diefenach and Mohamed's study had completed treatment within the first 6 months following diagnosis, and their measurements addressed regret while men were still in the active phase of recovering from their treatment and coping with its side effects. While overall low levels of decisional regret have been found in men with prostate cancer, various factors impact on this regret, such as side effects of treatment.

An additional aspect of decisional regret examined in the literature is well-informed patient decisions (Connolly & Reb, 2005). Men with metastatic prostate cancer in Clark et al.'s (2001) study who reported more regret were more dissatisfied with their role in decision making, believed they had been given less information than they required, and were more likely to feel that they did not have options open to them. Other research revealed that whether the men chose an active or collaborative role in

decision making with their doctors did not influence their degree of decisional regret (Davison & Goldenberg, 2003).

The above discussion around the importance of decisional regret signifies the need for additional data to determine, whether patients experience distress and regret in the long-term as they experience long-term disease outcomes, such as recurrence, and treatment choice side effects. The notion of anticipatory regret comes into play, whereby when individuals make decisions, they may feel regret as to whether they are making the wrong decision. They thus take this anticipated regret into account when they decide (Zeelenberg, 1999). Indeed, it is likely that complex interactions surface between anticipatory regret that impacts on earlier decisions, experience of actual regret resulting from those decisions, and anticipatory regret during ensuing decisions.

Decisional satisfaction.

On the opposite end of the spectrum to decisional regret, decisional satisfaction refers to one's level of satisfaction with a medical decision, however good or bad the ensuing prognosis (Holmes-Rovner et al., 1996). Decisional satisfaction was examined by Hoffman, Hunt, Gilliland, Stephenson, and Potosky (2003) and they found that 59.2% of men having treatment for clinically localised prostate cancer were delighted or pleased with their treatment decision. Only 3.5% reported being dissatisfied, unhappy, or feeling terrible with their decision. Satisfaction was highly correlated with willingness to undergo the same treatment. Among those who were satisfied with their treatment decision, 76.8% revealed that they would definitely make the same treatment selection again, while only 10.4% of the men not satisfied with their decision would make the same choice again.

In a recent study involving 1,542 men with prostate cancer, Abraham et al. (2010) found that most men were satisfied with their decision after undergoing radical prostatectomy. Post-operative factors, such as the duration of catheterisation, were

related to short-term satisfaction while sexual and urinary function, and biochemical failure were linked with long-term satisfaction. Therefore, as the above studies have showed, many factors influence decisional satisfaction and most men undergoing treatment for prostate cancer appear to be satisfied with their treatment decision. However, given only a handful of studies have examined satisfaction in men with prostate cancer, more research in this area is needed to fill this gap in the literature and provide more insight into decisional satisfaction in this population.

Decision Making and Age

Age is the most important risk factor for prostate cancer. The incidence of prostate cancer rises with age (Jemal et al., 2008). Despite the higher incidence of prostate cancer in older men, they are more likely to die from other conditions than from prostate cancer (Satariano, Ragland, & van den Eeden, 1998). Indeed, in older men prostate cancer is often an indolent disease with many patients diagnosed with organ-limited prostate cancer and experiencing no symptoms. Most older men diagnosed with prostate cancer have low to intermediate risk prostate cancers, yet more than 90% endure active treatments (Cooperberg et al., 2004). However, despite the high percentage of men undergoing treatment, older men may not experience a mortality benefit from aggressive treatments they choose (Mohile et al., 2008). Indeed, Holmberg et al. (2006) found that in men aged 65 years and over, the reduction in prostate cancer-specific death for surgery versus observation was 0.3% at 10 years compared to 11% for those under 65 years. These types of statistics present a challenge in the decision making process for older men with prostate cancer.

Deciding on a management plan for older adults is challenging because such patients often do not fit simply into guideline-based care (Boyd et al., 2005). There are often competing mortality risks and patients are on multiple medications. Furthermore, limited high-quality data exists regarding outcome and clinical time is very restricted.

As such, clinicians constantly have to make decisions based on extrapolations and interpolations from data obtained from younger cohorts without these complications (Mohile et al., 2008). Importantly, in making such decisions, one should be aware of two potential mistakes, those of ageism and overtreatment. Ageism is defined as denying effective management to someone based purely on age. Overtreatment is treating patients with toxic therapies for diseases which are unlikely to cause serious problems in the remaining time of their lives (Mohile et al., 2008).

Mohile et al. (2008) suggested that when making management decisions for men with prostate cancer two steps should be followed. Firstly, it is worth considering whether there are potential survival benefits from the decision. In order to do this, it is necessary to estimate the patient's Remaining Life Expectancy (RLE) and the chance that the treatment's expected benefits will occur within that RLE. Some issues that may affect RLE are co-morbidities, functional impairments, and geriatric syndromes including cognitive impairment. If survival gains are not likely, then quality of life should guide the decision. However, patient preferences must be considered in making the final determination of the benefit at all times.

As stated above, prostate cancer decision making for the older man is complex, and prostate cancer often has a long natural history and considerable potential side effects from treatment. Deciding on who should undergo treatment necessitates the assessment of both prostate cancer characteristics and the underlying health status of the individual (Mohile et al., 2008). Factors such as comorbidity have been identified as a significant prognostic indicator for survival of prostate cancer. Indeed, as alluded to earlier, it has been established that men diagnosed with prostate cancer die with the disease as opposed to from their disease (Satariano et al., 1998). Evidence for this was phenomenon was found by Fouad et al. (2004) who examined the medical records of more than 500 men with prostate cancer and found that over 50% of those men died

from other causes. Indeed, according to Carter et al. (2007), most older men diagnosed today with screen-detected prostate cancer do not increase their lifespan with curative intervention. Treatments for prostate cancer with intent of cure can significantly affect quality of life. In many men treated for localised disease, the potential negative impact from treatment complications overrides concerns over survival (Cowen et al., 1998; Diblasio & Kattan, 2003). At present, the optimal approach for managing localised prostate cancer in the older man is yet to be verified as there is a deficit of comparative randomised controlled trials of treatment options for localised disease (Mohile et al., 2008).

While the above discussion focuses on decision making in older men, Sidana et al. (2011) investigated decision making in younger men. As previously mentioned, treatment decisions are potentially more difficult for young men given the greater impact treatment will have due to their longer life expectancy. Furthermore, as previously discussed, issues relating to the preservation of sexual function are likely to be more influential in younger men. As such, younger men actively seek information from multiple sources and multiple doctors prior to making their final treatment decision (Sidana et al., 2011).

The sample in Sidana et al.'s (2011) study consisted of 488 men under the age of 50 who had a diagnosis of clinically localised prostate cancer with a Gleason score of 6. The men were grouped according to the various treatments they had undergone including surgery, radiation therapy, active surveillance, and other treatment. In all groups, the doctor's recommendation was the most influential source of information. However, this was somewhat less important in the active surveillance group. The Internet was the second most often used information source. The researchers found that men with higher levels of education and higher income deemed sexual function more important while making their treatment decision. Out of the sample only 2% of the men

preferred a passive role in the decision making process. It was found that informed decision making was the preference of more men who chose radiation and active surveillance while shared decision making was preferred more by men who opted for surgery. The majority (89%) of men reported no decisional regret. No difference in satisfaction levels was found between different treatment modalities.

In summary, it is clear from the above discussion that the decision making process for men with prostate cancer is complex. Furthermore, the various decision making outcomes, such as conflict, regret, and satisfaction, potentially impact on the men's well being. Therefore, it is vital for research to explore these aspects of the process in order to ensure men are making the right decision for themselves and are involved in a shared decision making process.

Aims and Expectations of the Study

The overall aim of the current study was to investigate the experience of men with prostate cancer over three time points and thereby contribute to the body of knowledge about the effects of prostate cancer on men's well being. The preceding review of the relevant literature has identified a number of factors that are important to our understanding of the experience of prostate cancer in men. On that basis, the current research was designed to ask a sample of Australian men to report on their psychological distress, physical symptom experience, and their experiences of decision making about treatment for prostate cancer. Psychological distress was operationalised as depression, anxiety, and trauma. Physical symptoms were urinary, bowel, and sexual function as well as pain and fatigue. Decision-related distress was operationalised as decisional conflict, regret, and satisfaction.

Few studies have examined the predictors of depression, anxiety, and trauma in men with prostate cancer. It is important to be able to identify the difficulties that may be precipitating and perpetuating psychological distress in order to manage these difficulties and thereby decrease distress. As such the current study aimed to explore the physical symptom and decision making predictors of psychological distress in men with prostate cancer. It was expected that men with more physical symptoms, symptom bother, symptom distress, and decision-related distress would report higher levels of depression, anxiety, and trauma. It was also expected younger men would exhibit greater levels of psychological symptoms and older men would exhibit more physical symptoms. Furthermore, while many studies have investigated the physical symptom experience in prostate cancer samples, most have neglected to examine the distress associated with these symptoms. Therefore, the current study aimed to rectify this by examining the distress associated with urinary, bowel, and sexual symptoms.

In the current study, a longitudinal design was employed and data were gathered at three time points. This was fundamental to this research approach as it allowed psychological distress, physical symptom experience and distress, and decision-related distress to be examined as a function of time; a factor that has received little consideration in previous research. It was predicted that the psychological variables at Time 1 would account for a large proportion of the variance of the psychological variables at Time 2 and 3 above and beyond the other Time 2 and 3 variables. It was also hypothesised that differences across time would be found for the psychological, physical, and decision making variables.

The study comprised a survey approach, using multiple self-report measures to assess men's psychological and physical symptoms as well as their decision making and coping styles. Participants who completed a questionnaire at Time 1 were contacted three months later and were asked to complete a Time 2 questionnaire. Participants who completed Time 2 questionnaires were contacted three months later and were asked to complete a Time 3 questionnaire. Regression analyses were principally used to offer insight into the predictors of psychological distress in men with prostate cancer over time.

Method

Participants

Men with prostate cancer attending a major Melbourne hospital were informed of the study and invited to participate by their treating physician, who referred them to the researcher if they were interested in participating. Of the 185 questionnaires that were handed out to eligible patients, 141 (67%) of those were returned completed at Time 1. At Time 2, 86 were completed and at Time 3, 66 were completed. There was approximately 3 months between each time period. The inclusion criteria required a diagnosis of prostate cancer. The following exclusion criteria applied to participants; namely having a cancer other than prostate cancer so as to reduce contamination of the results, previously or currently documented dementia or other psychiatric illness which would mean that individuals would have difficulty comprehending the information provided about the study and completing the study questionnaire, previously documented cognitive limitation that means participants would not be in a position to offer informed consent and complete the study questionnaire, and debilitation that, in the researcher's or physician's opinion, would have impaired the ability of the participant to complete the study questionnaire, or where participation would potentially have increased the distress of the participant.

Participants in the study were aged between 51 and 95 years (M = 70.53, SD = 10.43). Of the sample, 70% of the participants were born in Australia while the remaining 30% were born in a wide range of other countries across Europe and Asia. Regarding relationship status, 75% of the men in the study were married or in a de facto relationship, 6% were divorced, 11% were widowed, and 6% were single. The breakdown of the highest level of education completed by the men in the study included 18% primary school, 36% secondary school, 32% trade qualification/TAFE, 9% undergraduate university course, and 3% postgraduate university course. In terms of

employment, 14% of participants were employed full-time, 9% part-time, 68% were retired, 6% were unable to work because of disability, and 1% engaged in volunteer work. Regarding treatment at the time of the study, from those men whom treatment data were available, 40% were having no current treatment, 18% were having hormone treatment and 13% were having other treatment such as radiotherapy. However, because of logistical constraints concerning file access in the hospital setting, there were no treatment data available for 28% of the sample. Clinical data obtained found that less than 1% of men in the study had a Gleason score of 3 while 2% had a score of 5, 18% had a score of 6, 21% had a score 7, 7% had a score of 8 and 6% had a score of 9. There was no Gleason score available for 45% of the men in the study.

Measures

Participants completed a range of measures in questionnaire format to assess their physical and psychological symptoms, as well as their decision making and coping processes relating to their experience of prostate cancer. A copy of the questionnaire is shown in Appendix A, and each measure is described in detail below. Some of the questionnaires below were omitted from the Appendix for copyright reasons.

Tumour grade.

Gleason scores are the most commonly used tumour grading system (Gleason, 1992). This system assigns a grade for each prostate cancer from 1 (least aggressive) to 5 (most aggressive) based on the architectural differentiation of the tumour. Tumours often display several different grade “patterns” within the prostate or even a single core biopsy. Therefore, the Gleason score is acquired by assigning a primary grade to the most predominant grade present and a secondary grade to the second more predominant grade. In the situation where the most aggressive patterns present in a biopsy is not either the most predominant or second most predominant pattern, the Gleason score is acquired by adding the most predominant pattern grade with the highest grade. For

example, the Gleason score is exhibited as 3 + 4 where 3 would be the most common pattern of tumour and 4 the second most common pattern of tumour seen in the core. As the individual Gleason value can range from 1 to 5, the combined values can range from 1 + 1 to 5 + 5 or from 2 to 10. The majority of detected tumours have Gleason scores ranging from 5 to 10. With each increase in tumour score, such as from Gleason 5 to 6, there is an increase in tumour aggressiveness. High-grade cancer most often refers to the most aggressive tumours, generally Gleason scores of 8 to 10, but can also include Gleason 7 tumours (Thompson et al., 2007). In the current study, the Gleason score was obtained from participant's medical records.

Physical symptoms.

The International Prostate Symptom Score (IPSS; Barry et al., 1992) is a widely used practical symptom index for urinary problems. The IPSS recalls symptom severity over the past month. It comprises seven items, each with 5-point response options, relating to incomplete emptying, frequency, intermittency, urgency, weak stream, straining and nocturia, as well as one item about quality of life. Each question regarding urinary symptoms allows the patient to select one out of six responses indicating heightened severity of the particular symptom. The answers were assigned points from 0 to 5. The total score therefore ranged from 0 to 35 with higher scores indicating more symptoms. A score of 0–7 indicated mild, 8–19 moderate and 20–35 severe symptoms. The response for the quality of life question ranges from “delighted” to “terrible” or 0 to 6. The measure has been validated with patient groups and shows excellent discrimination between patients and normal controls (Barry et al., 1992). It has excellent test-retest reliability, 0.92 and internal consistency, 0.86 and is sensitive to change following prostatectomy (Barry et al., 1992). In the present study, the alpha coefficients for reliability were .76 at Time 1, .88 at Time 2, and .82 at Time 3.

The University of California, Los Angeles Prostate Cancer Index (UCLA-PCI) (Litwin et al., 1998) is a 20-item measure of health-related quality of life for men with prostate cancer. It includes six disease-targeted domains that measure function and bother in the urinary, sexual, and bowel domains, with participants rating their responses on a self-report scale. There is a total of 20 items whose scores were recoded to a value between 0-100, with higher scores indicating superior function and less bother. An average value was then calculated for the items in each of the three function scales. The recoded values for the three bother items were the scores for the bother scales. Missing data were ignored and the scale score was calculated without the missing item, as per the scale guidelines. If more than 50% of the items were missing from any one scale, it could not be calculated. In the current study, a distress item was added to the urinary and sexual sections to assess for symptom distress in these domains. The disease-targeted scales demonstrated excellent test-retest and internal consistency reliability. The reliability coefficients were 0.87, 0.65, and 0.93 for urinary, bowel, and sexual function, respectively. Exploratory factor analysis supported the hypothesis that urinary, bowel, and sexual factors are discrete domains that include both function and bother, with the correlations between factors ranging from 0.31 to 0.39 (Litwin et al., 1998). In the current study the reliability coefficients were 0.43, 0.39, and 0.39 for urinary function at Time 1, 2, and 3, respectively. The reliability coefficients were .59, .67, and .58 for bowel function and .94, .93, and .91 for sexual function at the respective time points.

The Brief Pain Inventory Short-Form (BPI-SF; Cleeland, 1991) is an 11-item self-report measure rating scale using simple numeric rating scales from 0 to 10 to assess pain severity and the degree to which pain interferes with functioning. The BPI-SF scoring was done by averaging the severity and interference subscales separately, which had four and seven items respectively. This resulted in two scores, a pain severity

score and overall pain interference score. Each score ranged from 0-10 with higher scores indicating a higher level of pain severity and interference. Evidence for the validity of the BPI-SF comes from several studies using the instrument with cancer patients and patients with other diseases who had pain (e.g., Cleeland & Ryan, 1994). The BPI-SF has demonstrated validity as a measure of disruption in daily life due to pain (Daut, Cleeland, & Flanery, 1983). The BPI-SF has demonstrated respectable test-retest reliability. Cronbach alpha reliability ranges from 0.77 to 0.91. Internal consistency of the seven-item interference scale has ranged from 0.86 to 0.92 (Serlin, Mendoza, Nakamura, Edwards, & Cleeland, 1995; Ward et al., 1993). Reliability coefficients in the current study were .91, .97 and .90 for pain severity and .93, .95 and .92 for pain interference at Times 1, 2, and 3 respectively.

The Brief Fatigue Inventory (BFI; Mendoza et al., 1999) is a 10-item self-report measure which assesses the severity of fatigue and the impact of fatigue on daily functioning in cancer patients. A global fatigue score was obtained by averaging all BFI items with a possible range of scores between 0-10, with a higher score indicating more fatigue. A factor analysis by Mendoza et al. (1999) was performed to determine the construct validity of the BFI and it identified a single underlying construct among the nine BFI items. The factor loadings were high, ranging from 0.81 for usual fatigue to 0.92 for activity, indicating the relationship of the nine BFI items with a single factor. Reliability of the BFI has been shown with an internal consistency coefficient of 0.96 (Mendoza et al., 1999). In the current study, reliability coefficients were .96, .97, and .96 for Times 1, 2, and 3 respectively.

Psychological distress.

The Beck Depression Inventory II (BDI-II; Beck, Steer, & Brown, 1996b) is a widely used inventory to assess depression. It consists of 21 groups of statements and participants are asked to select one statement in each group that best describes the way

they have been feeling during the past two weeks. Each item had a possible range of scores from 0-3. The scale was scored by summing the responses from the 21 items with total scores ranging from 0-63, where a higher score indicates more depression. According to Beck, Steer, and Brown (1996) scores ranging from 0 to 13 represent minimal depression, scores from 14-19 are mild, scores from 20 -28 are moderate, and scores from 29-63 are severe.

The domains of depressive symptomatology assessed by the BDI-II include sadness, pessimism, past failure, loss of pleasure, guilty feelings, punishment feelings, self-dislike, self-criticalness, suicidal thoughts or wishes, crying, agitation, loss of interest, indecisiveness, worthlessness, loss of energy, changes in sleeping pattern, irritability, changes in appetite, concentration difficulty, tiredness or fatigue, and loss of interest in sex. The BDI-II has been shown to be a reliable and valid measure of depression severity, demonstrating high internal consistency among college students and outpatients, with alpha coefficients ranging from 0.90 to 0.91 (Beck, Steer, Ball, & Ranieri, 1996; Dozois, Dobson, & Ahnberg, 1998). The reliability coefficients in the current study were .89 for Time 1, .94 for Time 2, and .90 for Time 3, which is comparable with the strong reliability found in previous studies stated above.

The Beck Anxiety Inventory (BAI; Beck, Epstein, Brown, & Steer, 1988; Beck & Steer, 1990) is a 21-item scale self-report measure of anxiety symptoms, including the physiological, cognitive, and somatic aspects of anxiety. Respondents indicated the extent to which they were bothered by each symptom. Each item was rated on a 4-point rating scale ranging from 0 (*not at all*) to 3 (*severely, I could barely stand it*). The total scores ranged from 0-63, which higher scores corresponding to higher levels of anxiety. According to the classification suggested by Beck and Steer (1990), a score of 0-9 is considered normal, 10-18 is considered to indicate mild-moderate anxiety, 19-29 moderate-severe anxiety, and 30-63 severe anxiety. A Cronbach alpha of 0.92 has been

reported for the BAI (Beck et al., 1988). In the present study, reliability coefficients were .89 for Time 1 and .92 for Times 2 and 3 which are similar values to those found in previous research.

The Impact of Events Scale (IES; Horowitz, Wilner, & Alvarez, 1979) is likely the most commonly used self-report measure in the domain of traumatic stress (Creamer, Bell, & Failla, 2003). The two subscales of the IES, intrusion and avoidance, were a reflection of the core phenomena of traumatic stress reactions as seen by Horowitz et al. (1979). Despite widespread use of the IES, the scale does not include the third major symptom cluster of PTSD, namely persistent hyperarousal. To deal with this insufficiency the Impact of Events Scale-Revised (IES-R; Weiss & Marmar, 1997) was published in 1997. In order retain comparability with the original version, only minor changes were made to the original items regarding intrusion and avoidance. The IES-R is a 22-item measure of trauma which includes three subscales, intrusion, avoidance, and hyperarousal. Participants were asked to rate each item on a scale of 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit) and 4 (extremely) according to the past 7 days. There are no "cut-off" points as the IES-R is intended to give an overall assessment of symptomatic status over the previous 7 days. The possible range of scores was 0-88 with higher scores indicative of higher levels of trauma.

Weiss and Marmar (1997) reported high internal consistency for the IES-R, with alpha coefficients ranging from 0.87 to 0.92 for intrusion, 0.84 to 0.85 for avoidance, and 0.79 to 0.90 for hyperarousal. Test-retest correlation coefficients ranged from 0.57 to 0.94 for intrusion, 0.51 to 0.89 for avoidance, and 0.59 to 0.92 for hyperarousal. Furthermore, findings by Creamer et al. (2003) indicated high internal consistency for the total scale with a Cronbach's alpha of 0.96, and also for the three subscales, intrusion, 0.94; avoidance, 0.87; and hyperarousal, 0.91. Reliability coefficients in the present research were .95 at all time points.

Decision making.

The Decisional Conflict Scale (DCS; O'Connor, 1995) is a 16-item measure consisting of three subscales that elicit uncertainty about choosing between alternatives, awareness of modifiable factors contributing to the uncertainty, and perceived effectiveness of decision making process. Each item was rated using on a 5-point Likert scale (strongly agree, agree, neither agree nor disagree, disagree, strongly disagree). Subscales were combined to give a total decisional conflict score, which could range from 16 to 80. Higher scores were indicative of higher decisional conflict.

The DCS has met acceptable standards of reliability and validity. No statistically significant difference was found between test and retest scores, with the test-retest correlation coefficient being 0.81. Internal consistency was high, with alpha coefficients ranging from 0.78 to 0.92. Validity data indicated that the DCS was consistent in significantly discriminating between those who accepted/rejected and those who delayed/were unsure of a healthcare decision, such as cancer screening (O'Connor, 1995). Similar patterns were seen with most subscales. Reliability coefficients in the present research were .97 for Time 1, .96 for Time 2, and .97 for Time 3.

The Decision Regret Scale (DRS; Brehaut et al., 2003) is a 5-item measure of distress/remorse after making a health-related decision. Each item was rated using a 5-point Likert-type response format. Two of the statements (items 2 and 4) were phrased in the negative to circumvent yea-saying bias. The two negatively-worded items were reverse scored and subsequently the mean of the 5 items was calculated. To assist with interpretation of the scores, the scores obtained were converted to a 0-100 scale by subtracting 1 from each item and multiplying by 25. To obtain a final score, each item was summed and averaged. Higher scores were suggestive of great levels of regret, whereby a score of 0 indicated no regret and a score of 100 indicated high regret.

In validating the DRS, four different studies were conducted, with the four samples including menopausal women deciding whether or not to choose hormone replacement therapy (HRT), patients with breast cancer deciding whether to proceed with adjuvant therapy after the primary surgical intervention (BCAT), women deciding between lumpectomy and mastectomy for the treatment of breast cancer, and finally men considering different options for prostate cancer treatment (Brehaut et al., 2003). Mean item scores were well below the midpoint of the scale on all items for all groups. Internal consistency was high for all groups, with alpha coefficients ranging from 0.81 to 0.92. Levels of regret were found to correlate well with a variety of other decision-related measures, demonstrating strong negative correlations with decision satisfaction (r = -0.40 to -0.60) and moderate positive correlations with decisional conflict (r = 0.31 to 0.52). Furthermore, the scale discriminated between predicted subgroups of patients. The above preliminary validation data indicate that the scale is able to identify a stable construct across various decisions and populations (Brehaut et al., 2003). In the present study, reliability coefficients were .79 at Time 1, .83 at Time 2, and .86 at Time 3.

The Satisfaction with Decision Scale (SWD; Holmes-Rovner et al., 1996) measures satisfaction with health care decisions. The six-item scale was rated using a 5-point Likert-type response format. The SWD has excellent reliability with a Cronbach's alpha of 0.86 and good discriminant validity. Higher scores on the SWD indicated increased satisfaction, with a range of possible scores being between 1 and 30.

The SWD as a specific measure of satisfaction with a decision, was required to be distinct from other measures of satisfaction. For example, satisfaction with a decision, should be negatively correlated with decisional conflict, and this was found to be the case with r = -0.54 (Holmes-Rovner et al., 1996). The SWD scale is not intended to assume a positive health outcome, but to measure satisfaction with the decision,

whether the prognosis is good or bad. Reliability coefficients in the current study were .96 at Time 1, .97 at Time 2, and .94 at Time 3, indicating a high level of reliability.

Coping.

The Brief COPE (Carver, 1997) consists of 14 scales each with two items, and measures coping responses known to be relevant to effective and ineffective coping. All items were scored on a 4-point scale from 0 = *I haven't been doing this at all*, to 3 = *I've been doing this a lot*. Examples of coping scales include active coping and behavioral disengagement. The Brief COPE is a modified version of the COPE (Carver, Scheier, & Weintraub, 1989) and is useful to minimise time demands on participants. Reliability and validity data were reported with Cronbach alphas ranging from .50 to .90. The reliability coefficient for the current study was .91 for the total scale score.

Resilience.

The Resilience Scale (RS; Wagnild & Young, 1993) is a 25-item measure that examines the degree of individual resilience, which is considered a positive personality characteristic that enhances individual adaptation to life stressors. All items were scored on a 7-point scale from 1 = disagree, to 7 = agree. Possible scores ranged from 25 to 175 with higher scores reflecting higher resilience. The RS has been deemed to have internal consistency, reliability, concurrent validity, and construct validity as indicated by a factor analysis. The reliability coefficient for the current study was .97.

Qualitative data.

Participants were asked to respond to questions about what was difficult about their cancer overall and at the time of the study, as well as whether they were satisfied with their treatment decision and why or why not.

Procedure

Participants in the study were recruited through the Urology and Oncology Clinics at a major Melbourne hospital. Due to unforeseen difficulties with recruitment

and to ensure sufficient numbers for analyses, participants were also recruited through private rooms of doctors from the hospital. Medical practitioners in the clinic were fully briefed about the study by the researchers and requested to discuss the study with potential participants. If the patient was eligible and interested in the study, the researcher went through the Participant Information and Consent Form and provided the participant with sufficient time to read and understand it, and to ask any questions they may have had. If the patients were satisfied that they understood what their participation in the study involved, and they had all their questions answered to their satisfaction, they were asked to sign the consent form to participate in research, in the event they were willing to participate. All potential participants had the opportunity to ask questions and seek clarification about any issues raised. Participants were then given the questionnaire by the researcher and completed the questionnaires at the hospital or at home. Questionnaires were returned to researchers and securely stored. Participants who completed a questionnaire at Time 1 were contacted three months later and were asked to complete a Time 2 questionnaire which was identical to the Time 1 questionnaire in content. Participants who completed Time 2 questionnaires were contacted three months later and were asked to complete a Time 3 questionnaire which was the same as Times 1 and 2 with the additional inclusion of measures to assess coping and resilience.

Results

Overview of Data Analysis

Prior to data analysis, data screening was undertaken. To replace missing values, Tabachnick and Fidell's (2007) suggestion of means substitution using available subscale data was applied. No pattern of missing values was apparent and the rate was deemed acceptable. Reverse scored items were recoded prior to the computation of scale scores.

Descriptive statistics for variables under investigation were calculated. Correlations and multiple regression analyses were performed to determine which variables best predicted depression, anxiety, and trauma in men with prostate cancer. Analyses of variance (ANOVA) were used to explore differences in patterns of symptoms and any associated distress over time and age in men with prostate cancer.

Data Screening

Prior to analyses, descriptive statistics for all variables were calculated and inspected. Frequency tables were produced and examined to check for correct minimum and maximum scores, out-of-range scores and any anomalies. All data were within the expected range on each variable.

Violations of assumptions of normality for later statistical tests were assessed. As many statistical procedures rely on assumptions of normal distributions of data (Tabachnick & Fidell, 2007), normality of continuous variables was assessed before parametric analyses were conducted. To determine whether the data were normally distributed both graphic and statistical methods were used. Inspection of histograms, box plots, expected normal probability plots and detrended expected normal probability plots for each variable provided an initial assessment of this assumption and suggested that several variables were not normally distributed. Overall the non-normality was considered to reflect essential features of the constructs rather than a problem in the data

set. Nevertheless, assumptions of normality were important for the planned analyses, so transformations were attempted but they appeared to have no discernible influence on the analyses and it was decided that all scores would remain in their original form to aid interpretation. Due caution in interpreting the results therefore needs to be exercised.

Descriptive Data

Means and standards deviations as well as observed and possible ranges of each of the variables in the current study across the three time points are shown below in Table 1.

Table 1

Mean, Standard Deviation, Observed and Possible Scale Range for Measures at Time 1, Time 2, and Time 3

	Time 1 (N = 141)			Time 2 (N = 86)			Time 3 (N = 66)			
	M	*SD*	Observed range	*M*	*SD*	Observed range	*M*	*SD*	Observed range	Possible range
Physical symptoms										
Prostate symptoms	8.76	6.39	0-35	9.10	7.65	0-30	8.12	6.72	0-30	0-35
Urinary function	70.67	14.99	13-100	69.21	15.55	13-87	70.89	14.74	23-87	0-100
Urinary bother	75.54	29.30	0-100	74.71	30.50	0-100	78.03	28.93	0-100	0-100
Urinary distress	0.49	0.77	0-3	0.52	0.80	0-3	0.45	0.79	0-3	0-3
Bowel function	86.25	15.96	22-100	88.99	13.47	39-100	88.43	11.81	56-100	0-100
Bowel bother	12.94	23.45	0-100	10.59	21.61	0-100	11.92	23.01	0-100	0-100
Sexual function	19.61	26.78	0-100	17.50	23.07	0-84	20.56	25.18	0-84	0-100
Sexual bother	52.29	43.79	0-100	46.04	43.30	0-100	45.83	42.73	0-100	0-100
Sexual distress	0.74	1.00	0-3	0.89	1.13	0-3	0.82	1.03	0-3	0-3
Pain severity	0.44	1.08	0-6	0.68	1.45	0-8	0.35	0.81	0-4	0-10
Pain interference	0.83	1.69	0-9	0.99	1.96	0-8	0.61	1.35	0-5	0-10
Fatigue	2.14	2.32	0-9	2.13	2.47	0-10	1.95	2.04	0-7	0-10
Psychological symptoms										
Depression	8.88	7.83	0-36	9.19	8.95	0-41	9.18	8.20	0-34	0-63
Anxiety	5.58	6.63	0-45	5.82	7.83	0-51	6.47	7.84	0-44	0-63
Trauma	9.66	13.64	0-67	8.65	12.98	0-72	9.02	12.86	0-54	0-88
Decision making										
Decisional conflict	18.13	16.37	0-100	16.19	14.04	0-53	17.58	15.89	0-61	0-100
Decisional regret	21.05	19.43	0-100	22.28	23.02	0-95	22.83	22.25	0-100	0-100
Decisional satisfaction	24.95	5.55	6-30	25.66	5.12	6-30	25.33	4.27	11-30	1-30

As mean scores were fairly consistent across time, the summary of the above findings will be discussed in relation to all three time points, unless otherwise specified. Scores for prostate symptoms as measured by the IPSS indicated that the participants reported being moderately symptomatic. For urinary function and urinary bother as measured by the UCLA PCI, the mean score indicated relatively good urinary function for most men; however the standard deviation and observed range indicate that for other men urinary function was problematic and there was a considerable amount of associated bother. Urinary distress scores were relatively low, indicating that most men did not find their urinary symptoms concerning. Bowel function mean scores were relatively high, indicating that most men did not have difficulties in this area. In line with this, most men did not report much bowel bother. In the final domain of the UCLA PCI which is sexual function, mean scores indicated substantial difficulties in this area. Bother related to sexual function was moderate for most participants; however the large standard deviation indicated that there was considerable variation with regards to bother. Distress about sexual function was relatively low across the sample. Scores on pain and fatigue, measured by the BPI-SF and BFI respectively, were low overall, suggesting that most men had minimal difficulties with pain and fatigue. Measures of psychological distress revealed low levels of reported depression and anxiety, as measured by the BDI and BAI respectively. Results from the IES-R indicated that men in the current sample reported minimal traumatic impact from their cancer experience. Regarding the decision making variables, there was evidence of minimal decisional conflict and high decisional satisfaction, as measured by the DCS and the SWD. The data suggest that decisional regret was low, which was measured by the DRS; however, the standard deviation and observed range should be considered when interpreting this figure.

In order to determine the percentages of the sample that were possibly depressed or anxious, cut-off scores for the BDI-II and BAI (Beck & Steer, 1990; Beck, Steer, & Brown, 1996) were utilised and the findings are reported in Table 2 and 3 below.

Table 2

Percentages of Sample Exceeding Cutoff Scores for Depression Levels at the Three Time Points

	Time 1	Time 2	Time 3
Minimal	77%	73%	75%
Mild	14%	16%	14%
Moderate	7%	5%	8%
Severe	2%	6%	3%

Table 3

Percentages of Sample Exceeding Cutoff Scores Anxiety Levels at the Three Time Points

	Time 1	Time 2	Time 3
Minimal	83%	79%	70%
Mild	11%	16%	23%
Moderate	5%	2%	6%
Severe	1%	2%	1%

As shown in Tables 2 and 3 above, across all three time points the majority of men reported minimal levels of depressive and anxiety symptoms. Less than a quarter of the sample was mildly depressed or anxious and even less were moderately or severely depressed or anxious. While there are slight trends for deterioration over time, this has not been tested statistically.

In order to gain a deeper understanding of decision satisfaction, patients were asked qualitatively whether they were satisfied with their prostate cancer treatment decision. The majority of patients maintained that they were satisfied with their decision, “I have advanced prostate (cancer) when diagnosed and believe the treatment I've been given has been the best for me”, “...satisfied to have commenced hormone therapy to maintain quality of life without undergoing aggressive or invasive treatment”. Several patients remarked that their satisfaction was around being pain-free, “...satisfied

because I have no pain", "...satisfied with my treatment...seems to be holding the cancer and I am in very little pain". Other patients commented on their satisfaction being around being able to live their life and do all the things they want to, "(having) returned to good health and able to do all things I need to do", "I can live a normal life", "Because I have a longer life span with my family". A number of men in the study reported that they were satisfied with their treatment due to improved PSA levels, "...PSA level has remained undetectable since having the surgery", "PSA has fallen...". Similar sentiments were reported at Times 2 and 3, with most patients being satisfied with their treatment decision. Men reported being "fully satisfied", "highly satisfied with my treatment decision", "strongly satisfied with the decision", and "satisfied with decision and treatment".

Correlational Data

Examination of the correlational data (see Appendix C) revealed that as expected, the three psychological variables of depression, anxiety, and trauma were all positively correlated with each other. The correlates of each of these psychological variables will now be discussed in turn. Regarding the relationships between depression and prostate symptoms, small correlations were found between depression and bowel and sexual variables across all time points. At Times 2 and 3 urinary variables were all correlated with depression. Furthermore, in line with the well-established link between depression and pain, these two variables were positively correlated at all three points. Similarly, the well known relationship between depression and fatigue was also confirmed in the correlational data consistently across time. Regarding the link between depression and decision making variables, the data was varied across time. At Time 1, associations were found between depression and decisional conflict and decisional regret, while at Time 2 depression was not correlated with any of the decision making

variables. However, at Time 3 depression was positively correlated with decisional conflict and regret, and negatively correlated with decisional satisfaction.

When considering the relationships between anxiety and prostate symptoms, correlations were found between anxiety and some of the urinary variables at each time point, as well as the bowel variables across all three time points. With anxiety and the sexual variables, at Time 1 anxiety had low correlations with sexual distress while at Time 2 anxiety was negatively correlated with sexual function and positively correlated with sexual bother. In contrast, at Time 3, anxiety was not correlated with any of the sexual variables. Correlations between anxiety and pain and anxiety and fatigue were low to moderate across all time points. Regarding the association between anxiety and the decision making variables, at Time 1 anxiety was weakly correlated with decisional conflict and regret, while at Times 2 and 3 anxiety was not correlated with any decision making variables.

Finally, with regard to trauma, there was considerable variability across time points. With the relationship between trauma and urinary symptoms, at Time 1 there were no correlations, while at Time 2 all urinary variables were correlated with trauma, and at Time 3 only urinary distress was correlated with trauma. No associations were found between trauma and bowel variables at Time 1 or 3 but moderate correlations were evident at Time 2. Low correlations were found between trauma and sexual bother and sexual distress at Times 1 and 2 but not at Time 3. The relationship found between trauma and pain varied across time with low positive correlations at Time 1, moderate correlations at Time 2, and no correlations at Time 3. Low correlations were found between trauma and sexual bother and sexual distress at Times 1 and 2 but no correlations were found at Time 3. The relationship found between trauma and pain varied across time with low correlations at Time 1, moderate correlations at Time 2, and no correlations at Time 3. With fatigue and trauma, low correlations were found at

Times 1 and 3, while a moderate correlation was found at Time 2. Correlations between the decision making variables and trauma also varied across time with small correlations found between trauma and decisional conflict and regret at Time 1 but no associations were found at Times 2 and 3. The relationships derived from the correlational data will be explored further in the analyses below.

With all of the regression analyses below, only variables that had significant bivariate correlations with the outcome variable under examination (e.g., depression) were used as predictor variables in each analysis. Non-significant correlates were omitted to preserve statistical power

Time 1 Results

Regression analyses: Psychological distress.

Multiple regressions were conducted to examine statistical predictors of depression, anxiety, and trauma at Time 1. First, a standard multiple regression was performed using physical prostate symptoms, pain, fatigue and decision making variables at Time 1 to predict the dependent variable of depression at Time 1.

Table 4

Results of Standard Regression Analysis for Prostate Symptoms, Pain, Fatigue, and Decision Making Variables Predicting Depression at Time 1

DV	Variables	B	β	R^2	adjusted R^2	R
Depression	Prostate symptoms	.03	.02			
	Bowel function	-.02	-.04			
	Bowel bother	-.02	-.05			
	Sexual bother	.01	.07			
	Sexual distress	1.15	.15			
	Pain severity	2.50	.32*			
	Pain interference	-1.19	-.24			
	Fatigue	1.91	.56**			
	Conflict	.02	.04			
	Regret	.05	.11			
				.47	.42	.69

Note. *$p < .05$. **$p < .01$.

Table 4 displays the unstandardised regression coefficients (*B*), standardised regression coefficients (β), *R*, R^2, and adjusted R^2. Significant predictors of depression were pain severity and fatigue, (Beta weights of .32 and .56 respectively), F (10, 101) = 9.03, $p < .001$, indicating that those with higher pain severity and fatigue reported higher levels of depression. According to this model, collectively the variables accounted for nearly half of the variance with 47% of the variance in depression at Time 1 being explained by this model.

A second standard multiple regression was performed using physical prostate symptoms, pain, fatigue, and decision making variables to predict anxiety at Time 1.

Table 5

Results of Standard Regression Analysis for Prostate Symptoms, Pain, Fatigue, and Decision Making Variables Predicting Anxiety at Time 1

DV	Variables	B	β	R^2	adjusted R^2	R
Anxiety	Prostate symptoms	-.07	-.07			
	Urinary bother	-.05	-.21*			
	Bowel function	-.02	-.05			
	Bowel bother	-.01	-.05			
	Sexual distress	.37	.06			
	Pain severity	1.65	.25			
	Pain interference	-.71	-.17			
	Fatigue	1.43	.50**			
	Conflict	-.01	-.02			
	Regret	.03	.09			
				.39	.34	.63

Note. *$p < .05$. **$p < .01$.

Table 5 shows that the significant predictors of anxiety were urinary bother and fatigue (Beta weights of -.21 and .50 respectively), F (10, 102) = 6.64, $p < .001$, indicating that men who were more bothered by their urinary symptoms and who had higher levels of fatigue displayed more anxiety symptoms. The results indicate that 39% of the variance in anxiety at Time 1 was explained by this model.

The final standard multiple regression performed at this stage used physical prostate symptoms, pain, fatigue, and decision making variables to predict trauma at Time 1.

Table 6

Results of Standard Regression Analysis for Prostate Symptoms, Pain, Fatigue, and Decision Making Variables Predicting Trauma at Time 1

DV	Variables	B	β	R^2	adjusted R^2	R
Trauma	Prostate symptoms	.14	.06			
	Sexual bother	-.03	-.10			
	Sexual distress	1.52	.11			
	Pain severity	5.51	.39*			
	Pain interference	-2.20	-.24			
	Fatigue	1.44	.23*			
	Conflict	.06	.07			
	Regret	.09	.13			
				.26	.21	.51

Note. *$p < .05$.

The results in Table 6 indicate that the significant predictors of trauma were pain severity and fatigue (Beta weights of .39 and .23 respectively), F (8, 103) = 4.63, $p <$ .001, demonstrating that men with higher pain and fatigue reported more trauma. The results indicate that 26% of the variance in trauma at Time 1 was explained by this model.

Age differences at Time 1.

A one-way between-groups ANOVA was conducted to explore the relationship of age and prostate symptoms, pain, fatigue, psychological distress and decision making distress. Participants were divided into 3 age groups (Middle Age: 50-64; Young Old: 65-74; Old Old: 75+) based on work by Harden et al. (2008). Table 7 below displays the significant age differences; Table D1 in Appendix D reports all non-significant age-related data from Time 1. Significant age differences were found between the age groups for urinary function, urinary distress, sexual function, and trauma. For urinary function [$F(2,117) = 4.89$, $p < .01$] eta squared was .07, indicating a small effect size.

Post-hoc comparisons using the Tukey HSD test indicated that the Middle Age men reported poorer urinary function than the Young Old men. The Old Old men did not significantly differ from Middle Age or Young Old men. Results for urinary distress [$F(2,133)=4.32$, $p<.05$] revealed a small effect size, with an eta squared of .06. Post-hoc comparisons revealed that the mean score for the Middle Age men was significantly different than from the Young Old men suggesting that the Middle Age men were more distressed by their urinary symptoms than the Young Old men. The Old Old men did not significantly differ from the Middle Age or the Young Old men. For sexual function [$F(2,112) = 3.82$, $p < .05$], the effect size, calculated by using eta squared was .07, indicating a medium effect. Post-hoc comparisons demonstrated that the Middle Age men had better sexual function than the Old Old men. The Young Old men did not significantly differ from the Middle Age or the Old Old men. The findings for trauma [$F(2,129) = 7.88$, $p < .01$] suggest a small effect size with an eta squared of .11. Post-hoc comparisons indicated that the Middle Age and the Young Old men reported significantly more trauma related to their cancer experience than the Old Old men. The Middle Age men did not significantly differ from the Young Old men.

These findings indicate that the Middle Age men had more difficulties than the the Young Old and the Old Old men. Specifically, they had more problems with urinary function and distress. With trauma, the Middle Age men and the Young Old men both reported more trauma than the Old Old men. The only symptom in which the Middle Age men reported less problems than the other groups was with sexual function.

Table 7

Means And Standard Deviations for Differences in Physical and Psychological Variables Across Age at Time 1

	Middle Age (n = 40)		Young Old (n = 47)		Old Old (n = 50)	
	M	*SD*	*M*	*SD*	*M*	*SD*
Urinary function	65.74 [a]	18.69	75.69 [a]	8.06	69.32	15.63
Urinary distress	.72 [a]	.93	.26 [a]	.49	.53	.79
Sexual function	27.41 [b]	28.44	21.63	28.49	10.61 [b]	21.11
Trauma	14.80 [b]	16.89	11.00 [c]	14.67	3.87 [b c]	5.03

[a] Indicates a significant difference between Middle Age and Young Old

[b] Indicates a significant difference between Middle Age and Old Old

[c] Indicates a significant difference between Young Old and Old Old

Differences in treatment groups at Time 1.

A one-way between-groups ANOVA was undertaken to determine whether any differences existed in Time 1 variables of prostate symptoms, pain, fatigue, psychological, and decision-related distress variables across the treatment groups. The only statistically significant difference was found for sexual function, [$F(2,87) = 4.97$, $p < .01$], which was found to have an effect size of .10, reflecting a medium effect. Post-hoc comparisons using the Tukey HSD test indicated that the Hormone Treatment group had inferior sexual function to the No Treatment group and the Other Treatment group. Significance values of pain interference was .052 and decisional satisfaction was .057, which are likely attributed to Type I errors. These findings are included in Table 8 below, which shows means and standard deviations for differences across treatment groups. Other non-significant findings can be found in Table D2 in Appendix D. The results of these analyses should be viewed with caution to due to the small sample and uneven group sizes.

Table 8

Means And Standard Deviations for Differences Across Treatment at Time 1

	No treatment (n = 57)		Hormone Treatment (n = 26)		Other treatment (n = 18)	
	M	*SD*	*M*	*SD*	*M*	*SD*
Sexual function	25.94 [a]	28.03	8.80 [ab]	22.55	35.70[b]	29.63
Pain interference	.78	1.74	.11	.57	1.37	2.31
Decisional satisfaction	26.53	3.88	23.96	5.63	25.93	3.10

[a] Indicates a significant difference between No Treatment and Hormone Treatment
[b] Indicates a significant difference between Hormone Treatment and Other Treatment

Time 2 Results

Regression analyses: Psychological distress.

Multiple regressions were conducted to examine predictors of depression, anxiety, and trauma at Time 2. In addition to the analyses below which have used Time 2 variables to predict Time 2 depression, anxiety, and trauma, other analyses were done using Time 1 variables to predict depression, anxiety, and trauma at Time 2 to capture the longitudinal aspect of the data. For these analyses see Tables E1, E2, and E3 in Appendix E.

A standard multiple regression was performed using prostate symptoms, pain, fatigue, and decision making variables to predict depression at Time 2.

Table 9

Results of Standard Regression Analysis for Prostate Symptoms, Pain, and Fatigue Predicting Depression at Time 2

DV	Variables	B	β	R^2	adjusted R^2	R
Depression	Prostate symptoms	.01	.01			
	Urinary bother	-.10	-.33			
	Urinary distress	-3.75	-.33			
	Bowel function	-.28	-.43*			
	Bowel bother	-.09	-.21			
	Sexual function	-.02	-.04			
	Sexual bother	.02	.07			
	Pain severity	-.37	-.06			
	Pain interference	.34	.07			
	Fatigue	2.12	.57**			
				.57	.50	.76

Note. *$p < .05$. **$p < .01$.

Table 9 shows that the significant predictors of depression were bowel function and fatigue (Beta weights of -.43 and .57 respectively), F (10, 59) = 7.85, $p < .001$, indicating that those with worse bowel function and more fatigue reported higher levels of depression. The results indicate that 57% of the variance in depression at Time 2 was explained by this model.

These analyses were repeated with anxiety as the dependent variable. A standard multiple regression was performed using physical prostate symptoms, pain, fatigue, and decision making variables to predict anxiety at Time 2.

Table 10

Results of Standard Regression Analysis for Prostate Symptoms, Pain, and Fatigue Predicting Anxiety at Time 2

DV	Variables	B	β	R^2	adjusted R^2	R
Anxiety	Prostate symptoms	-.11	-.11			
	Urinary bother	-.03	-.12			
	Urinary distress	-.79	-.08			
	Bowel function	-.24	-.41*			
	Bowel bother	.06	.16			
	Sexual function	-.01	-.04			
	Sexual bother	.02	.11			
	Pain severity	.43	.08			
	Pain interference	.29	.07			
	Fatigue	.65	.20			
				.53	.45	.72

Note. *$p < .05$.

Table 10 reveals that the only significant predictor of anxiety was bowel function (Beta weight of -.41), F (10, 59) = 6.60, $p < .001$, indicating those with worse bowel function reported higher levels of anxiety. The results indicate that 53% of the variance in anxiety at Time 2 was explained by this model.

Finally for this phase of the analyses, trauma was used as the dependent variable. A standard multiple regression was performed using physical prostate symptoms, pain, fatigue, and decision making variables to predict trauma at Time 2.

Table 11

Results of Standard Regression Analysis for Prostate Symptoms, Pain, and Fatigue Predicting Trauma at Time 2

DV	Variables	B	β	R^2	adjusted R^2	R
Trauma	Prostate symptoms	.09	.05			
	Urinary function	.11	.13			
	Urinary bother	-.05	-.12			
	Urinary distress	-.93	-.05			
	Bowel function	-.61	-.68**			
	Bowel bother	-.30	-.53**			
	Sexual bother	.04	.12			
	Sexual distress	3.02	.26*			
	Pain severity	1.57	.19			
	Pain interference	-.26	-.04			
	Fatigue	2.64	.51**			
				.74	.68	.86

Note. *$p < .05$. **$p < .01$.

Table 11 shows that bowel function, bowel bother, sexual distress, and fatigue, uniquely predicted trauma (Beta weights of -.68, .-.53, .26, and .51 respectively), F (11, 48) = 12.22, $p < .001$, indicating that those men with worse bowel function, more bowel bother, higher levels of sexual distress, and more fatigue, reported more trauma. The results indicate that 74% of the variance in trauma at Time 2 was explained by this model.

A series of hierarchical regressions were performed to determine the contribution of Time 1 depression, anxiety, and trauma values to variations in Time 2 depression, anxiety, and trauma respectively.

Table 12

Results of Hierarchical Regression Analysis for Depression at Time 1 and Physical Symptoms Predicting Depression at Time 2

Outcome Variable	Predictor Variables	B	*SE B*	β	R^2
Depression2	Step 1				
	Depression 1	.94	.08	.82	
					$R^2 = .68$
				Adjusted	$R^2 = .67$
	Step 2				
	Depression1	.78	.10	.68**	
	Prostate symptoms2	.11	.10	.09	
	Urinary bother2	-.05	.05	-.16	
	Urinary distress2	-2.43	1.59	-.22	
	Bowel function2	-.11	.09	-.17	
	Bowel bother2	-.01	.05	-.02	
	Sexual function2	.01	.03	.03	
	Sexual bother2	.02	.01	.10	
	Pain severity2	-.63	.69	-.10	
	Pain interference2	-.08	.69	-.02	
	Fatigue2	.90	.39	.25*	
					$R^2 = .78$
				Adjusted	$R^2 = .74$

Note. *$p < .05$. **$p < .01$.

A hierarchical regression was conducted to determine which Time 2 variables predicted depression at Time 2, over and above depression at Time 1. To do so, Time 1 depression was entered into the first step of the regression and not surprisingly accounted for 68% of the variance in Time 2 depression. Additional measures taken at Time 2, were then entered at step 2 of the regression. The results showed that the model was significantly improved ($F = 19.88$) but that only Time 2 fatigue ($\beta = .25$, $t = 2.33$, $p = .02$) significantly predicted depression at Time 2 over and above depression at Time 1. The final model accounted for 78% of the variance in depression at Time 2, but was principally due to depression at Time 1 being a large predictor of depression at Time 2.

Table 13

Results of Hierarchical Regression Analysis for Anxiety at Time 1 and Physical Symptoms Predicting Anxiety at Time 2

Outcome Variable	Predictor Variables	B	*SE B*	β	R^2
Anxiety2	Step 1				
	Anxiety1	1.01	.07	.85	
					$R^2 = .73$
				Adjusted	$R^2 = .73$
	Step 2				
	Anxiety1	.84	.09	.71**	
	Prostate symptoms2	-.06	.09	-.06	
	Urinary bother2	.02	.04	.09	
	Urinary distress2	.62	1.37	.06	
	Bowel function2	-.10	.07	-.16	
	Bowel bother2	.07	.04	.18	
	Sexual function2	-.01	.02	-.04	
	Sexual bother2	-.01	.01	.07	
	Pain severity2	.66	.59	.12	
	Pain interference2	-.65	.59	-.16	
	Fatigue2	.25	.31	.08	
					$R^2 = .79$
				Adjusted	$R^2 = .75$

Note. $^{**}p < .01$.

Like for depression, a hierarchical regression was conducted to determine which Time 2 variables were predictive of anxiety at Time 2, over and above anxiety at Time 1. Therefore, Time 1 anxiety was entered into the first step of the regression and accounted for 79% of the variance in anxiety at Time 2. Additional measures taken at Time 2, were subsequently entered at step 2 of the regression. The results indicated that the model was significantly improved ($F = 21.06$) but that no other variable uniquely predicted anxiety at Time 2 over and above anxiety at Time 1. The final model accounted for 79% of the variance in anxiety at Time 2.

Table 14

Results of Hierarchical Regression Analysis for Trauma at Time 1 and Physical Symptoms Predicting Trauma at Time 2

Outcome Variable	Predictor Variables	B	*SE B*	β	R^2
Trauma2					
	Step 1				
	Trauma 1	.83	.06	.87	
					$R^2 = .76$
				Adjusted	$R^2 = .76$
	Step 2				
	Trauma1	.64	.07	.67**	
	Prostate symptoms2	.12	.15	.07	
	Urinary function2	.07	.07	.09	
	Urinary bother2	.08	.06	.19	
	Urinary distress2	3.78	2.14	.23	
	Bowel function2	-.07	.11	-.08	
	Bowel bother2	-.04	.07	-.07	
	Sexual bother2	-.00	.02	-.02	
	Sexual distress2	1.53	.93	.13	
	Pain severity2	.55	.91	.06	
	Pain interference2	.03	.89	.04	
	Fatigue2	1.03	.47	.20*	
					$R^2 = .85$
				Adjusted	$R^2 = .82$

Note. *$p < .05$. **$p < .01$.

Similar to depression and anxiety, a hierarchical regression was conducted to determine which Time 2 variables predicted trauma at Time 2, over and above trauma at Time 1. Time 1 trauma was entered into the first step of the regression and not surprisingly accounted for 76% of the variance in Time 2 trauma. Additional measures taken at Time 2, were then entered at step 2 of the regression. The results showed that the model was significantly improved ($F = 25.40$) but that only Time 2 fatigue ($\beta = .20$, $t = 2.18$, $p = .03$) significantly predicted trauma at Time 2 over and above trauma at Time 1. The final model accounted for 85% of the variance in trauma at Time 2, but was mainly due to trauma at Time 1 being a large predictor of trauma at Time 2.

Age differences at Time 2.

A one-way between-groups ANOVA was conducted to explore the relationship of age and prostate symptoms, pain, fatigue, psychological distress and decision making distress. Statistically significant differences across age were found for urinary function, urinary bother, urinary distress, sexual distress and depression at Time 2. Urinary function [$F(2,65) = 4.67$, $p < .05$] was found to have an effect size of .13, reflecting a medium effect. Post-hoc comparisons using the Tukey HSD test indicated that the Young Old men had superior urinary function to the Middle Age men and the Old Old men had better urinary function than the Middle Age men. The Young Old and the Old Old men did not significantly differ. For urinary bother [$F(2,80) = 6.53$, $p < .01$], eta squared was .14 reflecting a large effect. Post-hoc comparisons found that the mean score for the Middle Age men was significantly different than from the Young Old men and the Old Old men, demonstrating that the Middle Age men were more bothered by their urinary symptoms than the other two groups. The Young Old and the Old Old men did not significantly differ. Results for urinary distress [$F(2,80) = 4.06$, $p < .05$] revealed an effect size of .09, suggesting a moderate effect between age and distress associated with urinary symptoms. Post-hoc comparisons indicated that there was a significant difference in urinary distress between the Middle Age and the Young Old men, whereby men in the Middle Age group reported more urinary distress than men in the Young Old group. For sexual distress [$F(2,75) = 4.85$, $p = .01$] there was a moderate effect size of .11. Post-hoc comparisons revealed that the Middle Age men were significantly more distressed than the Old Old men but there was no significant difference between the Middle Age and the Young Old or the Young Old and the Old Old men. The findings for depression at Time 2 [$F(2, 78) = 3.51$, $p < .05$] indicate a small effect with an eta squared of .08 because the Old Old men reported lower levels of depression than the Middle Age and the Young Old men. Post-hoc comparisons

indicated that the only significant difference found was between the Middle Age and the Old Old men. Table 15 below displays the significant findings for symptom rating differences across age and Table D3 in Appendix D displays the non-significant findings. Overall, like with Time 1, these findings indicate that the Middle Age men had more difficulties than their older counterparts.

Table 15

Means And Standard Deviations for Symptom Differences Across Age at Time 2

	Middle Age (n = 25)		Young Old (n = 32)		Old Old (n = 27)	
	M	*SD*	*M*	*SD*	*M*	*SD*
Urinary function	61.29 [a b]	19.68	72.34 [a]	13.26	73.65 [b]	9.51
Urinary bother	57.00 [a b]	35.74	85.39 [a]	24.27	78.85 [b]	26.17
Urinary distress	.88 [a]	1.05	.31 [a]	.59	.42	.64
Sexual distress	1.38 [b]	1.17	.90	1.11	.39 [b]	.94
Depression	11.48 [b]	9.88	10.63	10.43	5.54 [b]	4.47

[a] Indicates a significant difference between Middle Age and Young Old

[b] Indicates a significant difference between Middle Age and Old Old

[c] Indicates a significant difference between Young Old and Old Old

Time 3 Results

Regression analyses: Psychological distress.

Multiple regressions were conducted to examine predictors of depression, anxiety, and trauma at Time 3. Similar to Time 2, in addition to the analyses below which have used Time 3 variables to predict Time 3 depression, anxiety, and trauma, other analyses were done using Time 1 variables to predict depression, anxiety, and trauma at Time 3 to capture the longitudinal aspect of the data. For these analyses see Tables E4, E5, and E6 in Appendix E.

A standard multiple regression was performed using prostate symptoms, pain, fatigue, and decision making variables to predict depression at Time 3.

Table 16

Results of Standard Regression Analysis for Prostate Symptoms, Pain, Fatigue, and Decision Making Variables Predicting Depression at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Depression	Prostate symptoms	.28	.22			
	Urinary bother	.09	.30			
	Urinary distress	-.22	-.02			
	Bowel function	-.09	-.13			
	Bowel bother	.04	.12			
	Sexual function	-.06	-.17			
	Pain severity	2.92	.29			
	Pain interference	-2.40	-.40			
	Fatigue	2.93	.71**			
	Conflict	-.10	-.19			
	Regret	.00	.00			
	Satisfaction	-.48	-.24			
				.61	.45	.78

Note. **$p < .01$.

Table 16 shows that fatigue was the only unique predictor of depression (Beta weight of .71), F (12, 30) = 3.84, $p < .01$, indicating that men who were more fatigued reported more depression. The results below indicate that 61% of the variance in depression at Time 3 was explained by this model.

A standard multiple regression was performed using physical prostate symptoms, pain, fatigue, and decision making variables to predict anxiety at Time 3.

Table 17

Results of Standard Regression Analysis for Prostate Symptoms, Pain, and Fatigue Predicting Anxiety at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Anxiety	Prostate symptoms	.01	.01			
	Urinary bother	.04	.14			
	Urinary distress	1.00	.10			
	Bowel function	-.12	-.16			
	Bowel bother	.04	.13			
	Pain severity	1.12	.12			
	Pain interference	-1.21	-.21			
	Fatigue	2.26	.59**			
				.39	.29	.63

Note. $^{**}p < .01$.

Table 17 illustrates that fatigue was the only unique predictor of anxiety (Beta weight of .59), F (8, 49) = 3.92, $p < .01$, indicating that men who reported more fatigue reported more anxiety. The results below indicate that 39% of the variance in anxiety at Time 3 was explained by this model.

A standard multiple regression was performed using physical prostate symptoms, pain, fatigue, and decision making variables to predict trauma at Time 3.

Table 18

Results of Standard Regression Analysis for Prostate Symptoms and Fatigue Predicting Trauma at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Trauma	Urinary distress	2.57	.16			
	Fatigue	1.93	.31*			
				.15	.12	.39

Note. $^{*}p < .05$.

Table 18 demonstrates that fatigue was the only unique predictor of trauma (Beta weight of .31), F (2, 60) = 5.35, $p < .01$, indicating that men who reported more fatigue reported more trauma. The results below indicate that 15% of the variance in anxiety at Time 3 was explained by this model.

A series of hierarchical regressions were performed to determine the contribution of Time 1 depression, anxiety, and trauma values to variation in Time 3 depression, anxiety, and trauma respectively.

Table 19

Results of Hierarchical Regression Analysis for Depression at Time 1, Physical Symptoms, and Decision Making Variables Predicting Depression at Time 3

Outcome Variable	Predictor Variables	B	*SE B*	β	R^2
Depression3	Step 1				
	Depression 1	.89	.08	.85	
					$R^2 = .72$
				Adjusted	$R^2 = .71$
	Step 2				
	Depression1	.72	.12	.69**	
	Prostate symptoms3	.10	.16	.09	
	Urinary bother3	.02	.04	.07	
	Urinary distress3	.76	1.26	.07	
	Bowel function3	-.10	.09	-0.14	
	Bowel bother3	-.01	.04	-.03	
	Sexual function3	-.01	.03	-.04	
	Pain severity3	.37	1.18	.04	
	Pain interference3	-.57	.79	-.09	
	Fatigue3	.78	.59	.20	
	Conflict3	-.09	.08	-.18	
	Regret3	.03	.05	.08	
	Satisfaction3	-.29	.33	-.15	
					$R^2 = .79$
				Adjusted	$R^2 = .70$

Note. $^{**}p < .01$.

A hierarchical regression was conducted to determine which Time 3 variables predicted depression at Time 3, over and above depression at Time 1. To do so, Time 1 depression was entered into the first step of the regression and not surprisingly accounted for 72% of the variance in Time 3 depression. Additional measures taken at Time 3, were then entered at step 2 of the regression. The results showed that the model was significantly improved ($F = 9.16$) but that no other

variables uniquely predicted depression at Time 3 over and above depression at Time 1. The final model accounted for 79% of the variance in depression at Time 3.

Table 20

Results of Hierarchical Regression Analysis for Anxiety at Time 1 and Physical Symptoms Predicting Anxiety at Time 3

Outcome Variable	Predictor Variables	B	*SE B*	β	R^2
Anxiety3	Step 1				
	Anxiety1	.91	.10	.77	
					$R^2 = .59$
				Adjusted	$R^2 = .58$
	Step 2				
	Anxiety1	.73	.12	.61**	
	Prostate symptoms3	-.04	.15	-.03	
	Urinary bother3	-.02	.04	-.07	
	Urinary distress3	.12	1.15	.01	
	Bowel function3	-.14	.08	-.21	
	Bowel bother3	.01	.04	.02	
	Pain severity3	1.19	1.06	.12	
	Pain interference3	-.97	.73	-.17	
	Fatigue3	.77	.47	.20	
					$R^2 = .69$
				Adjusted	$R^2 = .63$

Note. **$p < .01$.

As for depression, a hierarchical regression was conducted to determine which Time 3 variables were predictive of anxiety at Time 3, over and above Time 1 anxiety. To do so, Time 1 anxiety was entered into the first step of the regression and not surprisingly accounted for 59% of the variance in Time 3 anxiety. Additional measures taken at Time 3, were subsequently entered at step 2 of the regression. The results showed that the model was significantly improved ($F = 12.32$) but no other variables significantly predicted anxiety at Time 3 over and above anxiety at Time 1. The final model accounted for 69% of the variance in anxiety at Time 3.

Table 21

Results of Hierarchical Regression Analysis for Trauma at Time 1 and Physical Symptoms Predicting Trauma at Time 3

Outcome Variable	Predictor Variables	B	*SE B*	β	R^2
Trauma3	Step 1				
	Trauma1	.79	.07	.84	
					$R^2 = .71$
				Adjusted	$R^2 = .70$
	Step 2				
	Trauma1	.77	.07	.82**	
	Urinary distress3	.83	1.25	.05	
	Fatigue3	.07	.51	.01	
					$R^2 = .71$
				Adjusted	$R^2 = .69$

Note. **$p < .01$.

As for depression and anxiety, a hierarchical regression was conducted to determine which Time 3 variables predicted trauma at Time 3, over and above trauma at Time 1. To do so, Time 1 trauma was entered into the first step of the regression and not surprisingly accounted for 71% of the variance in Time 3 trauma. Additional measures taken at Time 3, were then entered at step 2 of the regression. The results showed that the model was significantly improved ($F = 46.74$) but that no other variables uniquely predicted trauma at time 3 over and above trauma at Time 1. The final model accounted for 71% of the variance in trauma at Time 3.

Age differences at Time 3.

A one-way between groups ANOVA was conducted to explore the age differences in prostate symptoms, pain, fatigue, psychological distress, and decision making distress at Time 3. No statistically significant results were found. See Table D4 in Appendix D for the results.

Longitudinal Changes in Psychological Distress, Physical Symptoms and Distress, and Decision Making

For some of the analyses below, it is important to note that the *N* is quite small and as such the results should be viewed with some caution. Despite the small *N*, the longitudinal aspect of the data is worthy to examine given the importance of exploring whether symptoms change or are stable over the cancer trajectory, an aspect many previous studies have failed to address.

Depression, anxiety, and trauma across time.

Mixed model ANOVAs were conducted to assess for differences in depression, anxiety, and trauma between the various age groups across the three time points. For depression, the results indicated no interaction effect between Age and Time, Wilk's Lambda = .93, F (4,118) = 1.11, $p > .05$, with an Eta-square of .04. The mixed-model ANOVA revealed no main effect for Age F (2, 59) = 1.15, $p > .05$, Eta-squared = .04. Thus, there was no overall difference in depression scores of the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = 1.00, F (2,118) = .02, $p > .05$, with an effect size of .00 as measured by Eta-squared.

Results for anxiety indicated no interaction effect between Age and Time, Wilk's Lambda = .90, F (4,120) = 1.68, $p > .05$, with an Eta-square of .05. No main effect for Age was found F (2,60) = .52, $p > .05$, Eta-squared = .04. Thus, there was no overall difference in anxiety scores of the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .99, F (2,120) = .37, $p > .05$, with an effect size of .01 as measured by Eta-squared.

For trauma, the results indicated no interaction effect between Age and Time, Wilk's Lambda = .89, F (4,110) = 1.61, $p > .05$, with an Eta-square of .06. No main effect for Age was found F (2,55) = 2.39, $p > .05$, Eta-squared = .08. Thus, there was no

overall difference in trauma scores of the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .92, F (2,110) = 2.23, $p > .05$, with an effect size of .08 as measured by Eta-squared.

Symptom function across time.

The data for urinary function revealed no interaction effect between Age and Time, Wilk's Lambda = .94, F (4, 82) = .61, $p > .05$, with an Eta-square of .03.No main effect was found for Age F (2, 41) = 2.85, $p > .05$, Eta-squared = .12. Thus, there was no overall difference in urinary function scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .98, F (2,82) = .33, $p > .05$, with an effect size of .02 as measured by Eta-squared.

The results for bowel function indicated an interaction effect between Age and Time, Wilk's Lambda = .85, F (4, 120) = 2.52, $p < .05$, with an Eta-square of .08. No main effect was found for Age F (2, 60) = .48, $p > .05$, Eta-squared = .02. Thus, there was no overall difference in bowel function scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .93, F (2,120) = 2.23, $p > .05$, with an effect size of .07 as measured by Eta-squared.

The data for sexual function showed an interaction effect between Age and Time, Wilk's Lambda = .67, F (4, 82) = 4.37, $p < .01$, with an Eta-square of .18. No main effect was found for Age F (2, 41) = .98, $p > .05$, Eta-squared = .05. Thus, there was no overall difference in sexual function scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .90, F (2,82) = 2.31, $p > .05$, with an effect size of .10 as measured by Eta-squared.

Symptom bother across time.

The results for urinary bother indicated no interaction effect between Age and Time, Wilk's Lambda = .87, F (4, 122) = 2.17, $p > .05$, with an Eta-square of .07. No main effect was found for Age F (2, 61) = 1.26, $p > .05$, Eta-squared = .04. Thus, there

was no overall difference in urinary bother scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .98, F (2,122) = .73, $p > .05$, with an effect size of .02 as measured by Eta-squared.

The data for bowel bother revealed no interaction effect between Age and Time, Wilk's Lambda = .98, F (4, 120) = 24, $p > .05$, with an Eta-square of .08. No main effect was found for Age F (2, 60) = .09, $p > .05$, Eta-squared = .00. Thus, there was no overall difference in bowel bother scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .95, F (2,120) = 1.60, $p > .05$, with an effect size of .05 as measured by Eta-squared.

The results for sexual bother showed no interaction effect between Age and Time, Wilk's Lambda = .92, F (4, 108) = 1.11, $p < .05$, with an Eta-square of .04. No main effect was found for Age F (2, 54) = .65, $p > .05$, Eta-squared = .02. Thus, there was no overall difference in sexual bother scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .97, F (2,108) = .93, $p > .05$, with an effect size of .03 as measured by Eta-squared.

Pain and fatigue across time.

The data for pain severity indicated no interaction effect between Age and Time, Wilk's Lambda = .93, F (4, 116) = 1.08, $p > .05$, with an Eta-square of .06. No main effect was found for Age F (2, 58) = 1.06, $p > .05$, Eta-squared = .04. Thus, there was no overall difference in pain severity scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .94, F (2, 116) = 1.87, $p > .05$, with an effect size of .06 as measured by Eta-squared.

For pain interference, no interaction effect was found between Age and Time, Wilk's Lambda = .88, F (4, 110) = 1.79, $p > .05$, with an Eta-square of .06. No main effect was found for Age F (2, 54) = .28, $p > .05$, Eta-squared = .01. Thus, there was no overall difference in pain interference scores for the Middle Age, the Young Old, and

the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .95, F (2, 110) = 1.29, $p > .05$, with an effect size of .05 as measured by Eta-squared.

The results for fatigue indicated no interaction effect between Age and Time, Wilk's Lambda = .91, F (4, 116) = 1.31, $p > .05$, with an Eta-square of .04. No main effect was found for Age F (2, 58) = .00, $p > .05$, Eta-squared = .00. Thus, there was no overall difference in fatigue scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .99, F (2,116) = .38, $p > .05$, with an effect size of .01 as measured by Eta-squared.

Decision making across time.

The results for decisional conflict revealed no interaction effect between Age and Time, Wilk's Lambda = .98, F (4, 96) = .25, $p > .05$, with an Eta-square of .01. No main effect was found for Age F (2, 48) = .12, $p > .05$, Eta-squared = .01. Thus, there was no overall difference in decisional conflict scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = 1.00, F (2,96) = .06, $p > .05$, with an effect size of .00 as measured by Eta-squared.

For decisional regret no interaction effect was found between Age and Time, Wilk's Lambda = .95, F (4, 96) = .71, $p > .05$, with an Eta-square of .03. No main effect was found for Age F (2, 48) = .31, $p > .05$, Eta-squared = .01. Thus, there was no overall difference in decisional regret scores for the Middle Age, the Young Old, and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .95, F (2,96) = 1.31, $p > .05$, with an effect size of .03 as measured by Eta-squared.

With decisional satisfaction no interaction effect was found between Age and Time, Wilk's Lambda = .96, F (4, 96) = .31, $p > .05$, with an Eta-square of .01. No main effect was found for Age F (2, 48) = .56, $p > .05$, Eta-squared = .02. Thus, there was no overall difference in decisional satisfaction scores for the Middle Age, the Young Old,

and the Old Old men. No significant main effect for Time was obtained, Wilk's Lambda = .98, F (2,96) = .27, $p > .05$, with an effect size of .02 as measured by Eta-squared.

In summary, from these longitudinal findings, significant interaction effects were found between age and time for bowel function and sexual function. For bowel function, the Old Old group showed a decline over time compared to the other two groups, while for sexual function the Middle Age group deteriorated at Time 2 and then improved somewhat at Time 3 while the other groups were more stable over time.

Coping Results

Means and standard deviations as well as observed and possible ranges of each of the coping variables and resilience are shown in Table 22 below. Overall, the table shows that men were generally higher on positive coping styles (e.g., acceptance) and quite low on negative coping styles (e.g., self-blame).

Table 22

Means, Standard Deviations, Observed and Possible Scale Ranges for Coping and Resilience

	M	*SD*	Observed range	Possible range
Coping				
Active coping	1.59	1.89	0-6	0-6
Planning	1.40	1.88	0-6	0-6
Positive reframing	1.62	1.71	0-6	0-6
Acceptance	3.25	2.32	0-6	0-6
Humour	1.03	1.78	0-6	0-6
Religion	0.76	1.56	0-6	0-6
Use of emotional support	2.27	2.20	0-6	0-6
Use of instrumental support	1.33	1.62	0-6	0-6
Self-distraction	1.29	1.89	0-6	0-6
Denial	0.65	1.41	0-6	0-6
Venting	0.60	1.16	0-4	0-6
Substance use	0.27	0.88	0-4	0-6
Behavioural disengagement	0.54	1.09	0-5	0-6
Self-blame	0.19	0.64	0-4	0-6
Resilience	146.59	30.97	35-175	1-175

Note: $N = 63$

Regression analyses: Coping and resilience.

Multiple regressions were conducted to examine coping predictors, as measured at Time 3, of depression, anxiety, and trauma at Time 3. The variable active coping was

omitted from analyses due to the violation of multicollinearity. Active coping had significantly high correlations with planning, use of emotional support, and use of instrumental support.

A standard multiple regression was performed using coping variables to predict depression at Time 3.

Table 23

Standard Regression of Coping Variables on Depression at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Depression	Planning	.58	.13			
	Acceptance	-.03	-.01			
	Humour	.78	.17			
	Self-distraction	1.30	.30*			
	Denial	-.37	-.06			
	Venting	.38	.05			
	Behavioural disengagement	.48	.06			
	Self-blame	1.26	.49**			
				.51	.44	.71

Note. *$p < .05$. **$p < .01$.

Table 23 shows that self-distraction and self-blame were unique predictors of depression (Betas of .30 and .49 respectively), F (8, 53) = 6.89, $p < .001$. The results above indicate that 51% of the variance in depression at Time 3 was explained by this model, such that those men who used self-distraction and self-blame as coping techniques reported more depression.

A standard multiple regression was performed using coping variables to predict anxiety at Time 3.

Table 24

Standard Regression of Coping Variables on Anxiety at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Anxiety	Planning	1.32	.32*			
	Self-distraction	.73	.18			
	Denial	.89	.16			
	Venting	-1.15	-.17			
	Self-blame	3.31	.27*			
				.25	.19	.50

Note. *$p < .05$.

Table 24 demonstrates that planning and self-blame were unique predictors of anxiety (Beta weights of .32 and .27 respectively), F (5, 57) = 3.89, $p < .01$. The results above show that 25% of the variance in anxiety at Time 3 was explained by this model. These findings indicate that those men who utilised planning and self-blame reported higher levels of anxiety.

A standard multiple regression was performed using coping variables to predict trauma at Time 3.

Table 25

Standard Regression of Coping Variables on Trauma at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Trauma	Planning	1.98	.29*			
	Positive reframing	.78	.10			
	Acceptance	-.13	-.02			
	Use of emotional support	.66	.11			
	Use of instrumental support	1.95	-.25			
	Self-distraction	.98	.14			
	Denial	2.22	.24*			
	Venting	1.65	.15			
	Behavioural disengagement	.39	.03			
	Self-blame	8.25	.41**			
				.69	.63	.83

Note. *$p < .05$. **$p < .01$.

Table 25 demonstrates that planning, denial, and self-blame were unique predictors of trauma (Beta weights of .29, .24 and .41 respectively), F (10, 52) = 11.37, $p < .001$. The results above indicate that 69% of the variance in trauma at Time 3 was explained by this model, whereby men who engaged in more planning, denial, and self-blame exhibited more trauma symptoms.

Multiple regressions were conducted to determine whether resilience, which was measured at Time 3, was predictive of depression, anxiety, and trauma at Time 3.

A standard multiple regression was performed using resilience to predict depression at Time 3.

Table 26

Results of Standard Regression for Resilience Predicting Depression at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Depression	Resilience	-.13	-.48**	.23	.22	.48

Note. *$p < .05$. **$p < .01$.

Table 26 shows that resilience significantly predicted depression (Beta weight of -.48), F (1 , 60) = 5.13, $p < .05$. The results indicate that 23% of the variance in resilience was explained by this model, such that those with men with low resilience reported higher depression.

A standard multiple regression was performed using resilience to predict anxiety at Time 3.

Table 27

Results of Standard Regression for Resilience Predicting Anxiety at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Anxiety	Resilience	-.05	-.20	.04	.03	.20

Table 27 reveals that resilience did not significantly predict anxiety, F (1 , 61) = 2.56, $p > .05$.

A standard multiple regression was performed using resilience to predict trauma at Time 3.

Table 28

Results of Standard Regression for Resilience Predicting Trauma at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Trauma	Resilience	-.16	-.39*	.15	.14	.39

Note. *$p < .05$.

Table 28 demonstrates resilience significantly predicted trauma (Beta weight of -.39), F (1 , 61) = 10.90, $p < .01$. The results indicate that 15% of the variance in resilience was explained by this model, such that men with lower levels of resilience reported experiencing more trauma.

Discussion

The aim of this study was to examine changes over time in the patterns of psychological and symptom distress reported by men with prostate cancer. A further aim was to explore the prostate cancer patients' experiences of decision making about treatment. The expectations of the current study will now be discussed, followed by sections discussing what the findings say about psychological distress, coping, symptom distress, and decision making in men with prostate cancer. Finally there will be a methodological critique and clinical implications of the current research.

It was predicted that men with more physical symptoms, symptom bother, symptom distress, and decision-related distress would report higher levels of depression, anxiety, and trauma. Levels of psychological variables at Time 1 were predicted to account for a large proportion of the variance of the levels of psychological variables at Time 2 and 3 above and beyond the other Time 2 and 3 variables. It was also predicted that differences would be found across psychological and physical symptoms, whereby younger men would exhibit greater levels of psychological symptoms and older men would exhibit more physical symptoms. Finally, it was also hypothesised that differences across time would be found for the psychological, physical, and decision making variables.

Descriptive data indicated that while most men had good urinary function, for other men urinary function was problematic as indicated by some degree of associated bother. Urinary distress scores were relatively low across the board. Bowel function mean scores were relatively high and together with bowel bother scores, indicated that most men did not have difficulties in this area. Regarding sexual function, mean scores indicated substantial difficulties in this area, while the level of bother was variable across participants. Distress about sexual function was relatively low. Scores on pain and fatigue, measured by the BPI-SF and BFI respectively, were low, suggesting that

most men in the study had minimal difficulties with pain and fatigue. Measures of psychological distress revealed low levels of reported depression and anxiety, as well as minimal traumatic impact from the men's cancer experience. Regarding decision making, there was evidence of minimal decisional conflict, low levels of regret, and high decisional satisfaction.

Results at Time 1 indicated that fatigue was a significant statistical predictor of depression while urinary bother and fatigue were significant statistical predictors of anxiety, and furthermore fatigue statistically predicted trauma. Further analyses revealed that there were statistically significant differences between age groups for urinary function, urinary distress, sexual function, and trauma. The data were also compared across various treatment groups and the only statistically significant difference found was for sexual function, whereby men in the Hormone Treatment group had poorer sexual function than those in the Other Treatment group.

The findings at Time 2 showed that fatigue was statistically predictive of depression, while bowel function was significantly associated with anxiety, and bowel function, bowel bother, sexual distress, and fatigue were significantly related to trauma. Additional regression analyses revealed that depression at Time 1 explained 68% of the variance in depression at Time 2, anxiety at Time 1 explained 73% of the variance in anxiety at Time 2, and trauma at Time 1 explained 76% of the variance in trauma at Time 2. Further exploration of the data revealed statistically significant differences across age groups for urinary function, urinary bother, urinary distress, sexual distress, and depression.

Results at Time 3 indicated that fatigue was a significant predictor of depression, anxiety, and trauma. Additional regression analyses revealed that depression at Time 1 explained 72% of the variance in depression at Time 3, anxiety at Time 1 explained 59% of the variance in anxiety at Time 3, and trauma at Time 1 explained 71% of the

variance in trauma at Time 3. Further exploration of the data found no statistically significant differences across age across the variables examined in the study.

The data were explored across time and no statistically significant results were found for depression, anxiety, and trauma across the various age groups. Symptom function and symptom bother were also examined across time and age and there were no significant findings. The same was found to be true for pain and fatigue.

Analyses on the coping data at Time 3 found that the use of self-blame and self-distraction uniquely predicted depression, while planning and self-blame uniquely predicted anxiety, and planning, denial, and self-blame uniquely predicted trauma. Resilience was used to predict depression, anxiety, and trauma at Time 3 and it was found that resilience significantly predicted depression and trauma but not anxiety.

Psychological Distress

The following section aims to outline the findings of the current study as they relate to the three types of psychological distress under examination, namely depression, anxiety, and trauma. The discussion focuses on levels of psychological distress, predictors, relationships to age, and the longitudinal results.

Depression.

The majority of men in the sample reported minimal depression at all three time points. However, while fewer in number than those with low symptom levels, there were men in the study who did experience moderate to severe depressive symptoms. In the current sample, on average across the three time points, 10% of men reported moderate or severe depression. This result is similar to that of other studies, noted below. Also using the BDI, Pirl et al. (2002) found that 87% of their sample did not report significant depressive symptoms, 13% reported mild to moderate depression, and no patients reported moderate to severe depression. It is important to note that all men in the study by Pirl et al. were on ADT. The finding of the current study and Pirl et al. is

consistent with that of Bisson et al. (2002), Cliff and Macdonagh (2000), Hinz et al. (2009), and Lintz et al. (2003), who using the Hospital Anxiety and Depression Scale (HADS; Snaith, 2003), found similar rates of depression in their samples of men with prostate cancer. Regarding the study by Hinz et al. it should be kept in mind that they have used men with prostate cancer as well as other urological cancers. As such this is not perfect evidence but offers some potential support for the hypothesised prevalence of depression and anxiety in men with prostate cancer.

These consistent findings of relatively low levels of depression in these men can be viewed in light of the following factors. One is the treatment type used in the various studies reviewed. Past research has indicated that men undergoing hormone treatment are at a higher risk for depression than those men receiving other forms of prostate therapy (Pirl et al., 2002). The men in the current study and the studies by Bisson et al. (2002), Cliff and Macdonagh (2000), Hinz et al. (2009), and Lintz et al. (2003), had undergone various treatments for prostate cancer. This may be a possible reason for the overall low levels of depression found, and depression might be more common amongst those receiving a specific type of treatment such as ADT (Pirl et al., 2002). Another factor to consider is stage of disease. Dirksen et al. (2009) found a high level of depression in their study of men with prostate cancer, which they believed may have been influenced by the high proportion of men with advanced disease. However, the samples in the current study, as well as those of Hinz et al., and Cliff and Macdonagh, involved patients with a range of disease stages unlike that of Dirksen et al, which is possibly why these studies may have found consistently low levels of depression. While Lintz et al. found an overall low level of depression, they did find a significant difference in depression between those with local disease and those with advanced disease, with the latter presenting as more depressed. Therefore, while the current study did not specifically examine differences in depression across stages of disease, it is an

important factor to consider when looking at prevalence rates of depression in men with prostate cancer.

Yet another potential and noteworthy explanation for the low levels of depression found, is the possibility that men in general may not admit distress (Keller & Henrich, 1999; Kornblith et al., 1994, Roth et al., 1998). It has been suggested by Bisson et al. (2002) that at an early stage, especially when no physical disability is present, denial may be used as a defence mechanism or coping strategy (Roesch et al., 2005) by many men. More generally, females have been consistently linked to prevalence rates of about double those of males in large community studies of depression, anxiety, and posttraumatic stress disorder (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995). This gender difference may in some part explain the higher levels of reported psychopathology in women with breast cancer than in men with prostate cancer. The notion of potential underreporting of distress by men will be explored in more detail later in this discussion.

Depression and age.

Research has explored the relationship between age and depression in men with prostate cancer. A comparison of depression across age groups was conducted by Lintz et al. (2003), however they did not find any difference. This differs from the current study where at Time 2 there was a significant difference in depression between men aged 50-64 and men older than 75, with the younger group exhibiting more depressive symptoms than their older counterparts. Such a finding is consistent with that of Dirksen et al. (2009) who found that older men in their study reported less depressive symptom severity and distress than their younger counterparts.

Indeed, as pointed out by Blank and Bellizzi (2008), researchers have shown that younger adults with cancer are at a higher risk of reporting psychological distress than their older counterparts. The authors have suggested that age may serve as a protective

factor against cancer-related psychological distress. For younger men with prostate cancer, the impact of a diagnosis and treatment may be more distressing than for their older counterparts as it occurs during earlier stages of their life cycle when they might be still working, rearing children, and supporting their families. Indeed, the concerns for younger men around finances, family, and treatment side effects such as urinary and sexual function, may be more pressing than for older men (Diefenbach et al., 2008; Dirksen et al., 2009). Indeed, the findings of the current study suggest that perhaps it is for younger men with prostate cancer that support services are particularly important.

Depression across time.

Few studies have examined depression in men with prostate cancer over time. Data from the current study did not reveal any significant differences in depression scores across time, although slight fluctuations were evident between the three assessment periods. This is in contrast to a study by Bisson et al. (2002) who found an increase in depression from Assessment 1 to 2. The authors suggested that it was possible that an in-depth discussion about prostate cancer resulted in a fuller recognition of the implications of the diagnosis, with some increase in depressive symptoms. The authors also noted that given the low levels of psychopathology at both times, the difference in depression between the two assessments was likely of limited clinical significance (Bisson et al., 2002). For individuals, though, the increase is important and careful assessment of psychological distress is warranted to identify correctly the small portion of men whose distress does increase. Mixed results were found by Nordin et al. (2001) whereby men with non-advanced prostate cancer exhibited no significant difference in depression between diagnosis and 6 months, whereas in men with advanced prostate cancer over the same period there was a significant difference in depression. A possible reason for this result is that as the disease progresses over time, with all that the progression implies for survival, so too does depression for some men.

Therefore, while the above data indicate that there is little difference in depression over time in men with prostate cancer, this may be related to disease stage as indicated by the data from Nordin et al. and should be a factor considered in future longitudinal studies of depression in men with prostate cancer. The research to date on depression over time has involved mitigating factors and has not provided a clear indication of whether depression changes over time or whether it is stable over the cancer trajectory. While the current data is suggestive of stability over time, additional research is warranted to further explore the nature of depression over time in men with prostate cancer.

Predictors of depression.

Understanding the variables that predict depression in men with prostate cancer is crucial so that cases can be identified early in the trajectory and appropriate interventions can be implemented to manage such difficulties and thereby minimise risk of depression. In the current study, the variables that uniquely predicted depression at the three time points varied to some extent. The one consistent aspect was fatigue. Given the well-recognised link between fatigue and depression (e.g., Pirl et al., 2002) it is not surprising that consistently across all three time points, fatigue was a predictor of depression. This is consistent with findings by Stone et al. (2000), whereby fatigue was significantly associated with psychological symptoms including depression and Pirl et al. (2002) who found that depressive symptoms in men with advanced prostate cancer correlated with fatigue at baseline, 6 months, and 12 months. Pain severity was also a predictor of depression at Time 1. The relationship between depression and pain is another well recognised occurrence. While minimal research has examined this relationship in men prostate cancer, Heim and Oei (1993) found that men with prostate cancer who had pain were significantly more likely to exhibit depressive symptoms.

While at Time 3 fatigue was the sole unique predictor of depression levels, at Time 2 bowel function was also found to predict depression at Time 2. It is possible that

bowel function predicted depression as a result of the urgency aspect of bowel function, which as will be discussed further on, can interfere with daily functioning and result in individuals feeling depressed. However, the overall results across the three time points showed very few physical factors relating to prostate cancer predicting depression. It is likely that the low levels of difficulties in these areas, which are the primary suspects for precipitating depressive reactions, are consistent with the low levels of depression.

Anxiety.

In assessing anxiety in men with prostate cancer, studies have used various anxiety measures, such as the HADS, Brief Symptom Inventory (BSI; Derogatis, 1995), and the State-Trait Anxiety Inventory (STAI; Spielberger et al., 1970). As some measures are not comparable to that used in the current study, namely the BAI, only studies using the most similar measures will be referred to in the following discussion. The majority of men in the current sample reported minimal anxiety. However, while few in number, there were some who did experience moderate and severe symptoms of anxiety. On average across the three time points 5% of men reported anxiety levels in the moderate or severe ranges. This finding is consistent with that of Cliff and Macdonagh (2000), Hinz et al. (2009), and Lintz et al. (2003) who, using the HADS, found low rates of anxiety in their sample of men with prostate cancer. This result is somewhat surprising given the widely reported clinical observation that men are particularly anxious about their PSA levels after treatment (Lofters et al., 2002). It is possible that men in particular distract themselves from consideration of anxiety-provoking aspects of their condition, enabling them to distance themselves from the existential issues of a life-threatening condition. Or in fact, their anxiety may have been quelled by some reassurance about their condition and life prospects.

Anxiety and age.

The current study examined whether age impacted on anxiety levels in men with prostate cancer; however, no significant difference was found. This is in contrast to a study by Lintz et al. (2003) who found that men under the age of 65 were more anxious than their older counterparts. It is possible that younger men have higher levels of anxiety as a result of greater psychological distress associated with sexual dysfunction (Lintz et al., 2003; Steginga et al., 2001). A similar finding is reported by Hinz et al. (2009), who found that younger men were particularly affected by anxiety, especially at Time 1. It is unclear why the current study did not find an age effect as it was expected. The mean ages in the various studies were not substantially different.

Anxiety across time.

The current study found no significant differences in anxiety across time. In contrast, previous research has generally shown anxiety reduces over time. For example, research by Bisson et al. (2002) found that even though their sample had low levels of anxiety there was a reduction in anxiety levels between assessments 1 and 2. Similarly, Nordin et a. (2001) found a decrease in mean anxiety scores across time in their sample of men with prostate cancer. Bisson et al. proposed that anxiety levels may be lowered by an in-depth discussion of the diagnosis, treatment options, and prognosis, although no evidence to support the speculation was offered. However, the authors suggested that it is likely to be of limited clinical significance, due to the low levels of psychopathology at both times. The finding may also be an artefact of the research, as Hinz et al. (2009) found that approximately 20% of their patients changed category from *case* to *no case* and 10% moved in the other direction. Although the reason for disparate findings about the change in anxiety levels in men with prostate cancer is unclear, the clinical management of these men might be facilitated if regular monitoring of anxiety levels was conducted to rule out psychological morbidity.

Predictors of anxiety.

Awareness of the variables that are predictive of anxiety in men with prostate cancer is important so that appropriate interventions can be implemented to manage their anxiety. As with depression, in the current study, the predictors of anxiety were variable across time. Fatigue was found to predict anxiety at Times 1 and 3. Indeed, in their review of fatigue in cancer patients, Brown and Kroenke (2009) found that anxiety was significantly correlated with fatigue in 33 of the 35 studies. As minimal research has examined this relationship in men with prostate cancer, other cancer populations will be drawn on here; however, the generalisability to prostate cancer should be considered with caution. Research by Tchekmedyian, Kallich, McDermott, Fayers, and Erder (2003) in patients with lung cancer suggested that fatigue improvements were correlated with decreases in anxiety levels. The authors postulated that patients with cancer often become distressed, as a result of no longer being able to perform physical activities that they were able to in the past. The result of this can be manifested as frustration, loss of control, and anxiety. As such, it makes sense that decreases in fatigue, which are linked with improvement in functional status, may enable patients to act on their needs, regain some control, and feel less anxious (Tchekmedyian et al., 2003).

In addition to fatigue, at Time 1 urinary bother also uniquely predicted anxiety. It is likely that it is the urinary urgency aspect that results in the bother and anxiety. While little research exists on anxiety and urinary urgency in prostate cancer, more general research has shown that individuals report stigma with urinary frequency and urgency (Elstad, Taubenberger, Botelho, & Tennstedt, 2010). Individuals in Elstad et al.'s (2010) study reported feelings of embarrassment and shame related having to make frequent trips to the bathroom when with others. While stigma perceptions for frequency and urgency symptoms often suggested anxieties about the possibility for

leakage the researchers found that the stigma of frequency and urgency was ingrained in social interruption, loss of socially expected control of the body, speculation as to the nature of a non-specific 'problem', and the undesirable mixing of private behaviour in a public space. Specific to men which is relevant to the current sample of men with prostate cancer, the males in Elstad et al.'s study were especially worried about divulging a frequent need to urinate. One of the men reported anecdotally that a male may be stigmatised if he goes to the bathroom often as males are not meant to do that. Some men reported believing that other people may relate behaviours linked to urinary symptoms, such as frequent urination or visible wetness, with infertility or impotence (Elstad et al., 2010). Therefore, it is understandable that urinary bother was predictive of anxiety in the current study.

Bowel function was predictive of anxiety at Time 2. Given that one component of bowel function is bowel urgency it is not surprising that this may predict anxiety in some men with prostate cancer, especially given the social emotional aspects of this symptom, such as embarrassment. These aspects of urinary and bowel urgency will be discussed further in the section on physical symptoms.

Trauma.

Results from the current study revealed that the experience of prostate cancer did not impact on the men in a negative manner with regard to trauma-related sequelae. This finding is consistent with that of Blank and Bellizzi (2006) and Eton, Lepore, and Helgeson (2005), who also found minimal negative traumatic impact of prostate cancer in their sample. Indeed, Blank and Bellizzi (2006) reported that their IES data indicated a group of men who were not traumatised for the long term by having had and been treated for prostate cancer in their sample of 1-8-year survivors. Steginga et al. (2004) explored the two factors of the IES trauma measure, namely avoidance and intrusion. They found that before treatment but post diagnosis, most men reported low or

moderate psychological distress on the intrusion and avoidance measures and that both measures declined 2 months after treatment. At 12 months after treatment, the majority of men reported low avoidance and intrusion symptoms, with the other men reporting either moderate or high distress symptoms. With regards to trauma symptoms and physical symptoms, Steginga et al. found that high avoidance men had inferior urinary symptoms compared to those with low avoidance and men who reported moderate to high intrusion had inferior urinary symptoms and bowel symptoms compared with men with minimal intrusive symptoms. Although the current study revealed moderate correlations between trauma and urinary and bowel symptoms at Time 2 but not at Time 1 and 3, the reason for this difference at the various time points is not clear.

Trauma as a function of age and time.

To date, research has scarcely examined trauma and age in the prostate cancer population. In the current study, the Middle Age and the Young Old men reported significantly more trauma related to their cancer experience than the Old Old men at Time 1. It may be that for the relatively younger men, the cancer diagnosis comes as more of a shock, specifically with prostate cancer, which many people believe is a disease of older men; as such the diagnosis may be more traumatic in nature. Furthermore, for the younger men in the study the implications of a diagnosis, such as incontinence and impotence, may be more traumatising than for older men who may already be experiencing such symptoms as part of old age or may be expecting those changes to come with age.

Similar to depression and anxiety, the current study found no differences in trauma across measurement times indicating a certain level of psychological stability amongst the sample of men. It may be that the findings presented here are unique to this sample, who appear to report few negative psychological effects from their cancer diagnosis and treatment. In any case, it is important to clinically monitor the experience

of trauma across time and age in men with prostate cancer, given that this study has at least shown that age was related to trauma.

Predictors of trauma.

Very little research has been conducted about trauma in men with prostate cancer and less research has been done to ascertain those factors that are predictive of trauma in this population. As such, it is necessary to consider what variables are predictive of this trauma in order to assist these men as best as possible. Some men in the current study reported trauma reactions to their cancer experience. Like the other components of psychological distress, depression and anxiety, predictors of trauma varied across time in the current study. At all three time points fatigue uniquely predicted trauma. In considering this relationship it is possible that trauma symptoms induce sleeplessness that can contribute to fatigue. Alternatively, the bad news of advanced disease following treatment may be the traumatic experience rather than the treatment itself and result in fatigue. At Time 1 it was also found that pain severity was a unique predictor of trauma. It is possible that the experience of pain is a reminder of aspects of the cancer experience that some men may have found traumatising and as such this predictive relationship is apparent. At Time 2, in addition to fatigue, bowel function, bowel bother, and sexual distress predicted trauma. For some men, like with anxiety, it may be the bowel urgency aspect that is traumatising for them. With sexual distress, it may be that for men losing their ability to perform sexually causes them distress which is traumatising from their perspective of losing an important aspect of their identity. This notion will be discussed in more detail later in the chapter.

Predictors of distress across time.

In the discussion above, the predictors of depression, anxiety, and trauma at each time point were outlined. However, the prediction of psychological distress over time is also critically important theoretically and clinically. The data from the current study

revealed that fatigue at Time 1 significantly predicted Time 2 depression, anxiety, and trauma and Time 3 depression and anxiety. It is apparent from this data that fatigue at baseline is a clear risk factor for future psychological distress. In addition to fatigue, pain severity was a significant predictor for Time 2 trauma and Time 3 anxiety, indicating that more severe pain at baseline is associated with distress later on. These findings are of great importance from a clinical perspective, given that if fatigue and pain can be adequately managed, it is possible that levels of psychological distress can be decreased. A further finding from the current study indicated that men who were less satisfied with their treatment decision at Time 1, experienced more depression at Time 3. This discovery emphasises the need for decision-related distress to be managed as this data indicated that decision-related distress does indeed predict psychological distress down the track.

Additional data from the current study revealed that psychological distress at Time 1 accounted for a large proportion of the variance in psychological distress variables at Times 2 and 3. With Time 2 depression and trauma, fatigue was also a significant predictor, however, the main variance was still Time 1 depression and trauma. These findings are of clinical significance, given that initial psychological distress is a predictor of later distress. As such, if men with psychological distress can be identified early and their distress can be managed, this may have a substantial positive impact on later distress.

Overall distress levels.

As mentioned previously, the overall levels of psychological distress were low in the current study, which is line with previous research. Several explanations have been proposed as to why it is that so many men with prostate cancer exhibit low levels of self-reported distress. Blank and Bellizzi (2006) have proposed that men who are diagnosed with prostate cancer early and have early treatment are reassured that there is

a relatively low likelihood of recurrence and a very low likelihood of dying from prostate cancer as long as 15 to 20 years after diagnosis, if ever. Therefore, once men have undergone treatment, many deem their prostate cancer taken care of and do not spend much time thinking about it. Indeed, this is substantiated by men in the current study who reported, "I try not to think about it and get on with life" and "I do not think about it – as though it never happened".

Perhaps for some men the abovementioned attitudes reflect a level of resilience. Indeed, the current study found generally high levels of resilience in the sample of men with prostate cancer. This finding is substantiated by research by Steginga et al. (2004) who found that 12 months following treatment, most men in their study reported low levels of psychological distress, with the authors suggesting that in general men are resilient to the experience of prostate cancer and adjust well psychologically, at least superficially. While this was the case for the majority of men in Steginga et al.'s study, a small minority, a group of up to 12%, were still highly distressed 12 months following treatment. While fewer in number, it is perhaps these men that display ongoing high levels of distress that are the most important for psychological management as evident in previous research and the current study.

While for some men resilience may be at play, another important possibility to consider is posttraumatic growth. As pointed out by Sumalla et al. (2009) linking growth in adversity to low scores in rates of depression and anxiety on its own is too simplistic. However, this does mean that posttraumatic growth is not at play in the current sample of men with prostate cancer. For some of these men, it is possible that they did experience positive changes associated with their cancer experience and that may to some degree explain the low distress levels they reported in the current study.

It is also important to consider the other life events that men with prostate cancer may be experiencing or have experienced in the past. Indeed, there are suggestions from

anecdotal evidence that the group of men in the current study felt other life experiences to have had more influence on their current well-being. Along the same lines, Blank and Bellizzi (2006) have suggested that the generally high well-being in men with prostate cancer could reflect the fact that the disease characteristics are not as influential on mental health as other normative or non-normative life events faced by late middle-age and older men. In fact, Bellizzi (2004) found that some cancer survivors who reported little positive or negative impact by the disease were dealing with vision losses associated with ageing, recent loss of a loved one, and other more traumatic life events.

One striking aspect of the results by Blank and Bellizzi (2006) was the lack of strong correlations between treatment type and psychological well-being outcomes; this finding is true for the current study too. Blank and Bellizzi found that surgery was correlated with more adaptive changes than radiation, but treatment type was not found to be a significant factor in any positive or negative psychological outcome. As both surgery and radiation therapy have more or less equivalent high likelihoods of success, the differences in treatments in relation to quality of life are likely to be limited to the functional outcomes usually investigated, but not necessarily the more psychological outcomes. Moreover, the time that has lapsed since treatment beginning a year after diagnosis may of course be a factor in mitigating any treatment-specific impacts (Blank & Bellizzi, 2006). This may be true for the current study too, given that for some men the time from diagnosis and/or treatment to participation in the study could have been lengthy, during which initial psychological distress may have diminished.

Furthermore, the evidence indicates that for Caucasian men with middle-to-upper socioeconomic status and access to diagnosis and treatment during the early stages of prostate cancer, being male and older may, in some way, be “protective” against symptoms of depression. While this effect is now well documented the reasons for the effect are less clear and still speculative (Bennett & Badger, 2005).

Of further relevance to the low levels of reported distress in men with prostate cancer in the current study, Bennett and Badger (2005) have raised a further possible consideration for gender differences in depressive symptoms. They suggested that the instruments currently used to measure depression, and the diagnostic criteria on which those measures are based, are biased toward the manner in which women tend to express emotional distress in Western culture. For example, in a study where the BDI was administered to a community sample significant gender differences were found with women scoring higher on the items relating to crying and sex. Men did not score higher than women on any items on the BDI (Salokangas, Vaahtera, Pacriev, Sohlman, & Lehtinen, 2002). Indeed, a gender-specific analysis of the concept of depression maintains that whereas women tend to directly experience, acknowledge, and display depressive emotions, men are more likely to distance themselves from such feelings and communicate their depression through maladaptive behaviour destructive to themself, others, and relationships (Lee & Owens, 2002; Lynch & Kilmartin, 1999). While previous research has discussed denial and minimisation as negative coping strategies in men as mentioned above, the current data and sample characteristics indicate that this may actually be evidence of resilience. For these men, coping implies a more positive psychological orientation rather than defence which implies a pathological focus.

Also important to the discussion of low levels of distress is the previously mentioned notion that according to some, men may not admit experiencing distress. Indeed, Balderson and Towell (2003) proposed that the prevalence rate of distress in their study had to be tempered by the realisation that older men are at times reluctant to admit and report distress, which may result in underestimation of their difficulties (Kornblith et al., 1994; Roth et al., 1998). This notion has also been strongly debated by these authors in the context of such low levels of reported distress. It has been suggested that, for these patients, medical professionals should implement a lower threshold for

evaluation of psychological distress and referral to mental health practitioners (Roth & Scher, 1998). Balderson and Towell suggested that little is known about the psychosocial health and needs of this large group of chronically ill, sometimes elderly, men and the factors linked to any distress. This area of research is still in its very early stages. Of note, generalising empirical data from other cancer populations may have limited applicability to this age, gender, and site-specific population (Balderson & Towell, 2003). However, a critical issue to consider in the context of these low levels of distress and the notion of 'reluctance' is the biased nature of such a claim. In actual fact, for at least some men, they are brought up with stoicism and endurance as virtues, as discussed previously in terms of resilience, and these can be framed as very positive ways to deal with distress. Indeed, no evidence exists that they are defensive ways of dealing with the situation. Therefore, in understanding men with prostate cancer and the levels of distress they may or may not exhibit, their positive virtues should be considered, rather than painting them with the stereotype of the uncommunicative 'reluctant' males. It would be extremely valuable to further explore this notion that men have these enduring virtues that help them deal with their cancer experience.

Coping

As noted in the discussion above, the majority of men in the current study reported low levels of psychological distress as operationalised as depression, anxiety, and trauma. In addition, the men reported using minimal coping strategies to deal with the stressors of diagnosis and treatment. In considering reasons as to why there was reporting of only minimal use of coping strategies, it may be that men who report more negative outcomes, like depression, are likely to be those who continue to be affected by the disease years after treatment and continue to engage in coping strategies in an attempt to ease the negative psychological sequelae (Blank & Bellizzi, 2006). It is clear in the current study that most men did not endorse significant distress symptoms by way

of depression, anxiety, or trauma, and therefore did not feel it necessary to engage in the use of coping strategies. Indeed, it appears as though the men did not view their cancer as threatening and as such it was not seen as something to be coped with. However, some coping strategies were found to be predictive of the various types of psychological distress being explored in the current study.

In examining coping and depression, the current study found that self-blame significantly predicted depression. Self-blame occurs when individuals attribute the cause of specific events to some aspect of themselves. Blaming oneself for a negative event can result in psychological consequences, including augmented symptoms of depression (Malcarne, Compas, Epping-Jordan, & Howell, 1995). Indeed, Beck argued that self-blame is associated with depression, asserting that it is depressing to feel accountable for bad outcomes (Mirowsky & Ross, 1990). Both clinical observations and experimental studies have shown that self-blame and the tendency to assume personal responsibility for negative outcomes are major features of depression (Abramson & Sackeim, 1977). As such, it is not unexpected that the current study found a relationship between depression and self-blame.

To understand the issues around depression and self-blame it is important to consider behavioural and characterological self-blame. Janoff-Bulman (1979) described behavioural self-blame as the attribution of undesirable events to an individual's own behaviour, whereas characterological self-blame is the attribution of undesirable events to stable aspects of the self. It has been argued that behavioural self-blame can promote positive adjustment if the behaviour being blamed is deemed changeable and allows for the chance to regain a sense of control and invulnerability to further trauma. In contrast, characterological self-blame is suggested to be linked with maladjustment as individuals deem their character as more fixed and less controllable than their behaviour (Janoff-Bulman, 1979).

According to Malcarne et al. (1995), while cancer patients who engage in behavioural self-blame may not believe they have control over the course of their current disease, they may feel that modifications in their behaviour can prevent the cancer, once cured or in remission, from returning. The authors suggested that self-blame may be associated with psychological distress through its impact on perceptions of control over future cancer recurrence and not through control over progression of existing symptoms. Furthermore, self-blame attributions may be the product of psychological distress, whereby elevated levels of psychological distress may increase the tendency to create explanations for the event, including those that involve self-blame. Research by Malcarne et al. revealed that patients' attributions of self-blame for the cause of their cancer, especially the propensity to attribute the cause to features of one's character, seem to play a role in the psychological adjustment to cancer during the early months of diagnosis and treatment. The authors concluded that patients who make characterological self-blame attributions near the time of their diagnosis are likely to be more distressed than those who do not generate such attributions. The findings of the current study and Malcarne et al.'s study indicate a target for clinical intervention. If indeed individuals with cancer, including men with prostate cancer, do engage in self-blame which contributes to their experience of depression, addressing these attributions early may be able to reduce distress levels, including depression.

Self-distraction was also found to be a predictor of depression in the current study. Indeed, in their paper on rumination Nolen-Hoeksema, Wisco, and Lyubomirsky (2008) remarked that people who engage in many distracting activities may be moving from one to another, in a desperate attempt to get their minds off their negative mood and ruminations. However, they may not pay complete attention to any one of these activities and therefore find that none of the activities offer relief, and indeed may even perpetuate their negative cognitions. This explanation may account for why the current

study found self-distraction to be positively correlated with depression. From a clinical viewpoint this relationship is important as if people avoid their problems through constant distraction, these problems are likely to recur. In the case of the current sample of men with prostate cancer self-distraction may have included activities such as watching movies or television, reading, or, sleeping. As such, it is vital that behavioural interventions encourage individuals with depression to engage in problem solving following short-term distractions (Nolen-Hoeksema et al., 2008).

When examining the coping predictors of anxiety, it was found that planning and self-blame were significant predictors. Whilst in some cases planning may be an adaptive coping strategy and decrease levels of anxiety, for some men in the current study focusing on making plans was related to increased anxiety levels. It may be that focusing on the cancer experience by way of planning around treatment or strategies to target side effects, increases the rumination about their situation and their future, thereby increasing worry. With regards to self-blame and anxiety it is necessary to draw on other cancer literature, such as breast cancer, due of the lack of coping research in men with prostate cancer. Clearly, it is important to bear in mind the distinct gender differences in these two populations when considering coping styles. In research by Glinder and Compas (1999) on women with breast cancer, it was found that attributions of self-blame were associated with inferior psychological adjustment during the first year post-diagnosis and initial treatment. Concurrent with findings from the current study, the authors found correlations between self-blame and anxiety. It is possible that the association between self-blame and anxiety stems from individuals feeling worried that they themselves caused their disease.

With trauma, the current study found that the significant coping predictors were planning, denial, and self-blame. Similar to anxiety, it is possible that planning leads to increased rumination about the cancer experience and may result in flashbacks about

diagnosis or treatment, thereby increasing the experience of trauma. With regards to denial, the current findings are consistent with previous research Perczek et al. (2002) who found that avoidant coping including denial was predictive of poor adaptation. From a clinical perspective identifying patients with avoidant coping styles is important as it may prompt clinicians to provide education and appropriate psychosocial interventions (Perczek et al., 2002). Very little literature exists about avoidance coping in men with prostate cancer but research on other cancer types has found avoidance coping to be linked to both concurrent and prospective distress. With self-blame and trauma, as pointed out in some early literature, individuals who have experienced a traumatic life event, including those with cancer, have the tendency to take personal responsibility for the event, despite having done little, if anything to cause it. There are theorists who have suggested that this self-blame is maladaptive while others have suggested that it may be positive in that it results in individuals changing their behaviour (Davis, Lehman, Cohen Silver, Wortman, & Ellard, 1996). Whilst it is not possible for men to sensibly state they have caused their cancer, due to the nature of prostate cancer, it may be that they do blame themselves in some way for getting cancer.

Important to the findings on coping is the support for the stress coping model. Indeed the current study found that men use mostly positive coping styles which relates to the fact that they did not display much stress; thereby confirming the model that positive coping results in positive outcomes.

Physical Symptoms

Urinary domain.

When examining the data for the urinary domain, it is important to note the low reliability coefficients found. It is possible that the low indices are indicating that the scales are not unitary, but probably comprise a mixture of different dimensions in the

urinary domain, in the sample of the current study at least. Therefore, it would be an interesting direction for future research to consider different aspects of these urinary problems for different populations of men with prostate cancer.

The current study examined the relationship between age and urinary symptoms. As with the other relationships studied, the results for age and urinary symptoms varied across time. Regarding urinary function, it was found that the Middle Age men reported the poorest urinary function at Times 1 and 2 compared to the Young Old and the Old Old men. No difference was found at Time 3. With urinary bother, no difference was found at Times 1 and 3 but at Time 2 the Young Old men and the Old Old men were less bothered by their urinary symptoms than the Middle Age men. Data on urinary distress revealed that the Middle Age men were more distressed by their urinary symptoms than the Young Old men at Times 1 and 2. No age differences were found in urinary distress at Time 3. As little research has specifically examined the effect of age in the urinary domain, there is little comparative data. However, Hu et al. (2004) found that younger men, under the age of 65, which is comparable to the Middle Age group in the current study, was a significant predictor of return to baseline in the urinary domain. While the current study did not assess return to baseline, it was the Middle Age men who reported the poorest urinary function. In contrast, Harden et al. (2008) found that mean scores for urinary symptom distress were higher for their young old group than either of their other two groups suggesting a trend toward less bother and superior function for their young old group, given that higher scores indicate better function and less bother.

The overall picture in the urinary domain from the current study is indicative of the youngest men in the study, the Middle Age group, faring worst. In general, they were the ones with the poorest function and the highest levels of urinary-related distress. The reason for the youngest men faring worst may relate to treatment choice. Gwede et

al. (2005) found an age effect, whereby older men were less likely than younger men to choose prostatectomy. However, it is important to note that while it may be that younger men are more likely to choose prostatectomy, the data on urinary symptoms to date is variable, whereby in some studies men who have undergone a prostatectomy have more urinary dysfunction whereas in other studies men who have had radiotherapy have worse urinary function. The finding of the highest level of urinary related distress in the youngest men is not surprising. While this finding differs from that of Harden et al. (2008) who found no age difference in urinary related distress, it is possible that with the current study, for younger men, the impact of a prostate cancer diagnosis and treatment was more distressing than for older men as it happened during earlier stages of their life cycle at a time they are still working, raising children, and supporting their families (Diefenbach et al., 2008; Dirksen et al., 2009). As mentioned earlier, unlike older men who may attribute their physical problems like incontinence to old age and as a result be more accepting of it as an unavoidable result of aging, younger men may attribute their condition to the disease (Leventhal & Prochaska, 1986).

While the relationships between the urinary variables and other variables varied across the three time points, only the most commonly occurring relationships will be discussed here. Few relationships existed with the urinary function variable. With urinary bother and distress, relationships were found with depression, anxiety, and trauma. It is possible that it is the urinary urgency aspect that is resulting in bother and hence psychological distress. Indeed, Helgason et al. (1996) found urinary urgency to be related to distress in their study on men with prostate cancer. Given the minimal literature on psychological and/or emotional distress and urinary symptoms in men with prostate cancer, a broader range of literature was examined. In a study of older adults and urinary incontinence, it was found that urinary incontinence impacted on emotional well-being substantially. Half to one-third of the participants, more men than women,

experienced feelings of depression, anxiety, frustration, and embarrassment. Urinary incontinence was found to restrict travelling, visiting places where the participants did not know whether there was a toilet, and shopping. The most distressing consequences of urinary incontinence were said to be being out of control and feeling forced to take several precautions to prevent an "accident" (Teunissen, van den Bosch, van Weel, & Lagro-Janssen, 2006). Similar findings were found by O'Connell, Baker, and Munro (2007) and Chapple and Ziebland (2002) in samples of men with prostate cancer

Furthermore, Glover, Gannon, McLoughlin, and Emberton (2004) found in a sample of patients from a uro-oncology clinic, that the need to plan and the lifestyle changes that came with lower urinary tract symptoms were also seen as both a outcome of urinary symptoms and a cause of distress. For some men in the study, urinary symptoms had led to anxiety and embarrassment about social situations, had hindered them from going out as much and had negatively impacted on their sex life. In this light, the findings of the current study provide some confirmation of the link between urinary bother and urinary distress and depression, anxiety, and trauma. This finding of the association between urinary bother and urinary distress and psychological distress is of particular importance given the negative effect men may experience in terms of well-being and the negative effect there may be on their day to day functioning.

Bowel domain.

Regarding the data for the bowel domain, as can be seen from the mean scores, the results for bowel bother in the current study do not align with other studies. The writer and associate researchers attempted to establish if a coding error was responsible but nothing was found. While the bowel bother results should thus be interpreted with caution, this data is not central to the bigger picture of psychological and symptom distress.

When the impact of bowel function on age was examined in the current study, no differences were found according to age groups. This is consistent with the finding of O'Connell et al. (2007), which revealed that the men's overall rating of bowel habit problems was not related to age. It is possible no age difference was found as bowel symptoms are not expected by most men with prostate cancer and as such if they do occur they would be equally bothersome across all ages.

While scores on the bowel measures did not vary across age, an association was found between bowel function and bowel bother and depression, anxiety, and trauma. Similarly to the urinary domain, it is possible that it is rectal urgency that is the underlying aspect of the relationship to the psychological distress variables. Moreover, little research on bowel urgency and distress exists in the prostate cancer literature and the more broad literature. More general research on older adults has found faecal incontinence to be related to depression and anxiety (Edwards & Jones, 2001). Nonetheless, further research is needed in this area to determine what impact bowel urgency does indeed have on psychological well-being.

Sexual domain.

The relationship between age and sexual function, bother, and distress was assessed in the current study. Similar to the other domains, the data varied across the different time points. At Time 1 the Middle Age men, the youngest group, had better sexual function than the Old Old men, the oldest group. This finding differs from previous research whereby no significant difference was found among the three age cohorts for distress in regard to sexual symptoms in a study by Harden et al. (2008). This finding of the current study may relate to the treatment data which revealed that men in the Hormone Treatment group had inferior sexual function to men in the No Treatment group and the Other Treatment group. It is possible that the older men in the current study had poorer sexual function as a result of the treatment they were

undergoing. Indeed, in general more older men underwent hormone therapy than younger men. It is difficult to compare this finding to other studies as most studies which compare sexual function across treatment types do not include hormone therapy but rather focus on prostatectomy, external beam radiation therapy, and brachytherapy. This difference in sexual function found in the current study can be attributed to the known side effects of hormonal therapy which include decreased libido and sexual dysfunction (Hervouet et al., 2005; Visser et al., 2003).

With sexual distress, in the current study at Time 2 the Middle Age men were significantly more distressed than the Old Old men. These results indicate that the youngest men in the study were the most distressed by their sexual symptoms. For younger men who are more likely to be sexually active, sexual problems probably hit harder. Berterö (2001) suggested that the natural effect of age also was a cause for sexual dysfunction, under the assumption that sexuality should stop being of concern after a certain age. Some men in Berterö's study claimed that they were so old that their sexual activity decreased substantially, even prior to surgery. Similarly, Steginga et al. (2001) found that younger men reported more need in the area of sexual dysfunction than older men, which may be suggestive of life stage, in that the older men may already be facing a deterioration in sexual functioning prior to their prostate cancer diagnosis, which is seen as a typical consequence of the normal ageing process. As such, for older men, the loss of sexual function with treatment may be a less prominent need area than for younger men (Steginga et al., 2001). This decline in sexual function with age may also explain the above finding of the Old Old men having inferior sexual function to the Middle Age men.

For those men in the current study and in Potosky et al. (2004) who experienced distress related to sexual dysfunction, it has been suggested that it is reflective of the men’s misery at not being able to perform sexually. Furthermore, engaging in a sexual

experience may remind them of their ‘lack of manliness’, which can increase their distress over the loss of erectile function (Roth et al., 2008). Indeed, men in a study by Bokhour et al. (2001) reported that difficulty engaging with a partner sexually was part of a wider range of difficulties about their sexuality including their interactions with women, their fantasy life, and the manner in which they viewed themselves as men. It is these abovementioned difficulties that have the capacity to not only be distressing but also impact strongly on the relationship these men have with their partners (Roth et al., 2008).

Given the distress so many men experience as a result of sexual dysfunction, it is crucial for health professionals to appreciate the increasingly complex psychosocial issues that men attribute to sexual dysfunction (Bokhour et al., 2001). It is also vital that health professionals recognise that men may have difficulty discussing such issues given their sentiments of it being 'unmanly' to discuss emotions (O'Brien et al., 2010). So while men may not openly offer to discuss these issues if they are given the opportunity and support to do so, this may enable dialogue about this important issue (Bokhour et al., 2001).

Indeed, broader measures of psychological distress, including depression, anxiety, and trauma were found to be related to the sexual variables in this study. This is above and beyond the specific distress related to sexual dysfunction. Like with the other variables, the relationships between the sexual variables and the psychological distress variables varied over time. It is not surprising that relationships were found between the sexual variables and psychological distress. Studies (e.g., Helgason et al., 1996) have shown that sexual dysfunction can result in psychological distress in men having treatment for localised prostate cancer. It was found that men with prostate cancer reported ‘severe distress’ due to decreased erectile ability and ‘severe distress’ due to decreased pleasure of orgasm (Helgason et al., 1996). Furthermore, Lintz et al. (2003)

found that younger men had higher levels of anxiety, which the authors suggested may have been related to greater psychological distress associated with sexual dysfunction found in their study and that of Steginga et al. (2001).

A crucial aspect in the area of sexual functioning and the related psychological distress is the deep impact it has on these men as male beings. This issue is captured by the findings of Fergus, Gray, and Fitch (2002) who found that men who had treatment with the view of trading sexual function for life found that indeed the sexual sacrifice was never as simple as it initially seemed. For these men, they assumed that sexuality was a solitary function rather than the integral component of their identity and lifestyle. As it turned out, sex and life were far more entangled than the cost–benefit rationale made it appear. Further findings revealed that sexual performance was seen as a symbolic expression of manhood, demonstrable via procreation, the provision and receipt of erotic pleasure, the objectification of sexually desired others, and through competition with other men. Furthermore, most participants in the study revealed that sexual impairment posed a threat to who they were. Assertions such as, "You threaten a man's sex life, you threaten the man", or "I don't feel like a whole man anymore", were frequently reported. For these men, it was not the loss of sexual activity per se that was so distressing, so much as the loss of the ability. Therefore, for some men, the fact that they had not been sexually active prior to treatment did not necessarily decrease the distress they experienced in relation to their sexual dysfunction. (Fergus et al., 2002). As pointed out previously, men appear to be stoic in nature and in some cases this stoicism prevents men from talking, or being talked to about sexual dysfunction, and perhaps explains deficiencies in our understanding of men's sexuality (Oliffe, 2005). Given the impact of sexual dysfunction on the identity of men with prostate cancer, future research would benefit from working out ways in which to engage with men about this topic so interventions can be designed to assist them in adapting to their 'loss'

without detrimental effects on their sense of identity. It is interesting to note that while for some men the impact on their masculinity is paramount for others being alive is what matters as reflected in anecdotes from the current study, “The loss of sexual desire and capacity was I feel an integral part of the treatment. A trade off that I was quite happy to accept” and “Totally satisfied. It was a choice between having the operation with the total loss of libido, or not having it, with consequent deterioration of my medical problems”. Such sentiments suggest issues about loss of sexual function are a small part of the whole picture of prostate cancer.

Pain and fatigue.

As previously mentioned, psychological distress was related to pain and fatigue in the current study. From examining other relationships with pain and fatigue in the current study, it was apparent that many variables were involved, including from the urinary domain, bowel domain, sexual domain, and decision making. As such, it appears as though pain and fatigue are so pervasive that they affects all other areas of functioning. Indeed, both pain and fatigue can be recognised as markers of possible depression and therefore it is not surprising that they are both associated with other problems.

Physical symptoms over time.

Data on urinary, bowel, and sexual function and bother across time revealed no significant time effects, indicating a fairly stable pattern of symptom function and bother across time. This finding is interesting given that in the current study men were at different points of their cancer trajectory. This is to say that if all men were assessed at diagnosis and several post treatment points, this finding may be expected. It is important to note that a significant proportion of the cohort in the current study is ‘down the track’ from treatment so the symptoms will have somewhat settled by now and the data at Time 1 is likely a reflection of what is seen later in the prostate cancer trajectory.

Overall physical symptom experience.

When considering the physical symptoms that men with prostate cancer often endure, it is interesting to contemplate how some men adapt to what can be such distressing symptoms. Indeed, research by Korfage, Hak, de Koning, and Essink-Bot (2006) found that many men in their study accepted the side effects after treatment of prostate cancer due to sentiments of relief prevailing. The men reported that they were so happy to have survived a disease they saw as life threatening that side effects were of minimal significance to them. The experience of a diagnosis and treatment for a life-threatening disease seemingly led to a change in the concept of 'health'. Initially, both duration and quality of life were deemed important, but when duration was threatened (e.g., by disease), the men accepted a lower quality of life in order to preserve length of life. This mechanism of adaptation complicates the assessment of the importance of side effects to men with prostate cancer (Korfage et al., 2006). Such a mechanism has been explored by others in the context of response shift, a phenomenon in which, by adapting to their disease, patients change the internal standards by which they evaluate their symptoms (Rees, Waldron, O'Boyle, Ewings, & Macdonagh, 2003). While it cannot be said for certain that response shift was present in the current study, it is possible that given the consistently low scores on various domains, such as urinary and bowel symptoms, response shift has occurred in these men. In the current study, men were assessed at different points in their cancer trajectories so while there were not significant differences in symptom distress and bother across time, this may be due to the fact that men were already at the point of having changed the benchmark with which they were assessing their symptoms.

What is important to consider in these men is the double physical burden, including the cancer symptoms and the side effects. The current results demonstrated that physicians cannot afford to ignore the side effects of treatment because they are

independent of stage and progression, yet are burdensome to cancer patients/survivors. While psychological distress levels in the current study were generally low, there were relationships with the side effects, which may be reflective of these physical burdens exacting a psychological toll.

Decision Making

The findings in relation to decisional conflict, decisional regret, and decisional satisfaction will now be discussed.

Decisional conflict.

Findings from the current study revealed minimal decisional conflict amongst the sample of men with prostate cancer. Whilst this was measured longitudinally it was not possible to measure this at pre- and post-treatment due to the nature of the study. This is somewhat different to other studies which have assessed decisional conflict before and after treatment. In their research, Davison and Goldenberg (2003) found that after treatment, higher levels of decisional conflict were significantly correlated with lower levels of emotional function and lower levels of urinary function but not sexual function. Steginga et al. (2004) found at baseline, men reported high levels of decisional conflict which declined following treatment; prior to treatment, 63% of men had high decisional conflict, falling to 38% at 2 months after treatment and 44% at 12 months.

Decisional conflict and psychological distress.

The results of the current study found relationships between decisional conflict and psychological distress. This is consistent with findings by Davison, Goldenberg, Gleave, and Degner (2003) who found that following treatment, greater levels of decisional conflict were significantly correlated with lower levels of emotional function. In the current study, inconsistencies were found with regards to the relationships between decisional conflict and psychological distress across time. At Time 1 the data revealed that decisional conflict was correlated with depression, anxiety, and trauma

while at Time 2 there were no relationships found between decisional conflict and psychological distress. At Time 3 only depression was found to be correlated with decisional conflict.

Nevertheless, men who experienced higher levels of decisional conflict experienced higher levels of depressive symptoms as compared to those who experienced lower levels of decisional conflict. It is possible that the uncertainty as to what treatment to choose results in the men feeling depressed about their situation and also possibly depressed about what the future may hold depending on the treatment they choose. Indeed, when men are choosing a treatment, the impact of side effects on their future are paramount to the decision, including depressive feelings of the potential loss of sexual function. Regarding anxiety, it is not surprising that men with higher levels of decisional conflict reported higher levels of anxiety than men with lower levels of decisional conflict. Indeed, when there is a conflict between what treatment to choose this can result in elevated levels of worry about whether one is making the right decision and perhaps what the implications of the decision may be. In considering the relationship between trauma and decisional conflict, men with higher levels of decisional conflict reported more trauma than men with lower levels of decisional conflict. Perhaps this relates to the fact that if one is traumatised and depressed and anxious, it is only reasonable for them to ask themselves whether they did or are doing the right thing and whether their decision is the right one.

Decisional regret.

Findings from the current study revealed minimal levels of decisional regret among men with prostate cancer. This is consistent with data from Diefenbach and Mohamed's (2007) study, which also revealed generally low levels of decisional regret. However, they did find that regret increased significantly over time indicating the possible impact of treatment side effects over time while the current study did not find

any such significant change over time. Hu et al. (2003) also found low levels of decisional regret, with less than 4% of men reporting regret over their decision to have a radical prostatectomy. Similarly, Davison, So, and Goldenberg (2007) found that the majority of men had no regrets over their treatment choice of surgery, with only 4% of men exhibiting decisional regret.

Various studies have examined the relationship between physical prostate symptoms and decisional regret. Results have indicated that men with higher levels of regret are likely to report higher levels of urinary dysfunction, urinary bother, and sexual bother (Clark et al., 2001; Diefenbach & Mohamed, 2007; Hu et al., 2003). This is in contrast to the findings of the current study whereby no significant correlations were found between regret and urinary and sexual symptoms. A possible explanation for this finding may be that despite men in the study experiencing side effects from treatment as evidenced by the data, this did not mean that they were regretful of their treatment choice. Data from Davison et al.'s study (2007) revealed higher levels of decisional regret were significantly correlated with changes in quality of life (before and after radical prostatectomy) including increased pain. No significant correlations were found between changes in sexual function scores before and after radical prostatectomy and decisional regret (Davison et al., 2007). This finding is consistent with the results of the current study which revealed no associations between sexual function and levels of decisional regret. Furthermore, like the current study, urinary and bowel symptoms were not significantly related to decisional regret scores.

Data on whether decisional regret was related to treatment choice is variable. Due to small participant numbers, the current study grouped treatment as active treatment (hormone or other) or no current treatment, and found no differences in decision-related regret across these two groups. Diefenbach and Mohamed (2007) reported that men who opted for radical prostatectomy had greater decisional regret over

time, while Gwede et al. (2005) found no differences amongst treatment groups in terms of decisional regret. Further research is needed to examine the relationship between treatment type and decisional regret in order to determine whether men undertaking particular treatments are more prone to experiencing regret, which can in turn impact on psychological well-being.

Decisional regret and psychological distress.

In examining the relationships between decisional regret and depression, anxiety, and trauma, the current study only found decisional regret and depression at Time 3 to be correlated. Indeed, according to Davison et al. (2003), some clinicians assert that even patients who are informed about their treatment may have psychological consequences and decisional regret if the outcomes of their treatment are not as expected, or if the side effects of treatment compromise their quality of life. It is possible that some of men in the current study experienced regret about the treatment decision as a result of its side effects and it was the experience of side effects that resulted in depressive symptoms. Indeed, research has shown that side effects of prostate cancer treatment, such as incontinence and impotence, are a source of considerable distress for some men.

Decisional satisfaction.

Data from the current study is consistent with that of previous research, which found that men treated for prostate cancer have high levels of decisional satisfaction as is shown by the quantitative and qualitative data provided by men in the current study. The men provided anecdotes such as, “I am satisfied with the decision I made”, “I am satisfied with the treatment I’ve had”, “Satisfied because it was successful”, “I am totally satisfied that the treatment was the best option available”, “I am satisfied because I can live a normal life”, and “I am very satisfied with my prostate treatment because I can enjoy life like before”. Research by Miles, Giesler, and Kattan (1999) revealed that

78% of prostatectomy patients, 89% of radiation patients, and 82% of patients treated with hormonal therapy were satisfied with their treatment choice, while 12%, 10%, and 12%, respectively, were not satisfied, and the rest were uncertain. Furthermore, Berry et al. (2006) found high decisional satisfaction in their sample of men with prostate cancer and that knowing the specific options and associated benefits and risks has an effect on satisfaction with a particular treatment decision. Similarly high levels of decisional satisfaction were found by Carvalhal et al. (1999) who found that 89% of the men in their study whose cancer had been diagnosed between 2 and 74 months previously indicated satisfaction with their treatment. Satisfaction was equally high in early and metastatic prostate cancer patients and did not significantly differ by treatment type. In their study of men with localised prostate cancer, Hoffman et al. (2003) found that the most satisfied subjects were those receiving radiation therapy, while the least satisfied subjects were those receiving no active treatment.

The reasons for some men's dissatisfaction with their treatment were not directly assessed in the current study. However, correlational data revealed minimal associations between urinary symptom experience and dissatisfaction. Some low but significant correlations were found between decisional satisfaction and urinary symptoms at Time 1 and Time 3. No relationships were found between satisfaction and bowel or sexual function. Indeed, one man in the study stated "I was fully informed of the options available and the possible consequences. I am totally satisfied that the treatment was the best option available. The loss of sexual desire and capacity was I feel an integral part of the treatment. A trade off that I was quite happy to accept". Similar to the findings of the current study, Carvalhal et al. (1999) found urinary function and bother were the only correlates of dissatisfaction with treatment and not other physical indices such as sexual function. In addition, Miles et al. (1999) explored reasons for men's dissatisfaction and reported that dissatisfaction was in general ascribed by the men to

physical complications, including urinary and sexual problems. Consistent with data from the current study Carvalhal et al. found an association between dissatisfaction and physical complications, whereby urinary problems (both severity of incontinence and the degree to which men were bothered by urinary problems) were associated with greater dissatisfaction, whereas neither erectile dysfunction nor related sexual difficulties had a significant association. As previously argued, it is possible that the age of the men has an impact on such a finding, whereby older men expect their sexual function to decline and perhaps do not consider this a factor in their satisfaction with their treatment decision.

Decisional satisfaction and psychological distress.

Data on the relationships between decisional satisfaction and depression, anxiety, and trauma, showed decisional satisfaction and depression to be negatively correlated at Time 3. These results indicated that for the most part no relationships were found between satisfaction and distress. With depression and satisfaction at Time 3, men who were more satisfied with their decision were less depressed than those who were less satisfied with their treatment decision. The reason for this relationship is intuitive, in that men who are happier with the treatment choice they have made are less likely to feel depressed about their situation.

Decision making across age and time.

The findings from the current study indicate that decisional conflict, regret, and satisfaction were relatively stable over time, with no significant differences found across the three time points. Furthermore, there appeared to be no differences in decisional conflict, regret, or satisfaction across age. It is possible that these consistent time and age findings are a result of the overall low levels of conflict and regret and high levels of satisfaction found in the current study.

Overall decision making.

The data from the current study paint a picture of minimal decisional conflict, minimal decisional regret, and high decisional satisfaction for the majority of men. From the anecdotes provided by many men in the study, it appears as though this picture is the reflection of the trust that the men had in their treating medical professionals. For these men they were content following the advice of their doctor as a result of confidence and faith in their expertise or for some men the lack of other options for their particular situations. Furthermore, men reported being content with their decisions because they felt treatment had been successful. A number of men attributed their happiness with their decision to decreasing PSA levels, a standard by which many men assess the status of their prostate cancer.

Given the reports of urinary and sexual dysfunction, it is somewhat surprising that men have reported such high levels of satisfaction and such low levels of regret with their decision. It is possible that for the men in the current sample, they did not expect to come through their treatment with no consequences and perhaps they were therefore more accepting of the side effects they did experience. Nonetheless, this phenomenon remains a mystery and definitely deserves closer consideration empirically.

Overall, men with prostate cancer need to be given plenty of time and resources to facilitate what is sometimes a lengthy, difficult, and distressing decision making process. While the present results suggest that this cohort did not express difficulties with their decisions, the picture is complicated. Additional research is required to assess whether men experience distress and regret in the long-term as they endure long-term disease outcomes and sometimes chronic treatment-related side effects (Gwede et al., 2005).

Methodological Issues and Future Research

The findings of this study need to be considered in the light of some methodological issues. Firstly, the sample size was limited as a result of logistical limitations and a rate of volunteering that was below expected within the project management timeline. As such given the time available to recruit men for the study the ideal target, based on the statistical power analysis, was unable to be achieved. Given this limitation of sample size, the overall power and generalisability of the findings are restricted. Future research would be benefited by larger samples in order to give the study greater power and the ability to make the results more generalisable. Another issue with the current sample resulting from logistical limitations was that it was not possible to recruit a group of men at the same point in their cancer trajectory. Additional research examining psychological and symptom distress longitudinally would benefit from a sample of men at the same point in their cancer journey to best understand distress over time and various points in the cancer experience.

A further factor to consider with the current sample was that it was a convenience sample and men self-selected to some degree. While many men were given the opportunity to participate in the research, the ultimate decision to participate was up to the men themselves and as a result there may have been a sampling bias. Although it may be assumed that more reflective individuals would self-select for such a study, is it possible that those men who were experiencing high levels of distress chose not to engage in the study. In addition, a more representative sample would be advantageous and would include private patients and men from a wider range of socio-economic backgrounds.

In terms of the technique of the study, the self-report approach offers empirical merit and clinical relevance but it is susceptible to common response biases, such as social desirability, suggesting the need for supplementary data collection approaches.

This is particularly important in a population such as men with prostate cancer as if indeed men do underreport distress on qualitative measures, crucial information important to management may be missed. Using other techniques such as qualitative interviews may generate richer data and drawn on aspects of the cancer experience which men may not reveal in a quantitative questionnaire. Another issue related to the data of the current study was the substantial amount of missing clinical data, such as stage of disease and treatment type. While this lack of data limits the findings to some degree, the data from the research are unique in so many ways, and can contribute, however modestly, to the accumulated evidence in the field of psycho-oncology.

While significance was the criterion for reviewing the results of the current study, often the effect sizes were nevertheless small. Nonetheless, significance is a legitimate benchmark to employ and is the 'industry standard' in psychology.

On a positive note, the current study was longitudinal in nature, allowing for the examination of variables across time, which the majority of previous studies have failed to do. While it was not possible in this study to obtain patient data at the same point in the men's cancer trajectory, such as diagnosis, treatment and several post-treatment time points, it was still advantageous having longitudinal data to observe patterns over time.

Inspection of the measures used in this study suggests both strengths and weaknesses of the current research. The measures used in the study to measure depression and anxiety, namely the BDI-II and BAI, have known validity and reliability as evidenced by their widespread use in the research literature. Furthermore, these two tools have acceptability in the clinical world as they represent familiar and widely adopted measures. These measures are tolerated well by patients as the burden relating to time and number of questions is kept to a minimum. However, it should be kept in mind that these measures have limitations, which apply to most measures in this field,

namely the overlap between primary symptoms of the presenting disease such as fatigue and the symptoms of depression.

Directions for future research in this area are many, and numerous suggestions have been noted already. Despite many studies investigating emotional distress in cancer patients, general conclusions have been difficult to derive as a result of their methodological limitations and the use of diverse measures. Future research would benefit from using similar measures and standard cutoff scores for clinical significance to enable meaningful comparisons between them (Strong et al., 2007). In addition, a critical lack of research in the area of distress specific to prostate symptoms need to be rectified in order for interventions to be developed to address these specific issues and to address them early in the disease trajectory. It is also important that further research more closely examines the predictors of psychological distress as these predictors, which as shown in the current study were physical in nature, are important targets for management. It would be beneficial for further research to assess men longitudinally from directly after treatment to see the trajectory of symptoms over time. Finally, future research would benefit from employing large samples of men with a wide range of ages and socioeconomic backgrounds in order to gain a clearer picture of the diverse experiences of men of different ages and backgrounds and to examine how factors such as socioeconomic status impact on the experience of men with prostate cancer.

Clinical Implications

Crucial to the management of men with prostate cancer is the development of clear guidelines on the optimal methods of detecting and managing both psychological and physical symptom distress. As previously mentioned, the levels of psychological distress in men with prostate cancer may not be at a clinical level as classified by DSM-IV-TR but nonetheless may still have a significant impact on their lives. Unless those men who are distressed are identified and identified early and interventions are put in

place, negative effects on their psychological well-being will continue and ultimately may impact on their outcome. With regards to physical symptom distress, it is vital that clinicians are aware and screen for the potential negative impact that treatment side effects such as incontinence and impotence, may be having on these men. If this physical symptom distress can be managed it is possible that the effect the symptoms may be having on psychological distress for these men will be decreased.

When devising support services for men with prostate cancer it is important to bear in mind that many of these men may exhibit a stoical response to adversity and emphasise the importance of continuing to live a normal life. However, a recent review suggests that men may benefit from group cognitive behavioural interventions and psycho-education in terms of promoting better psychological adjustment (Chambers, Pinnock, Lepore, Hughes, & O'Connell, 2011). Furthermore, men with prostate cancer face the heartbreaking issue of loss of sexual function. For these men psycho-education about changes in sexuality should be part of their cancer care in order to reassure them there is support targeted at restoring intimacy and sexuality for them and their partners (Wittman et al., 2009).

Regarding decision making, from a clinical perspective it is important that clinicians do their utmost to make sure men are actively involved in the decision making process and are aware of what effects each treatment may have prior to making their decision. It is possible that if men know what to expect and the ways in which the potential effects can be managed, this may limit decision-related distress.

Conclusion

In conclusion, for the most part there were minimal levels of psychological distress associated with prostate cancer. However, men in the current study reported experiencing difficulties with physical symptoms. The current study found that that men with prostate cancer used relatively positive coping styles, expressed high decisional

satisfaction, and low decisional regret and conflict, which to some degree explains their reporting of low levels of psychological distress.

However, an important finding of the current study was that fatigue consistently predicted psychological distress, not only at each time point, but baseline fatigue was predictive of future psychological distress. This finding is of great clinical importance in that if appropriate interventions can be employed to manage fatigue it is possible that it will have a positive effect on psychological well-being. Furthermore, the data of the current study indicated that age differences exist in psychological and physical functioning. These differences are becoming increasingly important as the age range of men being diagnosed with prostate cancer is becoming broader and more men are living with the disease.

The current research adds to the existing literature on the experience of men with prostate cancer and points to the stoic and resilient nature that many of these men display. Despite this positive picture of men with prostate cancer, this is not to say that they do not face difficult treatment decisions and distressing times but as a group overall they demonstrate that their positive nature is central to their positive adaptation to difficult circumstances.

References

Abraham, N. E., Makarov, D. V., Laze, J., Stefanovics, E., Desai, R., & Lepor, H. (2010). Patient centered outcomes in prostate cancer treatment: Predictors of satisfaction up to 2 years after open radical retropubic prostatectomy. *The Journal of Urology, 184,* 1977-1981.

Abramson, L. Y., & Sackeim, H. A. (1977). A paradox in depression: Uncontrollability and self-blame. *Psychological Bulletin, 84,* 838-851.

Ahmad, M. M., Musil, C. M., Zauszniewski, J. A., & Resnick, M. I. (2005). Prostate cancer: Appraisal, coping, and health status. *Journal of Gerontological Nursing, 31,* 34-43.

Arora, N. K., Weaver, K. E., Clayman, M. L., Oakley-Girvan, I., & Potosky, A. L. (2009). Physicians' decision-making style and psychosocial outcomes among cancer survivors. *Patient Education and Counseling, 77,* 404-412.

Australian Institute of Health and Welfare & Australasian Association of Cancer Registries (AIHW). (2010). *Cancer in Australia: an overview, 2010.* Cancer series no. 60. Cat. no. CAN 56. Canberra: AIHW.

Bailey, D. E., Jr., Wallace, M., & Mishel, M. H. (2007). Watching, waiting and uncertainty in prostate cancer. *Journal of Clinical Nursing, 16,* 734-741.

Balderson, N., & Towell, T. (2003). The prevalence and predictors of psychological distress in men with prostate cancer who are seeking support. *British Journal of Health Psychology, 8,* 125-134.

Barry, M. J., Fowler, F. J., Jr., O'Leary, M. P., Bruskewitz, R. C., Holtgrewe, H. L., Mebust, W. K., Cockett, A. T. K., & The Measurement Committee of the American Urological Association. (1992). The American Urological Association Symptom Index for benign prostatic hyperplasia. *The Journal of Urology, 148,* 1549-1557.

Bar-Tur, L., & Levy-Shiff, R. (2000). Coping with losses and past trauma in old age: The separation-individuation perspective. *Journal of Personal & Interpersonal Losses*, *5*, 263-282.

Bauer-Wu, S., & Farran, C. J. (2005). Meaning in life and psycho-spiritual functioning: A comparison of breast cancer survivors and healthy women. *Journal of Holistic Nursing, 23,* 172-190.

Beck, A. T., Epstein, N., Brown, G., & Steer, R. A. (1988). An inventory for measuring clinical anxiety: Psychometric properties. *Journal of Consulting and Clinical Psychology, 56,* 893-897.

Beck, A. T., & Steer, R. A. (1990). *Beck Anxiety Inventory manual.* San Antonio: TX. Psychological Corporation, Harcourt Brace Jovanovich.

Beck, A. T., Steer, R. A., Ball, R., & Ranieri, W. (1996). Comparison of Beck Depression Inventories -IA and -II in psychiatric outpatients. *Journal of Personality Assessment, 67,* 588–97.

Beck, A. T., Steer, R. A., & Brown, G. K. (1996). *Manual for the Beck Depression Inventory-II*. San Antonio, TX: Psychological Corporation, Harcourt Brace Jovanovich.

Bellizzi, K. M. (2004) Generativity and posttraumatic growth in adult cancer survivors. The *International Journal of Aging and Human Development, 58,* 267-287.

Bennett, G., & Badger, T. A. (2005). Depression in men with prostate cancer. *Oncology Nursing Forum, 32,* 545-556.

Berry, D. L., Ellis, W. J., Russell, K. J., Blasko, J. C., Bush, N., Blumenstein, B., & Lange, P. H. (2006). Factors that predict treatment choice and satisfaction with the decision in men with localized prostate cancer. *Clinical Genitourinary Cancer, 5,* 219-226.

Berterö, C. (2001). Altered sexual patterns after treatment for prostate cancer. *Cancer Practice, 9,* 245-251.

Bisson, J. I., Chubb, H. L., Bennett, S., Mason, M., Jones, D., & Kynaston, H. (2002). The prevalence and predictors of psychological distress in patients with early localized prostate cancer. *British Journal of Urology International, 90,* 56-61.

Bjorck, J. P., Hopp, D. P., & Jones, L. W. (1999). Prostate cancer and emotional functioning: Effects of mental adjustment, optimism, and appraisal. *Journal of Psychosocial Oncology, 17,* 71–85.

Blank, T. O., & Bellizzi, K. M. (2006). After prostate cancer: Predictors of well-being among long-term prostate cancer survivors. *Cancer, 106,* 2128-2135.

Blank, T. O., & Bellizzi, K. M. (2008). A gerontologic perspective on cancer and aging. *Cancer, 112,* 2569-2576.

Bokhour, B. G., Clark, J. A., Inui, T. S., Silliman, R. A., & Talcott, J. A. (2001). Sexuality after treatment for early prostate cancer: Exploring the meanings of "erectile dysfunction". *Journal of General Internal Medicine, 16,* 649-655.

Bowman, K. F., Deimling, G. T., Smerglia, V., Sage, P., & Kahana, B. (2003). Appraisal of the cancer experience by older long-term survivors. *Psycho-Oncology, 12,* 226–238.

Boyd, C. M., Darer, J., Boult, C., Fried, L. P., Boult, L., & Wu, A. W. (2005). Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases: Implications for pay and performance. *The Journal of the American Medical Association, 294,* 716-724.

Brehaut, J. C., O'Connor, A. M., Wood, T. J., Hack, T. F., Siminoff, L., Gordon, E., & Feldman-Stewart, D. (2003). Validation of a Decision Regret Scale. *Medical Decision Making, 23,* 281-292.

Breitbart, W., Lederberg, M. S., Rueda-Lara M., & Alici Y. (2009) Psycho-Oncology. In: B. J. Sadock & V. A. Sadock, (Eds.), *Kaplan and Sadock's Synopsis of Psychiatry*, (10th ed., pp. 2314–2353) Philadelphia, PA: Lippincott Williams and Wilkins Press.

Bremner, W. J. (2010). Testosterone deficiency and replacement in older men. *The New England Journal of Medicine, 363,* 189-191.

Brown, L. F., & Kroenke, K. (2009). Cancer-related fatigue and its associations with depression and anxiety: A systematic review. *Psychosomatics, 50,* 440-447.

Carter, H. B., Kettermann, A., Warlick, C., Metter, E. J., Landis, P., Walsh, P. C., & Epstein, J. I. (2007). Expectant management of prostate cancer with curative intent: An update of the Johns Hopkins experience. *The Journal of Urology, 178,* 2359-2364.

Carvalhal, C. G. F., Smith, D. S., Ramos, C., Crygiel, J., Mager, D. E., Yan, Y., & Catalona, W. J. (1999). Correlates of dissatisfaction with treatment in patients with prostate cancer diagnosed through screening. *The Journal of Urology, 162,* 113-118.

Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. *International Journal of Behavioral Medicine, 4,* 92-100.

Carver, C. S., Scheier, M. F., & Weintraub, J. K. (1989). Assessing coping strategies: A theoretically based approach. *Journal of Personality and Social Psychology, 56,* 267-283.

Chambers, S. K., Pinnock, C., Lepore, S. J., Hughes, S., & O'Connell, D. L. (2011). A systematic review of psychosocial interventions for men with prostate cancer and their partners. *Patient Education & Counseling, 85,* 75-88.

Chapple, A., & Ziebland, S. (2002). Prostate cancer: Embodied experience and perceptions of masculinity. *Sociology of Health & Illness, 24,* 820-841.

Christie, K. M., Meyerowitz, B. E., Giedzinska-Simons, A., Gross, M., & Agus, D. B. (2008). Predictors of affect following treatment decision-making for prostate cancer: Conversations, cognitive processing, and coping. *Psycho-Oncology, 18,* 508 - 514.

Clark, J. A., Inui, T. S., Silliman, R. A., Bokhour, B. G., Krasnow, S. H., Robinson, R. A., Spaudling, M., & Talcott, J. A. (2003). Patients' perceptions of quality of life after treatment for early prostate cancer. *Journal of Clinical Oncology, 21,* 3777-3784.

Clark, J. A., Wray, N., & Ashton, C. M. (2001). Living with treatment decisions: Regret and quality of life among men treated for metastatic prostate cancer. *Journal of Clinical Oncology, 19,* 72-80.

Clarke, D. M., & Kissane, D. W. (2002). Demoralization: Its phenomenology and importance. *Australian & New Zealand Journal of Psychiatry, 36*, 733-742.

Cleeland, C. S. (1991). Brief Pain Inventory Short-Form.

Cleeland, C. S., & Ryan, K. M. (1994) Pain assessment: Global use of the Brief Pain Inventory. *Annals, Academy of Medicine, Singapore, 23,* 129-138.

Cliff, A. M., & MacDonagh, R. P. (2000). Psychosocial morbidity in prostate cancer: II. A comparison of patients and partners. *British Journal of Urology International, 86,* 834-839.

Connolly, T., & Reb, J. (2005). Regret in cancer-related decisions. *Health Psychology, 24,* S29-S34.

Connolly, T., & Zeelenberg, M. (2002). Regret in decision making. *Current Directions in Psychological Science, 11,* 212-220.

Cook Gotay, C., Isaacs, P., & Pagano, I. (2004). Quality of life in patients who survive a dire prognosis compared to control cancer survivors. *Psycho-Oncology, 13,* 882-892.

Cooperberg, M. R., Broering, J. M., Kantoff, P. W., & Carroll, P. R. (2007) Contemporary trends in low risk prostate cancer: Risk assessment and treatment. *The Journal of Urology, 178,* S14-S19.

Cooperberg, M. R., Lubeck, D. P., Meng, M. V., Mehta, S. S., & Carroll, P. R. (2004). The changing face of low-risk prostate cancer: Trends in clinical presentation and primary management. *Journal of Clinical Oncology, 22,* 2141-2149.

Couper, J., Bloch, S., Love, A., Macvean, M., Duchesne, G. M., & Kissane, D. (2006). Psychosocial adjustment of female partners of men with prostate cancer: A review of the literature. *Psycho-Oncology, 15,* 937-953.

Couper, J. W., Love, A. W., Dunai, J. V., Duchesne, G. M., Bloch, S., Costello, A. J., & Kissane, D. W. (2006). Psychosocial adjustment of female partners of men with prostate cancer: A review of the literature. *Psycho-Oncology, 15,* 937-953.

Cowen, M. E., Miles, B. J., Cahill, D. F., Giesler, R. B., Beck, J. R., & Kattan, M. W. (1998). Utilities in decision analyses of the treatment of localized prostate cancer in individual patients. *Medical Decision Making, 18,* 376-380.

Cox, J., & Amling, C. L. (2008). Current decision-making in prostate cancer therapy. *Current Opinion in Urology, 18,* 275-278.

Creamer, M., Bell, R., & Failla, S. (2003). Psychometric properties of the Impact of Events Scale-Revised. *Behaviour Research and Therapy, 41,* 1489-1496.

Dale, W., Hemmerich, J., Bylow, K., Mohile, S., Mullaney, M., & Stadler, W. M. (2009). Patient anxiety about prostate cancer independently predicts early initiation of androgen deprivation therapy for biochemcial cancer recurrence in older men: A prospective cohort study. *Journal of Clinical Oncology, 27,* 1557-1563.

Dall'era, M. A., Coopberberg, M. R., Chan, J. M., Davies, B. J., Albertsen, P. C., Klotz, L. H., Warlick, C. A., Holmberg, L., Bailey, D. E., Jr., Wallace, M. E., Kantoff, P. W., & Carroll, P. R. (2008). Active surveillance for early-stage prostate cancer: Review of the current literature. *Cancer, 112,* 1650-1659.

Daut, R. L., Cleeland, C. S., & Flanery, R. C. (1983). Development of the Wisconsin Brief Pain Questionnaire to assess pain in cancer and other diseases. *Pain, 17,* 197 - 210

Davis, C. G., Lehman, D. R., Cohen Silver, R., Wortman, C. B., & Ellard, J. H. (1996). Self-blame following a traumatic event: The role of perceived avoidability. *Personality and Social Psychology Bulletin, 22,* 557-567.

Davison, B. J., & Goldenberg, S. L. (2003). Decisional regret and quality of life after participating in medical decision-making for early-stage prostate cancer. *British Journal of Urology International, 91,* 14-17.

Davison, B. J., Goldenberg, S. L., Gleave, M. E., & Degner, L. F. (2003). Provision of individualized information to men and their partners to facilitate treatment decision making in prostate cancer. *Oncology Nursing Forum, 30,* 107-114.

Davison, B. J., Oliffe, J. L., Pickles, T., & Mroz, L. (2009). Factors influencing men undertaking active surveillance for the management of low-risk prostate cancer. *Oncology Nursing Forum, 36,* 89-96.

Davison, B. J., Parker, P. A., & Goldenberg, S. L. (2004). Patients' preferences for communicating a prostate cancer diagnosis and participating in medical decision-making. *British Journal of Urology International, 93,* 47-51.

Davison, B. J., So, A. I., & Goldenberg, S. L. (2007). Quality of life, sexual function and decisional regret at 1 year after surgical treatment for localized prostate cancer. *British Journal of Urology International, 100*, 780-785.

De Jonge, P. (2011). Depression deconstruction lessons from psychosomatic research. *Journal of Psychosomatic Research, 71,* 59-60.

Derogatis, L. R. (1975). *Brief Symptom Inventory.* Baltimore, MD: Clinical Psychometric Research.

Diblasio, C. J., & Kattan, M. W. (2003). Use of nomograms to predict the risk of disease recurrence after definitive local therapy for prostate cancer. *Urology, 62,* 9–18.

Diefenbach, M. A., Dorsey, J., Uzzo, R. G., Hanks, G. E., Greenberg, R. E., Horwitz, E., Newton, F., & Engstrom, P. F. (2002). Decision-making strategies for patients with localized prostate cancer. *Seminars in Urologic Oncology, 20,* 55-62.

Diefenbach, M. A., & Mohamed, N. E. (2007). Regret of treatment decision and its association with disease-specific quality of life following prostate cancer treatment. *Cancer Investigation, 25,* 449-457.

Diefenbach, M., Mohamed, N. E., Horwitz, E., & Pollack, A. (2008). Longitudinal associations among quality of life and its predictors in patients treated for prostate cancer: The moderating role of age. *Psychology, Health & Medicine, 13,* 146-161.

Dirksen, S. R., Epstein, D. R., & Hoyt, M. A. (2009). Insomnia, depression, and distress among outpatients with prostate cancer. *Applied Nursing Research, 22,* 154-158.

Dozois, D. J. A., Dobson, K. S., & Ahnberg, J. L. (1998). A psychometric evaluation of the Beck Depression Inventory-II. *Psychological Assessment, 10,* 83-89.

Dunkel-Schetter, C., Feinstein, L. G., Taylor, S. E., & Falke, R. L. (1992). Patterns of coping with cancer. *Health Psychology, 11,* 79-87.

Eckman, M. H., Ying, J., Hertzfeld, K., Kumar, N., & Barrett, W. (2010). Longitudinal analysis of genitourinary and bowel symptoms in prostate cancer patients following brachytherapy. *American Journal of Clinical Oncology, 33,* 1-10.

Edwards, A., Evans, R., & Elwyn, G. (2003). Manufactured but not imported: New directions for research in shared decision making support and skills. *Patient Education and Counseling, 50,* 33-38.

Edwards, N. I., & Jones, D. (2001). The prevalence of faecal incontinence in older people living at home. *Age and Ageing, 30,* 503-507.

Elstad, E. A., Taubenberger, S. P., Botelho, E. M., & Tennstedt, S. L. (2010). Beyond incontinence: The stigma of other urinary symptoms. *Journal of Advanced Nursing, 66,* 2460–2470.

Elstein, A. S., Chapman, G. B. & Knight, S. J. (2005). Patients' values and clinical substituted judgments: The case of localized prostate cancer. *Health Psychology, 24,* S85-92.

Eton, D. T., & Lepore, S. J. (2002). Prostate cancer and health-related quality of life: A review of the literature. *Psycho-Oncology, 11,* 307-326.

Eton, D. T., Lepore, S. J., & Helgeson, V. S. (2005). Psychological distress in spouses of men treated for early-stage prostate carcinoma. *Cancer, 103,* 2412-2418.

Farber, E., Schwartz, A., Schaper P., Moonen, D. J., & McDaniel, J. S. (2000) Resilience factors associated with adaptation to HIV disease. *Psychosomatics 41,* 140–146.

Feldman-Stewart, D., Brennenstuhl, S., Brundage, M. D., & Siemens, D. R. (2009). Overall information needs of early-stage prostate cancer patients over a decade: Highly variable and remarkably stable. *Supportive Care in Cancer, 17,* 429-435.

Felten, B. S. (2000). Resilience in a multicultural sample of community-dwelling women older than age 85. *Clinical Nursing Research*, *9*, 102-124.

Fergus, K. D., Gray, R. E., & Fitch, M. I. (2002). Sexual dysfunction and the preservation of manhood: Experiences of men with prostate cancer. *Journal of Health Psychology, 7,* 303-316.

Ferrer, M., Suárez, J. F., Guedea, F., Fernández, P., Macías, V., Mariño, A., Hervas, A., Herruzo, I., Oritz, M. J., Villavicencio, H., Craven-Bratle, J., Garin, O., Aguiló, F., & the Multicentric Spanish Group of Clinically Localised Prostate Cancer. (2008). Health-related quality of life 2 years after treatment with radical prostatectomy, prostate brachytherapy, or external beam radiotherapy in patients with clinically localized prostate cancer. *International Journal of Radiation Oncology Biology Physics, 72,* 421-432.

Folkman, S., Lazarus, R. S., Dunkel-Schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a stressful encounter: Cognitive appraisal, coping, and encounter outcomes. *Journal of Personality and Social Psychology*, *50*, 992-1003.

Fouad, M. N., Mayo, C. P., Funkhouser, E. M., Hall, H. I., Urban, D. A., & Kiefe, C. I. (2004). Comorbidity independently predicted death in older prostate cancer patients, more of whom died with than from their disease. *Journal of Clinical Epidemiology, 57,* 721–729.

Fowler, F. J., Jr., Barry, M. J., Lu-Yao, G., Wasson, J., & Bin, L. (1996). Outcomes of external-beam radiation therapy for prostate cancer: A study of Medicare beneficiaries in three surveillance, epidemiology, and end results areas. *Journal of Clinical Oncology, 14,* 2258-2265.

Fowler, F. J., Jr., McNaughton, C., Albertsen, P. C., Zietman, A., Elliott, D. B., & Barry, M. J. (2000). Comparison of recommendations by urologists and radiation oncologists for treatment of clinically localised prostate cancer. *The Journal of the American Medical Association, 283,* 3217-3222.

Fransson, P. (2010). Fatigue in prostate cancer patients treated with external beam radiotherapy: A prospective 5-year long-term patient-reported evaluation. *Journal of Cancer Research and Therapeutics, 6,*516-520.

Fransson, P., Lund, J.Å, Damber, J.-A., Klepp, O., Wiklund, F., Fosså, S., Widmark, A., for the Scandinavian Prostate Cancer Group Study 7 & the Swedish Association for Urological Oncology 3. (2009). Quality of life in patients with locally advanced prostate cancer given endocrine treatment with or without radiotherapy: 4 year follow-up of SPCG-7/SFUO-3, an open-label, randomised, phase III trial. *Lancet Oncology, 10,* 370-380.

Given, C. W., Given, B., Azzouz, F., Kozachik, S., & Stommel, M. (2001). Predictors of pain and fatigue in the year following diagnosis among elderly cancer patients. *Journal of Pain and Symptom Management, 21,* 456-466.

Gleason, D. F. (1992). Histologic grading of prostate cancer: A perspective. *Human Pathology, 23,* 273-279.

Glinder, J. G., & Compas, B. E. (1999). Self-blame attributions in women with newly diagnosed breast cancer: A prospective study of psychological adjustment. *Health Psychology, 18,* 475-481.

Glover, L., Gannon, K., McLoughlin, J., & Emberton, M. (2004). Men's experiences of having lower urinary tract symptoms: Factors relating to bother. *British Journal of Urology International, 94,* 563-567.

Gomella, L. G., Johannes, J., & Trabulsi, E. J. (2009). Current prostate cancer treatments: Effect on quality of life. *Urology, 73,* S28-S35.

Gray, R. E., Fitch, M., Phillips, C., Labrecque, M., & Klotz, L. (1999). Presurgery experiences of prostate cancer patients and their spouses. *Cancer Practice, 7,* 130-135.

Gwede, C. K., Pow-Sang, J., Seigne, J., Heysek, R., Helal, M., Shade, K., Cantor, A., & Jacobsen, P. B. (2005). Treatment decision-making strategies and influences in patients with localized prostate carcinoma. *Cancer, 104,* 1381-1390.

Hack, T. F., Pickles, T., Ruether, J. D., Weir, L., Bultz, B. D., Mackey, J., & Degner, L. F. (2010). Predictors of distress and quality of life in patients undergoing cancer therapy: Impact of treatment type and decisional role. *Psycho-Oncology, 19,* 606-616.

Harden, J., Northouse, L., Cimprich, B., Pohl, J. M., Liang, J., & Kershaw, T. (2008). The influence of developmental life stage on quality of life in survivors of prostate cancer and their partners. *Journal of Cancer Survivorship, 2,* 84-94.

Harden, J., Schafenacker, A., Northouse, L., Mood, D., Smith, D., Pienta, K., Hussain, M., & Baranowski, K. (2002). Couples' experiences with prostate cancer: Focus group research. *Oncology Nursing Forum, 29,* 701-709.

Heim, E. (1991). Coping and adaptation in cancer. In C. L. Cooper & M. Watson (Eds.), *Cancer and stress: Psychological, biological and coping studies* (pp. 197-231). New York: John Wiley & Sons.

Heim, H., & Oei, T. P. S. (1993). Comparison of prostate cancer patients with and without pain. *Pain, 53,* 159-162.

Helgason, Á. R., Adolfsson, J., Dickman, P., Fredrikson, M., Arver, S., & Steineck, G. (1996). Waning sexual function – the most important disease-specific distress for patients with prostate cancer. *British Journal of Cancer, 73,* 1417-1421.

Helgason, Á. R., Dickman, P. W., Adolfsson, J., & Steineck, G. (2001). Emotional isolation: Prevalence and the effect on well-being among 50-80-year-old prostate cancer patients. *Scandinavian Journal of Urology and Nephrology, 35,* 97-101.

Herr, H. W., & O'Sullivan, M. (2000). Quality of life of asymptomatic men with nonmetastatic prostate cancer on androgen deprivation therapy. *The Journal of Urology, 163,* 1743-1746.

Herrmann, C., Brand-Driehorst, S., Kaminsky, B., Leibing, E., Staats, H., & Ruger, U. (1998). Diagnostic groups and depressed mood as predictors of 22-month mortality in medical inpatients. *Psychosomatic Medicine, 60,* 570-577.

Hervouet, S., Savard, J., Simard, S., Ivers, H., Laverdière, J., Vigneault, È, Fradet, Y., & Lacombe, L. (2005). Psychological functioning associated with prostate cancer: Cross-sectional comparison of patients treated with radiotherapy, brachytherapy, or surgery. *Journal of Pain and Symptom Management, 30,* 474-484.

Hinz, A., Krauss, O., Stolzenburg, J.-U., Schwalenberg, T., Michalski, D., & Schwarz, R. (2009). Anxiety and depression in patients with prostate cancer and other urogenital cancer: A longitudinal study. *Urologic Oncology: Seminars and Original Investigations, 27,* 367-372.

Hoffman, R. M., Hunt, W. C., Gilliland, F. D., Stephenson, R. A., & Potosky, A. L. (2003). Patient satisfaction with treatment decisions for clinically localized prostate carcinoma. Results from the Prostate Cancer Outcomes Study. *Cancer, 97,* 1653-1662.

Hoffman, M., Ryan, J. L., Figueroa-Moseley, C. D., Jean-Pierre, P., & Morrow, G. R. (2007). Cancer-related fatigue: The scale of the problem. *Oncologist, 12,* 4-10.

Holland, J. C. & Alici, Y. (2010). Management of distress in cancer patients. *The Journal of Supportive Oncology, 8,* 4–12.

Holmberg, L., Bill-Axelson, A., Garmo, H., Palmgren, J., Norlen, B. J., Adami, H. O., Johansson, J. E., & SPCG-4 Study Group. (2006). Prognostic markers under watchful waiting and radical prostatectomy. *Hematology/Oncology Clinics of North America, 20,* 845-855.

Holmboe, E. S., & Concato, J. (2000). Treatment decisions for localized prostate cancer: Asking men what's important. *Journal of General Internal Medicine, 15,* 694-701.

Holmes-Rovner, M., Kroll, J., Schmitt, N., Rovner, D. R., Breer, L., Rothert, M. L., Padonu, G., & Talarczyk, G. (1996). Patient satisfaction with health care decisions: The Satisfaction with Decision Scale. *Medical Decision Making, 16,* 58-64.

Horowitz, M., Wilner, N., & Alvarez, W. (1979). Impact of Event Scale: A measure of subjective stress. *Psychosomatic Medicine, 41,* 209-218.

Hu, J. C., Elkin, E. P., Pasta, D. J., Lubeck, D. P., Kattan, M. W., Carroll, P. R., & Litwin, M. S. (2004). Predicting quality of life after radical prostatectomy: Results from CaPSURE. *The Journal of Urology, 171,* 703-708.

Hu, J. C., Kwan, L., Saigal, C., & Litwin, M. S. (2003). Regret in men treated for localized prostate cancer. *The Journal of Urology, 169,* 2279-2283.

Huang, G. J., Sadetsky, N., & Penson, D. F. (2010). Health related quality of life for men treated for localised prostate cancer with long-term followup. *The Journal of Urology, 183,* 2206-2212.

Incrocci, L. (2006). Sexual function after external-beam radiotherapy for prostate cancer: What do we know? *Critical Reviews in Oncology/Hematology, 57,* 265-273.

Irani, J. (2010). Is shared decision making in prostate cancer restrained by evidence-based medicine? *European Urology Supplements, 9,* 782-787.

Janoff-Bulman, R. (1979). Characterological versus behavioral self-blame: Inquiries into depression and rape. *Journal of Personality and Social Psychology, 37,* 1798-1809.

Jemal, A., Siegel, R., Ward, E., Hao, Y., Xu, J., Murray, T., & Thun, M. J. (2008). Cancer statistics. *CA: A Journal for Cancer Clinicians, 58,* 71-96.

Kangas, M., Henry, J. L., & Bryant, R. A. (2002). Posttraumatic stress disorder following cancer - a conceptual and empirical review. *Clinical Psychology Review, 22,* 499-524.

Keller, M., & Henrich, G. (1999). Illness-related distress: Does it mean the same for men and women? Gender aspects in cancer patients' distress and adjustment. *Acta Oncologica, 38,*747-755.

Kessler, R. C., Sonnega, A., Bromet, E., Hughes, M., & Nelson, C. B. (1995). Posttraumatic stress disorder in the National Comorbidity Survey. *Archives of General Psychiatry, 52,* 1048-1060.

Komura, K., & Hegarty, J. R. (2006). The appraisal of positive life changes following cancer diagnosis: An interview study. *Palliative and Supportive Care, 4,* 3–12.

Koppie, T. M., Grossfeld, G. D., Miller, D., Yu, J., Stier, D., Broering, J. M., Lubeck, D., Henning, J. M., Flanders, S. C., & Carroll, P. R. (2000). Patterns of treatment of patients with prostate cancer initially managed with surveillance: Results from the CaPSURE database. *The Journal of Urology, 164,* 81-88.

Korfage, I. J., Hak, T., de Koning, H. J., & Essink-Bot, M.-L. (2006). Patients' perceptions of the side effects of prostate cancer treatment - A qualitative interview study. *Social Science & Medicine, 63,* 911-919.

Kornblith, A., Herr, H. W., Ofman, U. S., Scher, H. I., & Holland, J. C. (1994). Quality of life of patients with prostate cancer and their spouses. *Cancer, 73,* 2791-2802.

Kupelian, P. A., Elshaikh, M., Reddy, C. A., Zippe, C., & Klein, E. A. (2002). Comparison of the efficacy of local therapies for localized prostate cancer in the prostate-specific antigen era: A large single-institution experience with radical prostatectomy and external-beam radiotherapy. *Journal of Clinical Oncology, 20,* 3376-3385.

Kyrdalen, A. E., Dahl, A. A., Hernes, E., Cvancarova, M., & Fossa, S. D. (2010). Fatigue in hormone-naïve prostate cancer patients treated with radical prostatectomy or definitive radiotherapy. *Prostate Cancer and Prostatic Diseases, 13,* 144–150.

Kyrdalen, A. E., Dahl, A. A., Hernes, E., Hem, E., & Fossa, S. D. (2010). Fatigue in prostate cancer survivors treated with definitive radiotherapy and LHRH analogs. *The Prostate, 70,* 1480-1489.

Latini, D. M., Hart, S. L., Knight, S. J., Cowan, J. E., Ross, P. L, DuChane, J., Carroll, P. R., & the CaPSURE Investigators. (2007). The relationship between anxiety and time to treatment for patients with prostate cancer on surveillance. *The Journal of Urology, 178,* 826-832.

Lazarus, R. S. (1990). Theory-based stress measurement. *Psychological Inquiry*, *1*, 3-13.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Lee, C., & Owens, G. R. (2002). *The psychology of men's health.* Buckingham, England: Open University Press.

Leventhal, E. M., & Prochaska, T. (1986). Age, symptom interpretation, and health behaviour. *Journal of the American Geriatrics Society, 34,* 185-191.

Lin, G. A., Aaronson, D. S., Knight, S. J., Carroll, P. R., & Dudley, R. A. (2009). Patient decision aids for prostate cancer treatment: A systematic review of the literature. *CA: A* Cancer *Journal for Clinicians, 59, 379-390.*

Lintz, K., Moynihan, C., Steginga, S., Norman, A., Eeles, R., Huddart R., Dearnaley, D., & Watson, M. (2003). Prostate cancer patients' support and psychological care needs: Survey from a non-surgical oncology clinic. *Psycho-Oncology, 12,* 769-783.

Litwin, M. S., Hays, R. D., Fink, A., Ganz, P. A., Leake, B., & Brook, R. H. (1998). The UCLA Prostate Cancer Index: Development, reliability, and validity of a health-related quality of life measure. *Medical Care, 36,* 1002-1012.

Litwin, M. S., Lubeck, D. P., Spitalny, G. M., Henning, J. M., & Carroll, P. R. (2002). Mental health in men treated for early stage prostate carcinoma. *Cancer, 95,* 54-60.

Litwin, M. S., Sadetsky, N., Pasta, D. J., & Lubeck, D. P. (2004). Bowel function and bother after treatment for early stage prostate cancer: A longitudinal quality of life analysis from CaPSURE. *The Journal of Urology, 172,* 515-519.

Lofters, A., Juffs, H. G., Pond, G. R., & Tannock, I. F. (2002). "PSA-itis": knowledge of serum prostate specific antigen and other causes of anxiety in men with metastatic prostate cancer. *The Journal of Urology, 168,* 2516-2520.

Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The construct of resilience: A critical evaluation and guidelines for future work. *Child Development, 71,* 543–562.

Lynch, J., & Kilmartin, C.T. (1999). *The pain behind the mask: Overcoming masculine depression.* Binghamton, NY: Haworth Press.

Malcarne, V. L., Compas, B. E., Epping-Jordan, J. E., & Howell, D. C. (1995). Cognitive factors in adjustment to cancer: Attributions of self-blame and perceptions of control. *Journal of Behavioral Medicine, 18,* 401-417.

Malcolm, J. B., Fabrizio, M. D., Barone, B. B., Given, R. W., Lance, R. S., Lynch, D. F., Davis, J. W., Shaves, M. E., & Schellhammer, P. F. (2010). Quality of life after open or robotic prostatectomy, cryoablation or brachytherapy for localised prostate cancer. *The Journal of Urology, 183,* 1822-1829.

Massie, M. J. & Holland, J. C. (1990). Depression and the cancer patient. *Journal of Clinical Psychiatry, 51,* 12-17.

Mendoza, T. R., Wang, X. S., Cleeland, C. S., Morrissey, M., Johnson, B. A., Wendt, J. K., & Huber, S. L. (1999). The rapid assessment of fatigue severity in cancer patients. *Cancer, 85,* 1186-1196.

Miaskowski, C., Paul, S. M., Cooper, B. A., Lee, K., Dodd, M., West, C., Aouizerat, B. E., Swift, P. S., & Wara, W. (2008). Trajectories of fatigue in men with prostate cancer before, during, and after radiation therapy. *Journal of Pain and Symptom Management, 35,* 632-643.

Miles, B. J., Giesler, B., & Kattan, M. W. (1999). Recall and attitudes in patients with prostate cancer. *Urology, 53,* 169-174.

Mirowsky, J., & Ross, C. E. (1990). Control or defense? Depression and the sense of control over good and bad outcomes. *Journal of Health and Social Behavior, 31,* 71-86.

Mohile, S. G., Lachs, M., & Dale, W. (2008). Management of prostate cancer in older men. *Seminars in Oncology, 35,* 597-617.

Moinpour, C. M., Hayden, K. A., Unger, J. M., Thompson, I. M., Jr., Redman, M. W., Canby-Hagino, E. D., Higgins, B. A., Sullivan, J. W., Lemmon, D., Breslin, S., & Crawford, E. D. (2008). Health-related quality of life results in pathologic stage C prostate cancer from a southwest oncology group trial comparing radical prostatectomy alone with radical prostatectomy plus radiation therapy *Journal of Clinical Oncology, 26,* 112-120.

Monahan, P. O., Champion, V., Rawl, S., Giesler, R. B., Given, B., Given, C. W., Burns, D., Bigatti, S., Reuille, K. M., Azzouz, F., Wu, J., & Koch, M. (2007). What contributes more strongly to predicting QOL during 1-year recovery from treatment for clinically localized prostate cancer: 4-weeks-post-treatment depressive symptoms or type of treatment? *Quality of Life Research, 16,* 399-411.

Moos, R. H., & Schaeffer, J. A. (1984). The crisis of physical illness: An overview and conceptual approach. In R. H. Moos (Ed.), *Coping with physical illness. Vol. 2: New perspectives* (pp. 3-25). New York: Plenum Medical Book Company.

Nelson, C. J., Weinberger, M. I., Balk, E., Holland, J., Breitbart, W., & Roth, A. J. (2009). The chronology of distress, anxiety, and depression in older prostate cancer patients. *The Oncologist, 14,* 891-899.

Nolen-Hoeksema, S., Wisco, B. E., & Lyubomirsky, S. (2008). Rethinking rumination. *Perspectives on Psychological Science, 3,* 400-424.

Nordin, K., Berglund, G., Glimelius, B., & Sjödén, P.-O. (2001). Predicting anxiety and depression among cancer patients: A clinical model. *European Journal of Cancer, 37,* 376-384.

O'Brien, R., Rose, P., Campbell, C., Weller, D., Neal, R. D., Wilkinson, C., Mcintosh, H., & Watson, E. (2011). "I wish I'd told them": A qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Education and Counseling, 84,* 200-207.

O'Connell, B., Baker, L., & Munro, I. (2007). The nature and impact of incontinence in men who have undergone prostate surgery and implications for nursing practice. *Contemporary Nurse: A Journal for the Australian Nursing Profession, 24,* 65-78

O'Connor, A. M. (1995). Validation of a decisional conflict scale. *Medical Decision Making, 15,* 25-30.

Oliffe, J. (2005). Constructions of masculinity following prostatectomy-induced impotence. *Social Science & Medicine, 60,* 2249-2259.

Parker, C. (2004). Active surveillance: Towards a new paradigm in the management of early prostate cancer. *Lancet Oncology, 5,* 101-106.

Parry, C. (2003) Embracing uncertainty: An exploration of the experiences of childhood cancer survivors. *Qualitative Health Research, 13,* 227–246.

Pasquini, M., & Biondi, M. (2007). Depression in cancer patients: A critical review. *Clinical Practice and Epidemiology in Mental Health, 3.*

Passik, S. D., Donaghy, K. B., Theobald, D. E., Lundberg, J. C., Holtsclaw, E., & Dugan, W. M. (2000). Oncology staff recognition of depressive symptoms on videotaped interviews of depressed cancer patients: Implications for designing a training program. *Journal of Pain and Symptom Management, 19,* 329-338.

Penson, D. F., McLerran, D., Feng, Z., Li, L., Albertsen, P. C., Gilliland, F. D., Hamilton, A., Hoffman, R. M., Stephenson, R. A., Potosky, A. L., & Stanford, J. L. (2005). 5-year urinary and sexual outcomes after radical prostatectomy: Results from the Prostate Cancer Outcomes Study. *The Journal of Urology, 173,* 1701-1705.

Pentz, M. (2005). Resilience among older adults with cancer and the importance of social support and spirituality-faith: "I don't have time to die". *Journal of Gerontological Social Work, 44,* 3-22.

Perczek, R. E., Burke, M. A., Carver, C. S., Krongrad, A., & Terris, M. K. (2002). Facing a prostate cancer diagnosis: Who is at risk for increased distress? *Cancer, 94,* 2923-2929.

Pickett, M., Brunner, D. W., Joseph, A., & Burggraf, V. (2000). Prostate cancer elder alert: Living with treatment choices and outcomes. *Journal of Gerontological Nursing, 26,* 22-34.

Pirl, W. F., Greer, J. A., Goode, M., & Smith, M. R. (2008). Prospective study of depression and fatigue in men with advanced prostate cancer receiving hormone therapy. *Psycho-Oncology, 17,*148-153.

Pirl, W. F., Siegel, G. I., Goode, M. J., & Smith, M. R. (2002). Depression in men receiving androgen deprivation therapy for prostate cancer: A pilot study. *Psycho-Oncology, 11,* 518-523.

Potosky, A. L., Davis, W. W., Hoffman, R. M., Stanford, J. L., Stephenson, R. A., Penson, D. F., & Harlan, L. C. (2004). Five-year outcomes after prostatectomy or radiotherapy for prostate cancer: The Prostate Cancer Outcomes Study. *Journal of the National Cancer Institute, 96,* 1358-1367.

Ptacek, J. T., Pierce, G. P., Ptacek, J. J. & Nogel, C. (1999). Stress and coping process in men with prostate cancer: The divergent views of husbands and wives. *Journal of Social and Clinical Psychology, 18,* 299-324.

Radloff, L. S. (1977). The CES-D scale: A self report depression scale for research in the general population. *Applied Psychological Measurement, 1,* 85-401.

Raison, C. L. & Miller, A. H. (2003). Depression in cancer: New developments regarding diagnosis and treatment. *Biological Psychiatry, 54,* 283-294.

Ramsey, S. D., Zeliadt, S. B., Arora, N. K., Potosky, A. L., Blough, D. K., Hamilton, A. S., van den Eeden, S. K., Oakley-Girvan, I., & Penson, D. F. (2009). Access to information sources and treatment considerations among men with local stage prostate cancer. *Urology, 74,* 509-516.

Rees, J., Waldron, D., O'Boyle, C., Ewings, P., & Macdonagh, R. (2003). Prospective vs retrospective assessment of lower urinary tract symptoms in patients with advanced prostate cancer: The effect of 'response shift'. *British Journal of Urology International, 92,* 703-706.

Reich, M. (2008). Depression and cancer: Recent data on clinical issues, research challenges and treatment approaches. *Current Opinion in Oncology, 20,* 353-359.

Rodin, G., Lloyd, N., Katz, M., Green, E., Mackay, J. A., & Wong, R. K., Supportive Care Guidelines Group of Cancer Care Ontario Program in Evidence-Based Care. (2007). The treatment of depression in cancer patients: A systematic review. *Supportive Care in Cancer, 15,* 123-136.

Roesch, S. C., Adams, L., Hines, A., Palmores, A., Vyas, P., Tran, C., Pekin, S., & Vaughn, A. A. (2005). Coping with prostate cancer: A meta-analytic review. *Journal of Behavioral Medicine, 28,* 281-293.

Rosenfeld, B., Roth, A. J., Gandhi, S., & Penson, D. (2004). Differences in health-related quality of life of prostate cancer patients based on stage of cancer. *Psycho-Oncology, 13,* 800-807.

Roth, A. J., Kornblith, A. B., Batel-Copel, L., Peabody, E., Scher, H. I., & Holland, J. C. (1998). Rapid screening for psychologic distress in men with prostate carcinoma. *Cancer, 82,* 1902-1908.

Roth, A. J., & Scher, H. I. (1998). Genitourinary malignancies. In J. Holland (Ed.), *Psycho-oncology* (pp. 1135–1146). New York: Oxford University Press.

Roth, A. J., Weinberger, M. I., & Nelson, C. J. (2008). Prostate cancer: Psychosocial implications and management. *Future Oncology, 4,* 561-568.

Rowland, J. H. (1989). Developmental stage and adaptation: Adult model. In J. C. Holland and J. H. Rowland (Eds.), *Handbook of Psychooncology* (pp. 25-45). New York: Oxford University Press.

Rowland, J. H. & Baker, F. (2005). Introduction: Resilience of cancer survivors across the lifespan. *Cancer, 104,* 2543-2548.

Salminen, E., Portin, R., Korpela, J., Backman, H., Parvinen, L.-M., Helenius, H., & Nurmi, M. (2003). Androgen deprivation and cognition in prostate cancer. *British Journal of Cancer, 89,* 971-976.

Salminen, E. K., Portin, R., & Nurmi, M. J. (2007). Distress among prostate cancer patients and spouses is associated with hormone treatment and participation in decision-making. *Clinical Medicine: Oncology, 1,* 21-29.

Salokangas, R. K., Vaahtera, K., Pacriev, S., Sohlman, B., & Lehtinen, V. (2002). Gender differences in depressive symptoms. An artefact caused by measurement instruments? *Journal of Affective Disorders, 68,* 215-220.

Sanda, M. G., Dunn, R. L., Michalski, J., Sandler, H. M., Northouse, L., Hembroff, L., Lin, X., Greenfield, T. K., Litwin, M. S., Saigal, C. S., Mahadevan, A., Klein, E., Kibel, A., Pisters, L. L., Kuban, D., Kaplan, I., Wood, D., Ciezki, J., Shah, N., & Wei, J. T. (2008). Quality of life and satisfaction with outcome among prostate-cancer survivors. *The New England Journal of Medicine, 358,* 1250-1261.

Sartor, O. (2008). Decision-making in clinically localized prostate cancer: Evaluating and communicating risks. *Clinical Genitourinary Cancer, 6,* 63-64.

Satariano, W. A., Ragland, K. E., & van den Eeden, S. K. (1998). Cause of death in men diagnosed with prostate carcinoma. *Cancer, 83,* 1180-1188

Schover, L. R., Fouladi, R. T., Warneke, C. L., Neese, L., Klein, E. A., Zippe, C., & Kupelian, P. A. (2002). Defining sexual outcomes after treatment for localized prostate carcinoma. *Cancer, 95,* 1773-1785.

Sellick, S. M., & Crooks, D. L. (1999). Depression and cancer: An appraisal of the literature for prevalence, detection, and practice guideline development for psychological interventions. *Psycho-Oncology, 8,* 315-333.

Serlin, R. C., Mendoza, T. R., Nakamura, Y., Edwards, K. R., & Cleeland, C. S. (1995). When is cancer pain mild, moderate or severe? Grading pain severity by its interference with function. *Pain, 61,* 277-284.

Shikanov, S. A., Eng, M. K., Bernstein, A. J., Katz, M., Zagaia, G. P., Shalhav, A. L. & Zorn, K. C. (2008). Urinary and sexual quality of life 1 year following robotic assisted laparoscopic radical prostatectomy. *The Journal of Urology, 180,* 663-667.

Shores, M., Moceri, V., Sloan, K., Matsumoto, A., & Kivlahan, D. (2005). Low testosterone levels predict incident depressive illness in older men: Effects of age and medical morbidity. *Journal of Clinical Psychiatry, 66,* 7-14.

Sia, M., Rodrigues, G., Menard, C., Bayley, A., Bristow, R., Chung, P., Gospodarowicz, M., Milosevic, M., Warde, P., & Catton, C. (2010). Treatment-related toxicity and symptom-related bother following postoperative radiotherapy for prostate cancer. *Canadian Urological Association Journal, 4,* 105-111.

Sidana, A., Hernandez, D. J., Feng, Z., Partin, A. W., Trock, B. J., Saha, S., & Epstein, J. I. (2011). Treatment decision-making for localized prostate cancer: What younger men choose and why. *The Prostate,* doi:10.1002/pros.21406.

Sinfield, P., Baker, R., Agarwal, S., & Tarrant, C. (2008). Patient-centred care: What are the experiences of prostate cancer patients and their partners? *Patient Education and Counseling, 73,* 91-96.

Snaith, R. P. (2003). The Hospital Anxiety And Depression Scale. *Health and Quality of Life Outcomes*, *1,* 29.

Sommers, B. D., Beard, C. J., D'Amico, A. V., Kaplan, I., Richie, J. P., & Zeckhauser, R. J. (2008). Predictors of patient preferences and treatment choices for localized prostate cancer. *Cancer, 113,* 2058-2067.

Spielberger, C. D., Gorsuch, R. L., Lushene, R., Vagg, P R., & Jacobs, G.A. (1979). State-Trait Anxiety Inventory.

Stark, D. P. H., & House, A. (2000) Anxiety in cancer patients. *British Journal of Cancer, 83,* 1261-1267.

Steineck, G., Helgesen, F., Adolfsson, J., & Dickman, P. W., Johansson, J.-E., Norlén, B. J., & Holmberg, L. (2002). Quality of life after radical prostatectomy or watchful waiting. *The New England Journal of Medicine, 347,* 790-805.

Steginga, S. K., & Occhipinti, S. (2004). The application of the heuristic-systematic processing model to treatment decision making about prostate cancer. *Medical Decision Making, 24,* 573-583.

Steginga, S. K., & Occhipinti, S. (2006). Dispositional optimism as a predictor of men's decision-related distress after localized prostate cancer. *Health Psychology, 25,* 135-143.

Steginga, S. K., & Occhipinti, S., Dunn, J., Gardiner, R. A., Heathcote, P., & Yaxley, J. (2001). The supportive care needs of men with prostate cancer. *Psycho-Oncology, 10,* 66-75.

Steginga, S. K., & Occhipinti, S., Gardiner, R. A., Yaxley, J., & Heathcote, P. (2002). Making decisions about treatment for localized prostate cancer. *British Journal of Urology International, 89,* 255-260.

Steginga, S. K., & Occhipinti, S., Gardiner, R. A., Yaxley, J., & Heathcote, P. (2004). Prospective study of men's psychological and decision-related adjustment after treatment for localized prostate cancer. *Urology, 63,* 751-756.

Steginga, S. K., Turner, E., & Donovan, J. (2008). The decision-related psychosocial concerns of men with localised prostate cancer: Targets for intervention and research. *World Journal of Urology, 26,* 469-474.

Stewart, D. E., Wong, F., Duff, S., Melancon, C. H., & Cheung, A. M. (2001). "What doesn't kill you makes you stronger": An ovarian cancer survivor survey. *Gynecologic Oncology, 83,* 537-542.

Stone, P., Hardy, J., Huddart, R., A'Hern, R., & Richards, M. (2000). Fatigue in patients with prostate cancer receiving hormone therapy. *European Journal of Cancer, 36,* 1134-1141.

Strong, V., Waters, R., Hibberd, C., Rush, R., Cargill, A., Storey, D., Walker, J., Wall, L., Fallon, M., & Sharpe, M. (2007). Emotional distress in cancer patients: The Edinburgh Cancer Centre symptom study. *British Journal of Cancer, 96,* 868-874.

Sumalla, E. C., Ochoa, C., & Blanco, I. (2009). Posttraumatic growth in cancer. Reality or illusion? *Clinical Psychology Review, 29,* 24-33.

Tabachnick, B. G., & Fidell, L. S. (2007). *Using Multivariate Statistics* (5th ed.). Boston, Massachusetts: Allyn and Bacon.

Talcott, J. A., Manola, J., Clark, J. A., Kaplan, I., Beard, C. J., Mitchell, S. P., Chen, R. C., O'Leary, M. P., Kantoff, P. W., & D'Amico, A. V. (2003). Time course and predictors of symptoms after primary prostate cancer therapy. *Journal of Clinical Oncology, 21,* 3979-3986.

Tariman, J. D., Berry, D. L., Cochrane, B., Doorenbos, A., & Shepp, K. (2010). Preferred and actual participation roles during health care decision making in persons with cancer: A systematic review. *Annals of Oncology, 21,* 1145- 1151.

Tchekmedvian, N. S., Kallich, J., McDermott, A., Favers, P., & Erder, M. H. (2003). The relationship between psychologic distress and cancer-related fatigue. *Cancer, 98,* 198-203.

Teunissen, D., van den Bosch, W., van Weel, C., & Lagro-Janssen, T. (2006). "It can always happen": The impact of urinary incontinence on elderly men and women. *Scandinavian Journal of Primary Health Care, 24,* 166-173.

Thompson, I., Thrasher, J. B., Aus, G., Burnett, A. L., Canby-Hagino, E. D., Cookson, M. S., D'Amico, A. V., Dmochowski, R. R., Eton, D. T., Forman, J. D., Goldenberg, S. L., Hernandez, J., Higano, C. S., Kraus, S. R., Moul, J. W., & Tangen, C. M. (2007). Guideline for the management of clinically localised prostate cancer: 2007 update. *The Journal of Urology, 177,* 2106-2131.

Thornton, A. A., Perez, M. A., & Meyerowitz, B. E. (2004). Patient and partner quality of life and psychosocial adjustment following radical prostatectomy. *Journal of Clinical Psychology in Medical Settings, 11,* 15-30.

Tosoian, J. J., Trock, B. J., Landis, P., Feng, Z., Epstein, J. I., Partin, A. W., Walsh, P. C., & Carter, H. B. (2011). Active surveillance program for prostate cancer: An update of the Johns Hopkins Experience. *Journal of Clinical Oncology,* doi: 10.1200/JCO.2010.32.8112.

van den Bergh, R. C. N., Essink-Bot, M.-L., Roobol, M. J., Schröder, F. H., Bangma, C. H., & Steyerberg, E. W. (2010). Do anxiety and distress increase during active surveillance for low risk prostate cancer. *The Journal of Urology, 183,* 1786-1791.

van den Bergh, R. C. N., Essink-Bot, M.-L., Roobol, M. J., Wolters, T., Schröder, F. H., Bangma, C. H., & Steyerberg, E. W. (2009). Anxiety and distress during active surveillance for early prostate cancer. *Cancer, 115,* 3868-3878.

Visser, A., van Andel, G., Willems, P., Voogt, E., Dijkstra, A., Rovers, P., Goodkin, K., & Kurth, K.-H. (2003). Changes in health-related quality of life in men with prostate cancer 3 months after diagnosis. The role of psychological factors and comparisment with benign prostate hyperplasia patients. *Patient Education and Counseling, 49,* 225-232.

Wagnild, G. M., & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement, 1,* 165-178.

Wallace, M. (2003). Uncertainty and quality of life of older men who undergo watchful waiting for prostate cancer. *Oncology Nursing Forum, 30,* 303-309.

Wallace, M., & Storms, S. (2007). The needs of men with prostate cancer: Results of a focus group study. *Applied Nursing Research, 20,*181-187.

Walsh, P. C., DeWeese, T. L., & Eisenberger, M. A. (2007). Localized prostate cancer. *New England Journal of Medicine, 357,* 2696-2705.

Ward, S. E., Goldberg, N., Miller-McCauley, V., Mueller, C., Nolan, A., Pawlik-Plank, D., Robbins, A., Stormoen, D., & Weissman, D. E. (1993). Patient-related barriers to management of cancer pain. *Pain, 52,* 319-324.

Wei. J., Dunn, R. L., Litwin, M. S., Sandler, H. M., & Sanda, M. S. (2000). Development and validation of the Expanded Prostate Cancer Index Composite (EPIC) for comprehensive assessment of health-related quality of life in men with prostate cancer. *Urology, 56,* 899-905.

Weiss, D. S., & Marmar, C. R. (1997). The Impact of Event Scale-Revised. In J. P. Wilson, & T. M. Keane (Eds.), *Assessing psychological trauma and PTSD: A handbook for practitioners* (pp. 399-411). New York: Guilford Press.

Wenzel, L. B., Donnelly, J. P., Fowler, J. M., Habbal, R., Taylor, T. H., Aziz, N., & Cella, D. (2002). Resilience, reflection, and residual stress in ovarian cancer survivorship: A gynecologic oncology group study. *Psycho-Oncology, 11,* 142-153.

Whitaker, K. L., Brewin, C. R., & Watson, M. (2008). Intrusive cognitions and anxiety in cancer patients. *Journal of Psychosomatic Research, 64,* 509-517.

Williams, S., & Dale, J. (2006). The effectiveness of treatment for depression/depressive symptoms in adults with cancer: A systematic review. *British Journal of Cancer, 94,* 372-390.

Wittman, D., Northouse, L., Foley, S., Gilbert, S., Wood, D. P., Jr., Balon, R., & Montie, J. E. (2009). The psychosocial aspects of sexual recovery after prostate cancer treatment. *International Journal of Impotence Research, 21,* 99-106.

Zeelenberg, M. (1999). Anticipated regret, expected feedback and behavioral decision making. *Journal of Behavioral Decision Making, 12,* 93-106.

Zeliadt, S. B., Ramsey, S. D., Penson, D. F., Hall, I. J., Ekueme, D. U., Stroud, L., & Lee, J. W. (2006). Why do men choose one treatment over another?: A review of patient decision making for localized prostate cancer. *Cancer, 106,* 1865-1874.

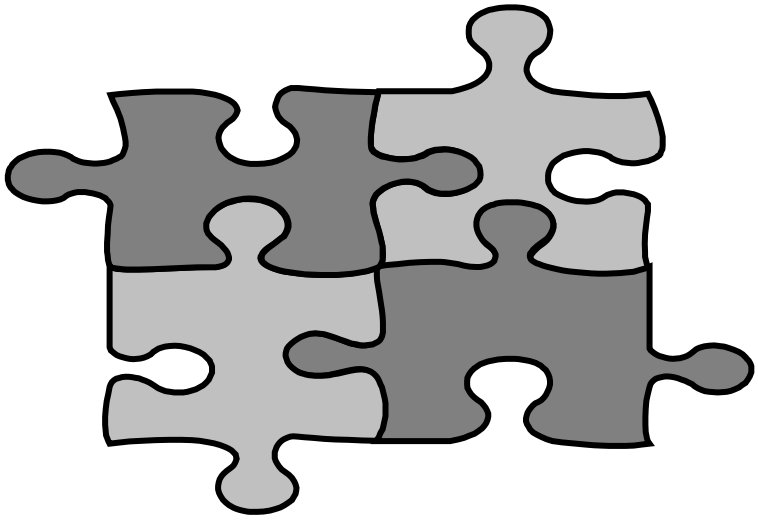
Appendix A: Questionnaire

Austin Health

LA TROBE UNIVERSITY

PROSTATE CANCER STUDY

Thank you for choosing to participate in this study examining the experience of men with prostate cancer.



Office use: _____

What is the current situation regarding your cancer?
How is your treatment going?

_____

_____

_____

What would you say has been the most difficult thing about the cancer overall?

_____

_____

_____

What would you say is the most difficult thing about the cancer right now?

_____

_____

_____

The following questions relate to your prostate symptoms. Please circle one number for each question that most accurately describes your symptoms.

	Not at all	Less than 1 time in 5	Less than half the time	About half the time	More than half the time	Almost always	**Score**
Incomplete emptying Over the past month, how often have you had a sensation of not emptying your bladder completely after you finish urinating?	0	1	2	3	4	5	
Frequency Over the past month, how often have you had to urinate again less than two hours after you finished urinating?	0	1	2	3	4	5	
Intermittency Over the past month, how often have you found you stopped and started again several times when you urinated?	0	1	2	3	4	5	
Urgency Over the last month, how difficult have you found it to postpone urination?	0	1	2	3	4	5	
Weak stream Over the past month, how often have you had a weak urinary stream?	0	1	2	3	4	5	
Straining Over the past month, how often have you had to push or strain to begin urination?	0	1	2	3	4	5	

	None	1 time	2 times	3 times	4 times	5 times or more	**Score**
Nocturia Over the past month, how many times did you most typically get up to urinate from the time you went to bed until the time you got up in the morning?	0	1	2	3	4	5	

Quality of life due to urinary symptoms	Delighted	Pleased	Mostly satisfied	Mixed - equally satisfied and dissatisfied	Mostly dissatisfied	Unhappy	Terrible
If you were to spend the rest of your life with your urinary condition the way it is now, how would you feel about that?	0	1	2	3	4	5	6

URINARY FUNCTION

This section is about your urinary habits.
Please consider ONLY THE LAST 4 WEEKS. Please tick the appropriate box.

1. Over the LAST 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

4. How big a problem, if any, has each of the following been for you?

(Circle one number on each line)	**No problem**	**Very small problem**	**Small problem**	**Moderate problem**	**Big problem**
Dripping urine or wetting your pants?	0	1	2	3	4
Urine leakage interfering with your sexual activity?	0	1	2	3	4

5. 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

6. How much distress has your urinary function caused you during the LAST 4 WEEKS?

- ❑ Severe distress
- ❑ Moderate distress
- ❑ A little distress
- ❑ No distress

BOWEL FUNCTION

This section is about your bowel habits and abdominal pain.
Please consider ONLY THE LAST 4 WEEKS. Please tick the appropriate box.

1. How often have you had rectal urgency (felt like you had to pass a 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
- ❑ A 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

5. Overall, how big a problem has your bowel habits been for you during the LAST 4 WEEKS?

- ❑ No problem
- ❑ Very small problem
- ❑ Small problem
- ❑ Moderate problem
- ❑ Big problem

SEXUAL FUNCTION

This section is about your sexual function and sexual satisfaction. Many questions are very personal, but they will help us understand the important issues that you face. Remember that your answers to this questionnaire will be kept confidential and will be used only for research purposes. Please consider ONLY THE LAST 4 WEEKS. Please tick the appropriate box.

1. How would you rate each of the following during the LAST 4 WEEKS?

(Circle one number on each line)	**Very poor**	**Poor**	**Fair**	**Good**	**Very good**
a. Your level of sexual desire?	1	2	3	4	5
b. Your ability to have an erection?	1	2	3	4	5
c. Your ability to reach orgasm (climax)?	1	2	3	4	5

2. How would you describe the 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

3. 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

4. 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)

5. During the LAST 4 WEEKS did you have vaginal or anal intercourse?

- ❑ No
- ❑ Yes, once
- ❑ Yes, more than once

6. Overall, how would you rate your ability to function sexually during the LAST 4 WEEKS?

- ❑ Very poor
- ❑ Poor
- ❑ Fair
- ❑ Good
- ❑ Very good

7. Overall, how big a problem has your sexual function been for you during the LAST 4 WEEKS?

- ❑ No problem
- ❑ Very small problem
- ❑ Small problem
- ❑ Moderate problem
- ❑ Big problem

8. How much distress has your sexual function caused you during the LAST 4 WEEKS?

- ❑ Severe distress
- ❑ Moderate distress
- ❑ A little distress
- ❑ No distress

Thinking about the choice you made regarding your prostate cancer treatment, please look at the following comments some people make when deciding about treatment. Please show how strongly you *agree* or *disagree* with these comments by ticking the appropriate box that best shows how you feel about the decision you made.

Please specify your treatment decision: _____

	Strongly Agree	**Agree**	**Neither Agree or Disagree**	**Disagree**	**Strongly Disagree**
1. I know which options are available to me.					
2. I know the benefits of each option.					
3. I know the risks and side effects of each option.					
4. I am clear about which benefits matter most to me.					
5. I am clear about which risks and side effects matter most.					
6. I am clear about which is more important to me (the benefits or the risks and side effects).					
7. I have enough support from others to make a choice.					
8. I am choosing without pressure from others.					
9. I have enough advice to make a choice.					
10. I am clear about the best choice for me.					
11. I feel sure about what to choose.					
12. This decision is easy for me to make.					
13. I feel I have made an informed choice.					
14. My decision shows what is important to me.					
15. I expect to stick with my decision.					
16. I am satisfied with my decision.					

Please reflect on the decision you made about prostate cancer treatment. Please show how strongly you agree or disagree with these statements by ticking the appropriate box which best fits your views about your decision.

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
1. It was the right decision.					
2. I regret the choice that was made.					
3. I would go for the same choice if I had to do it over again.					
4. The choice did me a lot of harm.					
5. The decision was a wise one.					

Please reflect on the decision you made about prostate cancer treatment. Please show how strongly you agree or disagree with these statements by ticking the appropriate box which best fits your views about your decision.

	Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree
1. I am satisfied that I was adequately informed about the issues important to my decision.					
2. The decision I made was the best possible decision for me personally.					
3. I am satisfied that my decision was consistent with my personal values.					
4. I successfully carried out (or continue to carry out) the decision I made.					
5. I am satisfied that this was my decision to make.					
6. I am satisfied with my decision.					

Please indicate if you are satisfied with your prostate cancer treatment decision and why or why not?

_____

_____

_____

_____

_____

_____

The following is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you during the **PAST TWO WEEKS** with respect to your cancer experience. How much were you distressed or bothered by these difficulties?

	Not at all	A little bit	Moderately	Quite a bit	Extremely
1. Any reminder brought back feelings of it.					
2. I had trouble staying asleep.					
3. Other things kept making me think about it.					
4. I felt irritable and angry.					
5. I avoided letting myself get upset when I thought about it or was reminded of it.					
6. I thought about it when I didn't mean to.					
7. I felt as if it hadn't happened or wasn't real.					
8. I stayed away from reminders of it.					
9. Pictures about it popped into my mind.					
10. I was jumpy and easily startled.					
11. I tried not to 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. My feelings about it were kind of numb.					
14. I found myself acting or feeling like I was back at that time.					
15. I had trouble falling asleep.					
16. I had waves of strong feelings about it.					
17. I tried to remove it from my memory.					
18. I had trouble concentrating.					
19. Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.					
20. I had dreams about it.					
21. I felt watchful and on guard.					
22. I tried not to talk about it.					

There are many ways people cope with stressful events including cancer. Please circle the most appropriate response for each item to indicate the way you cope. Please treat each item separately from every other item.

	I haven't been doing this at all			**I've been doing this a lot**
1. I've been concentrating my efforts on doing something about the situation I'm in.	0	1	2	3
2. I've been trying to come up with a strategy about what to do.	0	1	2	3
3. I've been trying to see it in a different light, to make it seem more positive.	0	1	2	3
4. I've been accepting the reality of the fact that it has happened.	0	1	2	3
5. I've been making jokes about it.	0	1	2	3
6. I've been trying to find comfort in my religion or spiritual beliefs.	0	1	2	3
7. I've been getting emotional support from others.	0	1	2	3
8. I've been trying to get advice or help from other people about what to do.	0	1	2	3
9. I've been turning to work or other activities to take my mind off things.	0	1	2	3
10. I've been saying to myself "this isn't real".	0	1	2	3
11. I've been saying things to let my unpleasant feelings escape.	0	1	2	3
12. I've been using alcohol or other drugs to make myself feel better.	0	1	2	3
13. I've been giving up trying to deal with it.	0	1	2	3
14. I've been criticising myself.	0	1	2	3
15. I've been taking action to try to make the situation better.	0	1	2	3
16. I've been thinking hard about what steps to take.	0	1	2	3
17. I've been looking for something good in what is happening.	0	1	2	3
18. I've been learning to live with it.	0	1	2	3
19. I've been making fun of the situation.	0	1	2	3
20. I've been praying or meditating.	0	1	2	3

	I haven't been doing this at all			**I've been doing this a lot**
21. I've been getting comfort and understanding from someone.	0	1	2	3
22. I've been getting help and advice from other people.	0	1	2	3
23. I've been doing something to think about it less, such as going to the movies, watching TV, reading, daydreaming, sleeping, or shopping.	0	1	2	3
24. I've been refusing to believe that it has happened.	0	1	2	3
25. I've been expressing my negative feelings.	0	1	2	3
26. I've been using alcohol or other drugs to help me get through it.	0	1	2	3
27. I've been giving up the attempt to cope.	0	1	2	3
28. I've been blaming myself for things that happened.	0	1	2	3

Appendix B: Patient Information and Consent Form

Participation and Consent Form
Version 3 Dated 2 July 2007
Site: Austin Health

Full Project Title: Psychosocial and symptom distress in patients with prostate cancer.

Principal Researcher: Professor Annette Street.

Associate Researcher(s): A/Prof Ian Davis; A/Prof Damien Bolton; Dr Anthony Love; Ms Leah Lederman.

This Participant Information and Consent Form is **5** pages long. Please make sure you have all the pages.

1. Your Consent

You are invited to take part in this research project.

This Participant Information Form contains detailed information about the research project. Its purpose is to explain to you, as openly and clearly as possible, all the procedures involved in this project before you decide whether to take part in it.

Please read the Participant Information carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend or your local health worker. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you under-stand the information and that you give your consent to participate in the research project.

You will receive a copy of the Participant Information and Consent Form to keep as a record.

2. Purpose and Background

Previous research has shown that many people with prostate cancer experience distressing symptoms that can significantly impact on their quality of life. However, very few studies have examined this experience over time.

The aim of this project is to examine patients' emotional responses to prostate cancer and their experience of prostate cancer-related symptoms over a period of time. The purpose is to provide information that will guide nursing and medical care of people with prostate cancer to assist them to manage distressing symptoms.

A total of 120 people will participate in this project.

You are invited to participate in this research project because information about your illness experience will help us identify strategies to improve the care for people like yourself. The results of this research may be used to help researcher Leah Lederman to obtain a Doctorate of Clinical Psychology degree.

3. Procedures

Your doctor will have discussed the project with you. Participation in this project will involve meeting with a researcher to discuss the study and obtain informed consent.

First meeting

At this meeting you will be asked to complete a questionnaire which will include questions regarding aspects of your functioning including urinary, bowel, and sexual function. If you wish to complete it in your own time, a reply paid envelope will be provided in which to return the questionnaire to the researcher.

For the purpose of the study, your treating team will be asked to provide some basic medical information to the researchers about your prostate cancer, such as the type of treatment you have received.

Postal questionnaires
Following this initial meeting you will be asked to complete the same questionnaire (without the personal information) ***three*** months later and at ***six*** months after the first meeting and each time return the completed questionnaire in the envelope provided. These will be posted to your home address. You will need to complete each questionnaire within a week of receiving it and return it to us within 2 days after completion. The questionnaire will take about 30-40 minutes to complete each time but if you find you need to take a break then that is fine.

Reminder phone calls
You will receive a telephone call from the researcher each time a questionnaire is mailed to you. This is to remind you to complete and return the questionnaire to us as well as answer any questions you may have and if necessary arrange to meet with you if you require any assistance with completion of the questionnaire.

After completion of the project, the computer records and written form will be stored in a locked archive cabinet in the research office at Austin Health for the statutory period, when it will be destroyed in a secure manner.

4. Possible Benefits

There may be no benefit to you from participation in this project. Information gained from this project may allow future development of procedures to help other patients with prostate cancer.

5. Possible Risks

Occasionally people find it emotionally difficult or tiring filling out the questionnaire or may become upset being interviewed.

If you experience any discomfort during the interview please tell the researcher, the interview will be interrupted and you will be reassured and allowed to rest. Then you can choose to continue the interview, complete it at another time or stop the process.

If you should remain emotionally distressed, you will be referred to a nurse or a counsellor at Austin Health who will be available to offer reassurance and support. If you experience further distress, please contact the researcher who will ensure that further counselling and/or support will be made available to you.

6. Alternatives to Participation

Participation is purely voluntary and if you decide not to take part then you will receive treatment as usual. Your relationship with Austin Health and with your treatment team will not be affected in any way.

7. Privacy, Confidentiality and Disclosure of Information

We will keep information you give us in a locked filing cabinet at Austin Health. Information will be identified by a code number only and your name will not appear on any forms.

Data files in software computer programs will be protected by password and accessible only to the investigators and research assistants. On completion of the study, questionnaires will be kept for 7 years as required by law. Data files will be archived in a locked filing cabinet for 7 years, in the research office at Austin Health. At the end of this time the disks will be destroyed.

Any information obtained in connection with this project and that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law.

In any publication, information will be provided in such a way that you cannot be personally identified.

8. New Information Arising During the Project

During the research project, new information about the risks and benefits of the project may become known to the researchers. If this occurs, you will be told about this new information. This new information may mean that you can no longer participate in this research. If this occurs, the person(s) supervising the research will stop your participation. In all cases, you will be offered all available care to suit your needs and medical condition.

If your answers to the questionnaire suggest that you are anxious or depressed, the researcher will not discuss this with you. You can ask the researcher to refer you to a counsellor or talk to your doctor about your feelings.

9. Results of Project

If you give us your permission by signing the Consent Form, we plan to publish the results of this study in scientific journals. A summary report of the study will be available on request.

10. Further Information or Any Problems

If you require further information or if you have any problems concerning this project (for example, any side effects), you can contact the principal researcher or interviewer. The researchers responsible for this project are:

- Professor Annette Street - phone 9479 4455
- Dr Anthony Love – phone 9496 4454
- A/Professor Ian Davis – phone 9496 5763
- A/Prof Damien Bolton – phone 9457 4049
- Ms Leah Lederman – phone 9496 4454

11. Other Issues

If you wish to contact someone independent of the study about ethical issues or your rights, you may contact Mr Andrew Crowden, Chair of the Austin Health Human Research Ethics Committee, phone 9496 2901. You may also contact Kaye Collins, Faculty of Science, Technology, and Engineering Ethics Committee, La

Trobe University, Victoria, 3086, phone 9479 3698. Please give the names of the researchers in section 10 above.

12. Participation is Voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part, not to take part, or to take part and then withdraw, will not affect your routine treatment, your relationship with those treating you or your relationship with Austin Health.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify a member of the research team.

13. Ethical Guidelines

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia. This statement has been developed to protect the interests of people who agree to participate in human research studies.
The ethical aspects of this research project have been approved by the Human Research Ethics Committee of this Institution, La Trobe University Faculty of Science, Technology, and Engineering Ethics Committee and, the Director Cancer Services at Austin Health.

14. Reimbursement for your costs

You will not be paid for your participation in this project.

Office use: _____

Consent Form
Version 3 Dated 2 July 2007
Site Austin Health

Full Project Title: Psychosocial and symptom distress in patients with prostate cancer.

I have read, and I understand the Participant Information version 3 dated 2 July 2007.

I freely agree to participate in this project according to the conditions in the Participant Information.

I will be given a copy of the Participant Information and Consent Form to keep.

The researcher has agreed not to reveal my identity and personal details if information about this project is published or presented in any public form.

Participant's Name (printed)
…….

Signature Date

Name of Witness to Participant's Signature (printed)
…….

Signature Date

Declaration by researcher*: I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Researcher's Name (printed)
……

Signature Date

* A senior member of the research team must provide the explanation and provision of information concerning the research project.

Note: **All parties signing the Consent Form must date their own signature.**

Appendix C: Correlation Matrices

Correlations of Time 1 Variables

	IPSS	Urinary function	Urinary bother	Urinary distress	Bowel function	Bowel bother	Sexual function	Sexual bother	Sexual distress	Pain severity	Pain interference	Fatigue	Depression	Anxiety	Trauma	Conflict	Regret	Satisfaction
IPSS	1																	
Urinary function	-.22*	1																
Urinary bother	-.58**	.60**	1															
Urinary distress	.48*	-.48**	-.68**	1														
Bowel function	-.28**	.07	.20*	-.38**	1													
Bowel bother	.23**	.05	-.23**	.29**	-.64**	1												
Sexual function	-.12	.19	.11	-.12	.07	-.04	1											
Sexual bother	-.18*	.14	.16	-.20*	-.00	-.02	.14	1										
Sexual distress	.19*	-.13	-.25**	.32**	-.07	.04	-.05	.63**	1									
Pain severity	.19*	-.05	-.12	.16	-.26**	.26**	-.02	-.10	.10	1								
Pain interference	.17*	-.05	-.09	.24**	-.28**	.21*	.04	-.07	.09	.73**	1							
Fatigue	.27**	-.17	-.15	.19*	-.34**	.34**	-.15	.20*	.25**	.41**	.50**	1						
Depression	.23**	-.08	-.16	.11	-.25**	.25**	-.13	-.17*	.29**	.39**	.29**	.65**	1					
Anxiety	.27**	-.11	-.25**	.15	-.29**	.25**	-.09	-.16	.26**	.29**	.29**	.59**	.75**	1				
Trauma	.27**	-.06	-.17	.15	-.17	.13	.07	.25**	.28**	.30**	.21*	.39**	.64**	.64**	1			
Conflict	.30**	.13	-.09	.12	-.03	.22*	-.01	-.05	.15	.11	.16	.23**	.25**	.18*	.22*	1		
Regret	.26**	.03	-.10	.23*	-.13	.24**	-.11	-.02	.15	.07	.20*	.22*	.24**	.18*	.22*	.58**	1	
Satisfaction	-.28**	.14	.17	-.11	-.02	-.12	.18	-.11	-.03	-.21*	-.17	-.19*	-.16	-.10	-.16	-.48**	-.54**	1

Note. *$p < .05$. **$p < .01$

Correlations of Time 2 Variables

	IPSS	Urinary function	Urinary bother	Urinary distress	Bowel function	Bowel bother	Sexual function	Sexual bother	Sexual distress	Pain severity	Pain interference	Fatigue	Depression	Anxiety	Trauma	Conflict	Regret	Satisfaction
IPSS	1																	
Urinary function	-.23	1																
Urinary bother	-.63**	.68**	1															
Urinary distress	.55**	-.68**	-.89**	1														
Bowel function	-.50**	.21	.33**	-.34**	1													
Bowel bother	.51**	-.28*	-.38**	.30**	-.84**	1												
Sexual function	.05	.15	.02	-.06	-.07	.11	1											
Sexual bother	-.12	.25*	.37**	-.35**	.13	-.12	.17	1										
Sexual distress	.09	-.39**	-.48**	.45**	-.20	.18	-.08	-.64**	1									
Pain severity	.40**	-.16	-.35**	.30**	-.57**	.48**	-.11	-.17	-.24*	1								
Pain interference	.33**	-.13	-.27*	.25*	-.66**	.61**	-.07	-.10	.24*	.69**	1							
Fatigue	.46**	.31**	-.19	.40**	.43**	-.56**	.40**	-.10	-.33**	.41**	.71**	1						
Depression	.33**	-.19	-.30**	.35**	-.36**	.28*	-.24*	-.29**	.17	.36**	.40**	.51**	1					
Anxiety	.36**	-.16	-.28*	.35**	-.61**	.53**	-.26*	-.31**	.18	.55**	.56**	.57**	.81**	1				
Trauma	.44**	-.30*	-.47**	.45**	-.57**	.53**	-.20	-.36**	.37**	.71**	.56**	.64**	.50**	.71**	1			
Conflict	-.03	-.07	-.04	.01	.05	.01	-.17	.05	-.06	.25*	.12	.01	.08	.13	.12	1		
Regret	.15	-.08	-.14	.16	-.05	-.02	-.14	-.12	.10	.17	.01	.21	.03	.06	.08	.44**	1	
Satisfaction	-.08	.04	.13	-.15	-.04	.11	.23	.13	-.07	.28*	.01	-.24*	-.04	-.05	-.09	-.61**	-.73**	1

Note. *$p < .05$. **$p < .01$

Correlations of Time 3 Variables

	IPSS	Urinary function	Urinary bother	Urinary distress	Bowel function	Bowel bother	Sexual function	Sexual bother	Sexual distress	Pain severity	Pain interference	Fatigue	Depression	Anxiety	Trauma	Conflict	Regret	Satisfaction
IPSS	1																	
Urinary function	-.33**	1																
Urinary bother	-.73*	.47**	1															
Urinary distress	.63**	-.62**	-.71**	1														
Bowel function	-.41**	.25	.39**	-.30*	1													
Bowel bother	.20	-.13	-.27*	.21	-.62**	1												
Sexual function	-.04	.28	.02	-.03	.11	.00	1											
Sexual bother	.07	.23	-.13	-.05	.02	.18	.43**	1										
Sexual distress	.05	-.21	-.00	.23	.14	-.16	.03	-.49**	1									
Pain severity	.35**	-.02	-.23	.18	-.53**	.35**	-.03	.13	-.21	1								
Pain interference	.35**	-.18	-.27*	.21	-.53**	.33*	-.16	-.12	-.22	.64**	1							
Fatigue	.39**	-.22	-.49**	.34**	-.37**	.20	-.35*	-.11	-.06	.37**	.60**	1						
Depression	.38**	-.11	-.37**	.32**	-.40**	.25*	-.37**	-.14	.18	.37**	.43**	.65**	1					
Anxiety	.31*	-.05	-.36**	.31*	-.47**	.35**	-.22	-.03	.05	.34**	.37**	.58**	.73**	1				
Trauma	.24	-.04	-.16	.27*	-.22	.14	-.14	-.09	.21	.22	.18	.36**	.75**	.57**	1			
Conflict	.28*	-.14	-.38**	.19	-.24	.09	-.19	-.06	-.05	.34*	.38**	.50**	.35**	.24	.22	1		
Regret	.14	-.10	-.20	.17	-.17	.01	-.16	.07	-.00	.21	.22	.22	.32*	.16	.22	.62**	1	
Satisfaction	-.23	.08	.31*	-.18	.08	-.07	.16	.06	.01	-.18	-.15	-.22	-.27*	-.22	-.25	-.77**	-.75**	1

Note. *$p < .05$. **$p < .01$

Appendix D: Tables of Non-Significant Findings

Table D1

Means And Standard Deviations for Prostate Symptoms, Pain, Fatigue, Psychological Distress, and Decision-related Distress Across Age at Time 1

	Middle Age (*n* = 40)		Young Old (*n* = 47)		Old Old (*n* = 50)	
	M	*SD*	*M*	*SD*	*M*	*SD*
IPSS	9.10	7.09	7.91	5.76	9.29	6.41
Urinary bother	68.75	29.28	82.98	26.64	74.49	29.53
Bowel function	82.37	19.47	88.42	12.83	88.78	12.60
Bowel bother	15.62	23.81	9.57	20.56	12.00	23.28
Sexual bother	48.12	42.13	48.91	43.77	60.71	45.24
Sexual distress	.88	1.02	.89	1.07	.45	.88
Pain severity	.44	1.11	.42	1.09	.39	1.03
Pain interference	.73	1.51	.88	2.01	.80	1.51
Fatigue	2.40	2.26	2.07	2.37	1.84	2.19
Depression	9.18	8.89	9.81	8.60	7.26	5.54
Anxiety	6.15	6.82	6.30	8.43	4.31	3.62
Decisional conflict	16.55	15.25	18.39	18.27	18.90	15.52
Decisional regret	20.97	21.81	19.15	21.50	21.93	15.37
Decisional satisfaction	25.36	5.47	25.10	5.75	24.51	5.70

Table D2

Means And Standard Deviations for Prostate Symptoms, Pain, Fatigue, Psychological Distress, and Decision-related Distress Across Treatment at Time 1

	No treatment (*n* = 57)		Hormone treatment (*n* = 26)		Other treatment (*n* = 18)	
	M	*SD*	*M*	*SD*	*M*	*SD*
IPSS	8.28	6.16	8.31	4.45	9.00	4.86
Urinary function	68.06	17.18	76.64	6.18	73.71	11.10
Urinary bother	73.68	31.13	80.77	24.81	79.17	24.63
Urinary distress	.53	.85	.31	.47	.44	.51
Bowel function	86.00	16.05	92.41	9.59	89.11	14.10
Bowel bother	11.40	21.17	6.73	18.11	15.28	24.46
Sexual bother	43.52	42.39	63.54	46.03	55.88	40.05
Sexual distress	.96	1.08	.40	.87	.67	.97
Pain severity	.41	1.07	.06	.20	.60	1.37
Fatigue	2.14	2.31	1.45	1.75	2.11	2.15
Depression	8.26	7.26	6.81	4.13	8.61	8.29
Anxiety	5.14	6.10	4.46	4.51	5.78	5.98
Decisional conflict	16.11	11.76	21.06	21.49	18.08	14.05
Decisional regret	16.60	17.07	23.08	24.13	25.36	18.65

Table D3

Means And Standard Deviations for Prostate Symptoms, Pain, Fatigue, Psychological Distress, and Decision-related Distress Across Age at Time 2

	Middle Age (*n* = 25)		Young Old (*n* = 32)		Old Old (*n* = 27)	
	M	*SD*	*M*	*SD*	*M*	*SD*
IPSS	11.44	9.54	8.38	7.35	8.07	5.89
Bowel function	85.66	17.31	89.49	13.43	91.38	8.98
Bowel bother	16.00	28.76	10.16	18.90	6.73	16.67
Sexual function	20.88	23.64	18.04	25.88	13.06	18.67
Sexual bother	36.46	42.34	53.91	44.95	47.92	42.30
Pain severity	.97	1.90	.50	1.25	.48	.92
Pain interference	1.23	2.05	.90	2.23	.75	1.51
Fatigue	2.84	2.87	1.97	2.59	1.68	1.81
Anxiety	6.60	8.61	6.83	9.61	4.19	4.06
Trauma	11.56	11.70	10.26	16.77	3.39	5.48
Decisional conflict	17.06	14.16	15.05	15.30	17.33	12.64
Decisional regret	23.60	25.31	23.28	25.54	20.00	18.00
Decisional satisfaction	25.12	5.53	25.69	5.62	26.25	5.62

Table D4

Means And Standard Deviations for Prostate Symptoms, Pain, Fatigue, Psychological Distress, and Decision-related Distress Across Age at Time 3

	Middle Age (*n* = 19)		Young Old (*n* = 25)		Old Old (*n* = 21)	
	M	*SD*	*M*	*SD*	*M*	*SD*
IPSS	8.26	7.66	7.72	6.05	8.57	7.03
Urinary function	67.57	20.05	71.33	14.03	73.91	7.09
Urinary bother	78.95	30.35	82.00	24.50	71.43	32.87
Urinary distress	.63	1.07	.32	.63	.48	.68
Bowel function	89.08	11.61	90.44	10.62	85.05	13.42
Bowel bother	14.47	28.03	12.00	21.79	10.00	20.52
Sexual function	27.30	24.20	16.27	27.00	17.20	24.84
Sexual bother	39.47	42.75	51.09	42.29	48.53	44.61
Sexual distress	1.16	1.07	.75	1.03	.44	.89
Pain severity	.32	.68	.21	.67	.59	1.05
Pain interference	.47	1.23	.30	.86	1.10	1.78
Fatigue	1.67	1.92	1.94	2.00	2.31	2.24
Depression	9.58	10.11	9.64	8.91	8.15	5.26
Anxiety	4.42	10.11	9.64	8.91	8.15	5.26
Trauma	12.67	16.54	9.24	12.65	4.67	7.25
Decisional conflict	20.07	16.45	16.25	15.48	16.56	16.29
Decisional regret	26.58	27.13	17.14	21.94	25.25	16.66
Decisional satisfaction	24.63	4.94	25.41	4.65	25.90	3.13

Appendix E: Additional Analyses

Time 2 Analyses

Table E1

Standard Regression of Prostate Symptoms, Pain, Fatigue, and Decision Making Variables at Time 1 on Depression at Time 2

DV	Variables	B	β	R^2	adjusted R^2	R
Depression	Prostate symptoms	.05	.03			
	Bowel function	-.03	-.06			
	Bowel bother	-.01	-.03			
	Pain severity	.55	.07			
	Pain interference	.06	.01			
	Fatigue	1.95	.51**			
	Conflict	.03	.06			
	Satisfaction	-.15	-.09			
				.37	.29	.61

Note. **$p < .01$.

As is shown in Table E1 above, the only unique predictor was fatigue at Time 1 (Beta weight of .51), F (8, 65) = 4.79, $p < .001$, indicating that those men with more fatigue at Time 1 reported more depression at Time 2. The results indicate that 37% of the variance in depression at Time 2 was explained by this model.

Table E2

Standard Regression of Prostate Symptoms, Pain, Fatigue, and Decision Making Variables at Time 1 on Anxiety at Time 2

DV	Variables	B	β	R^2	adjusted R^2	R
Anxiety	Bowel function	-.01	.06			
	Bowel bother	.01	.04			
	Pain severity	1.07	1.04			
	Pain interference	.19	.70			
	Fatigue	1.42	.39**			
				.30	.26	.55

Note. **$p < .01$.

As demonstrated in Table E2 above, the only unique predictor was fatigue (Beta weight of .39), F (5, 76) = 6.54, $p < .001$, indicating those with more fatigue at Time 1 reported more anxiety at Time 2. The results indicate that 30% of the variance in anxiety at Time 2 was explained by this model.

Table E3

Standard Regression of Prostate Symptoms, Pain, Fatigue, and Decision Making Variables at Time 1 on Trauma at Time 2

DV	Variables	B	β	R^2	adjusted R^2	R
Trauma	Prostate symptoms	.12	.06			
	Urinary distress	.04	.00			
	Bowel bother	.00	.00			
	Sexual bother	-.05	-.16			
	Sexual distress	2.28	.18			
	Pain severity	3.92	.33*			
	Pain interference	-.23	-.03			
	Fatigue	1.57	.28*			
	Conflict	.08	.10			
				.46	.38	.68

Note. *$p < .05$.

The results in Table E3 above show that pain severity and fatigue were unique predictors (Beta weights of .33 and .28 respectively), F (9, 63) = 5.92, $p < .001$, indicating that men with more pain and fatigue at Time 1 reported more trauma at Time 2. The results indicate that 46% of the variance in depression at Time 2 was explained by this model.

Time 3 Analyses

Table E4

Standard Regression of Prostate Symptoms, Pain, Fatigue, and Decision Making Variables at Time 1 on Depression at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Depression	Prostate symptoms	.19	.15			
	Urinary bother	-.01	-.02			
	Bowel bother	.04	.10			
	Pain severity	.03	.00			
	Fatigue	1.62	.46**			
	Conflict	-.00	-.00			
	Regret	.02	.04			
	Satisfaction	-.47	-.32*			
				.54	.46	.74

Note. *$p < .05$. **$p < .01$.

Table E4 above shows that fatigue and decisional satisfaction were unique predictors (Beta weights of .46 and -.32 respectively), F (8, 47) = 6.93, $p < .001$, indicating that those men with more fatigue and those who were less satisfied with their treatment decision at Time 1, reported more depression at Time 3. The results indicate that 54% of the variance in depression at Time 3 was explained by this model.

Table E5

Standard Regression of Prostate Symptoms, Pain, Fatigue, and Decision Making Variables at Time 1 on Anxiety at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Anxiety	Prostate symptoms	.07	.06			
	Urinary bother	-.03	-.12			
	Bowel bother	.02	.06			
	Sexual function	-.04	-.15			
	Pain severity	2.41	.33*			
	Pain interference	-.90	-.19			
	Fatigue	1.53	.45**			
	Satisfaction	-.17	-.12			
				.50	.42	.71

Note. *$p < .05$. **$p < .01$.

Table E5 above demonstrates that pain severity and fatigue were unique predictors (Beta weights of .33 and .45 respectively), F (8, 49) = 6.17, $p < .001$, indicating that those men who reported more severe pain and more fatigue at Time 1 reported more anxiety at Time 3. The results indicate that 50% of the variance in anxiety at Time 3 was explained by this model.

Table E6

Standard Regression of Prostate Symptoms, Pain, Fatigue, and Decision Making Variables at Time 1 on Trauma at Time 3

DV	Variables	B	β	R^2	adjusted R^2	R
Trauma	Prostate symptoms	.33	.16			
	Urinary bother	.01	.02			
	Bowel function	-.09	-.11			
	Bowel bother	.04	.06			
	Sexual bother	-.05	-.15			
	Sexual distress	2.10	.16			
	Fatigue	1.23	.22			
	Regret	.00	.00			
	Satisfaction	-.54	-.23			
				.38	.26	.62

While the overall ANOVA of the regression was significant, F (9, 46) = 3.12, $p < .01$, there were no unique predictors. The results indicate that 38% of the variance in trauma at Time 3 was explained by this model.