An Internet-Based Psychosocial Intervention for Men Treated for Prostate Cancer

by

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Submitted in partial fulfilment of the requirements for the award of:

Doctor of Psychology (Health)

Deakin University
Melbourne Australia
April 2013
I am the author of the thesis entitled  The Development and Evaluation of an Internet-Based Psychosocial Intervention for Men Treated for Prostate Cancer

submitted for the degree of Doctor of Psychology (Health)

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Acknowledgements

I would like to thank several people in relation to the completion of this thesis.

Firstly I would like to thank my supervisor, Professor Marita McCabe, for more than three years of support and assistance during every step of this doctoral thesis. Particularly for guiding me when I became lost in the details and needed deadlines, and for taking the time to introduce me to other researchers at conferences. Thank you also for clearly caring that I finish my thesis and do a good job of it.

In addition I would like to thank Dr Addie Wootten and Dr Jo Abbott who I collaborated with in the creation of the program that was developed as part of my thesis. It was fantastic to have the creative energy in input from a variety of individuals and organisations.

I would also like to thank the funding partners for the development of the internet-based program, Beyondblue and the Prostate Cancer Foundation of Australia. In addition, thanks to Web Elements and Engaging Partners for their assistance and creative input into developing the website.

I have made many good friends during the DPsych, who now that I’m finishing I realise will be great friends for a lot longer. During the last three years I don’t know what I would have done without your support and friendships.

Finally, many thanks to my family and friends who have supported me by listening to me express the highs and lows in completing this thesis and for spending time with me, and simply for being themselves.
Publications and Conference Presentations

During my DPsych Candidature, the following research paper was published and presentations at conference took place.


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Abstract

The aim of this thesis was to develop and evaluate an internet-based cognitive behavioural therapy (CBT) program for men treated for localised prostate cancer. The internet-based program, *My Road Ahead*, was developed to address the unmet psychosocial needs of men treated for prostate cancer. These needs include enhanced support to manage psychological distress, sexual difficulties, and relationship difficulties. In addition the program addressed urinary dysfunction, uncertainty about the future and communication with friends and health professionals. Partner involvement was also an important aspect of this program. *My Road Ahead* consisted of six modules covering the above areas and an asynchronous forum which was moderated with weekly topics posted to promote discussion. *My Road Ahead* was a self-directed intervention and several functions were used to enhance engagement, including a highly interactive interface (e.g., videos and online exercises), weekly email reminders and encouragement to continue moving through the program, offline exercises, a mood monitor, and open access to modules. Fifty-seven men who had been treated for prostate cancer were randomised into one of three treatment groups: Modules only, Modules-plus-Forum, and Forum-only. It was predicted that those in the Modules-plus-Forum group (and to a lesser extent those in the Modules only group) of *My Road Ahead* would demonstrate greater improvement across sexual, psychological, and relationship functioning measures from pre-test to post-test than those only accessing the forum. After attrition, a total of 41 men participated in the evaluation of the efficacy of *My Road Ahead*. Findings failed to reveal any significant effects for the different groups across sexual, psychological and relationship functioning measures. There were trends towards significance in some of the sexual and relationship variables. The small sample size may have led to a lack of significant findings. Participants also provided feedback on the usability and
feasibility of *My Road Ahead*. Limitations of this research are discussed both in terms of the content of the internet-based program and the research methodology. Strategies to improve *My Road Ahead* and the direction for general internet-based interventions for men with prostate cancer in the future are discussed.
Chapter 1: Introduction and Overview of Thesis

This chapter provides an overview of prostate cancer, including epidemiological data with regards to prevalence and survival, information on the most common treatment options and an overview of the psychosocial impact of prostate cancer and its treatment. It concludes with a summary of the aims and outline of this thesis.

Prostate Cancer and Epidemiology

Prostate cancer is a form of cancer located in the prostate. Cancer results when a lump of cells form to make a tumour as a result of abnormal and uncontrolled cell division (Robbins, 2010). The prostate gland is located below the bladder and surrounding the urethra and is responsible for producing part of the fluid that makes semen (Cousins, 2010a). The malignant growth or tumour may be confined to the prostate (localised prostate cancer) or the cancer may metastasise beyond the prostate becoming more serious as it enters the lymph nodes or the blood stream (Robbins, 2010).

Cancer of the prostate is the second most common serious cancer diagnosed (after breast cancer), with 889,102 cases diagnosed worldwide in 2008 (Ferlay et al., 2010). It is the second most common cancer in Australia, after non-melanoma skin cancer, and the most common form of cancer in Australian males, making up 32% of all male cancer diagnoses in 2007 (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2010). In Australia, 19,403 new cases were reported in 2007 (AIHW & AACR, 2010). Prostate cancer was expected to continue to be the most common cancer diagnosed in men in Australia in 2012 (AIHW & AACR, 2012). Prostate cancer is largely diagnosed in older men, where
AIHW 2007 statistics found that the risk of a prostate cancer diagnosis increased from one in seven before 75 years of age to one in four before the age of 85 (AIHW & AACR, 2010).

Survival rates for prostate cancer are generally high. Worldwide survival rates are around 71% (Ferlay et al., 2010). In Australia, the five year survival rate for those diagnosed between 1998 and 2004 was 85% (AIHW & AACR, 2010). Early detection and treatment methods are likely to contribute to high survival rates (Ferlay et al., 2010; National Health and Medical Research Council and Australian Cancer Network, 2002). Prostate-specific antigen (PSA) levels are considered the most sensitive marker for prostate cancer, and PSA levels are frequently used to aid diagnosis, contributing to treatment choice and providing prognosis information (Kunkel, Bakker, Myers, Oyesanmi, & Gomella, 2000). Screening techniques using PSA levels have allowed detection of the disease at an earlier and less aggressive stage (NHMRC & ACN, 2002). Consequently, in around 91% of men diagnosed with prostate cancer, the cancer is localised in the prostate (Yan, Carvalhal, Catalona, & Young, 2000).

**Treatment for Prostate Cancer**

Improved detection methods and subsequent increases in the number of patients diagnosed with localised prostate cancer, has led to an examination of the various treatment methods available (Yan et al., 2000). As such, there are many guidelines written across the world regarding the optimal treatment options for prostate cancer, both for consumers and urologists, for example, from the European Association of Urology (Heidenreich et al., 2012) and the American Urological Association (2008). Once a diagnosis is confirmed, treatment decisions can be difficult, largely due to the controversy and unclear consensus of the optimal
treatment and management of prostate cancer. Cooperberg, Broering and Carroll (2010) suggested that this is partly a result of the lack of clinical trials evaluating the efficacy of the main treatment options.

Treatment decisions are dependent on several variables including age, general health, tumour stage, PSA levels, outcome of prior prostate cancer treatment, and physicians’ and patients’ preferences (Incrocci, 2006a; Incrocci et al., 2001; Smith et al., 2009; Yan et al., 2000). The goal of treatment for prostate cancer is often a balance between risk, cure, and aiming to minimise the impact of several areas of quality of life (QoL) (Anandadas, Davidson et al., 2011; Eller et al., 2006).

Localised prostate cancer is generally treated by active surveillance, surgery (radical prostatectomy), external beam radiotherapy, or brachytherapy (implantation of radioactive seeds in the prostate) (Baade et al, 2012; Yan et al., 2000). Active surveillance has been introduced as a treatment option for localised prostate cancer in recent years, moving away from the term watchful waiting. Watchful waiting is now used for older men or men with a shorter life expectancy where a more regimented surveillance protocol as used in active surveillance, is not deemed to be appropriate. It is often used as a method for older patients who have other serious medical comorbidities, making them poor surgical candidates, and in patients who are less likely to die from prostate cancer than other medical illnesses (Duchesne, 2011; Kunkel et al., 2000). In fact, an asymptomatic patient is unlikely to die from prostate cancer if their life expectancy is under 10 years, making watchful waiting a good option (Eylert, 2012; Kunkel et al., 2000).

Radical prostatectomy and radiation therapy are the two most commonly used treatments across the various stages of disease and are also used with curative intent (Baade et al., 2012; Lu-Yao & Yao, 1997; Penedo et al., 2006). Radical prostatectomy involves surgical removal of the prostate, seminal vesicles, the vas
deferens, and the bladder cuff (Kunkel et al., 2000). NHMRC and ACN (2002) suggested that radical prostatectomy has the best prognosis for localised prostate cancer. In comparison to open surgical techniques, laparoscopic and robotic surgery are thought to reduce the rate and impact of side effects (Menon, Shrivastava, and Tewari, 2005). Patients opting for surgery tend to be younger than those undergoing radiation therapies (Lu-Yao & Yao, 1997; Duchesne, 2011), have a long life expectancy (> 10 years), low volume PSA, and display no surgical risk factors (NHMRC & ACN, 2002). The major advantage for a patient undergoing surgery is that, if successful, it can provide a definitive cure, as well as more detailed information regarding the nature and severity of the cancer (Walsh, 2010).

Radiotherapy also plays a significant role in the management of prostate cancer. External-beam radiotherapy offers an attractive alternative to surgery, most often involving a 7-9 week course consisting of 35-41 treatments (Castles, 2010). It is usually considered suitable for those with no risk factors for radiation toxicity, those with low PSA volume, or those who simply have a preference for radiotherapy (NHMRC & ACN, 2002). Brachytherapy is a form of internal radiotherapy where the radiation is placed in the area affected, allowing high doses of radiation to be given to the prostate whilst protecting surrounding tissue (Duchesne, 2011). Although not heavily used in Australia, brachytherapy is growing in popularity (NHMRC & ACN, 2002).

Active surveillance is offered to men with low and intermediate risk prostate cancer, taking into account the man’s age, comorbidities and life expectancy (Eylert, 2012). There are various active surveillance protocols used by different treatment centres across the world and often clinicians tailor their approach to the patient or clinical setting. Active surveillance typically involves PSA testing every 3-12 months and regular biopsies to monitor cancer status or growth (Eylert, 2012). More invasive
treatment is undertaken if there is any sign of PSA rise or cancer growth (Duchesne, 2011; Eylert, 2012).

Androgen Deprivation Therapy (ADT) deprives prostate cancer with the hormonal fuel it requires to grow; by reducing the available androgens in the system. ADT is used to treat locally advanced or advanced prostate cancer as well as metastatic prostate cancer (Maugham, 2010). ADT may also, but very rarely, be used to reduce the size of a tumour prior to surgery (Fergus, Gray, & Fitch, 2002). ADT may also be used in combination with radiotherapy to treat advanced prostate cancer (Cousins, 2010b). While ADT is effective in slowing down the growth of cancer cells, it is not a curative treatment option (Maugham, 2010). Prostate cancer will become castrate resistant after a period of time, which is variable for each individual, and PSA will start to rise again indicating prostate cancer cell growth (Maugham, 2010). When this occurs ADT has failed and other drug therapies including chemotherapy are used (Cousins, 2010b).

**Overview of the Impact of Prostate Cancer and Prostate Cancer Treatment**

While the incidence of prostate cancer is growing, treatment of localised disease has become very effective and many patients are reportedly living longer (AIHW & AACR, 2010). Over the last few decades PSA testing has changed the profile of men with prostate cancer, with the majority now diagnosed with low risk early stage localised disease (Anandadas, Davidson et al., 2011). Considering survival rates of prostate cancer are high, issues surrounding QoL become significant, as many men live with both the impact that cancer and treatment has on their lives. Prostate cancer and its treatment are widely accepted to have an impact on both a patient’s physical and emotional QoL (Manne, Badr, Zaider, Nelson, & Kissane, 2010). Similar to most cancers, men with prostate cancer need to adjust to
the shock of diagnosis and the confrontation of facing the possibility of death and cancer recurrence. There may also be physiological symptoms including insomnia, fatigue, and pain (Hervouet et al., 2005; Lintz et al., 2003). As with other cancers, prostate cancer can negatively impact on many areas of a patient and their family’s life, including work and social functioning, financial strain as a result of treatment costs or decreased employment, emotional health, and general QoL (Albaugh & Hacker, 2008; Holland, Watson, & Dunn, 2011; Jayadevappa, Bloom, Fomberstein, Wein, & Malkowicz, 2005).

In addition to these factors, men who undergo treatment for prostate cancer are faced with major morbidities including urinary incontinence, bowel dysfunction, and erectile dysfunction (ED). These side effects are thought to pose particular challenges to a man’s social, mental, emotional and physical well-being (Albaugh & Hacker, 2008; Stanford et al., 2000; Weber & Sherwill-Navarro, 2005). In particular, ED is highly prevalent in men treated for prostate cancer and is thought to pose particular challenges to a man’s wellbeing and can be difficult to adjust to (Manne et al., 2010; Weber & Sherwill-Navarro, 2005).

A man’s intimate partner relationship is also likely to be impacted by prostate cancer directly and as a consequence of the impact of side effects from treatment, particularly sexual changes (Banthia et al., 2003; Beck, Robinson, & Carlson, 2009; Boehmer & Babayan, 2004; Bokhour, Clark, Inui, Silliman, & Talcott, 2001; Galbraith & Crighton, 2008). In fact prostate cancer is often referred to as the “relationship disease” (Gray, Fitch, Phillips, Larecque, & Klotz, 1999).

Physical side effects such as erectile dysfunction (ED) as well as psychological outcomes have both been found to have lasting effects (Schover et al., 2002a; Wootten, Burney, Frydenberg et al., 2007). Considering these factors, survivorship issues in the prostate cancer population therefore pose unique challenges in terms of
QoL over the long term. In order to provide support for this population, research needs to focus on ways to support these men and their partners in order to minimise the impact of cancer on their psychological health, relationships and overall well-being (Newton, Burney, Frydenberg, Millar, & Ng, 2007).

**Overview of this Thesis**

This thesis was conducted to address limitations associated with the current literature regarding the effectiveness of psychosocial treatments with men treated for localised prostate cancer, and to examine the suitability of the internet as a medium to provide psychological treatment to men who have been treated for prostate cancer. It involved the development and evaluation of an internet-based cognitive behavioural therapy (CBT) program for men treated for localised prostate cancer. The program also encouraged the participation of partners. This thesis forms part of a larger study which plans to evaluate the efficacy of the program with a larger sample over extended time points. This thesis focuses on the development, useability and feasibility of the internet-based program and provides preliminary efficacy findings.

In order to explore psychosocial treatment for men treated for prostate cancer, it is important to understand the areas of a man’s life that are likely to be impacted by prostate cancer and its treatment in more detail. Therefore, the next three chapters explore the current literature related to sexual functioning, psychological functioning, and relationship functioning in men treated for prostate cancer. Chapter 5 discusses medical treatments that have been used to treat ED, followed by an evaluation of psychosocial interventions that have been used to target sexual, psychological and relationship functioning in men treated for prostate cancer. This chapter concludes with a discussion of the current limitations associated with psychosocial approaches. Chapter 6 explores the growing literature regarding online psychological treatment in
different areas including cancer. Chapter 7 provides a rationale for our research and outlines the development of a psychosocial internet-based program for men with prostate cancer (*My Road Ahead*).

The empirical component of this thesis evaluates the efficacy of this program specifically related to sexual, psychological and relationship functioning. The hypotheses and method are outlined in Chapter 8, and the results of this study are in Chapters 9 and 10. Chapter 11 provides an overall discussion of the development and evaluation of *My Road Ahead*. Implications of the findings from this thesis for the treatment of psychosocial issues in men treated for prostate cancer, limitations of the research, and recommendations for future research are also explored.
Chapter 2: Sexual Functioning and Prostate Cancer Survivors

Erectile dysfunction (ED) is considered to have a significant impact on a prostate cancer survivor’s life. This chapter presents a general overview of ED in men treated for prostate cancer. The incidence of ED in this population is summarised, followed by how prostate cancer treatment may impact on multiple areas of sexuality. Masculinity theory as a way of conceptualising how ED may impact on sexual functioning and intimacy is also explored. This chapter concludes with consideration of the implications for treatment of ED in prostate cancer survivors.

ED and Prostate Cancer Treatment

During a normal erectile response, both vascular and neurological mechanisms are activated by either psychological or physical stimulation (Darst, 2007). Such stimulation leads to relaxation of the smooth muscle in the penis, allowing blood to flow into spongy tissue of the penis, thus creating an erection (Darst, 2007). ED has been described as “the incapacity to achieve and maintain a penile erection enough to attain satisfactory sexual relations” (Castelo-Branco, Huezo, & Lagarda, 2008, p. 55).

ED is highly prevalent in men treated for prostate cancer because many nerve fibres involved in normal erectile functioning surround the prostate and these nerves are damaged during treatment for prostate cancer (Schover et al., 2002a). For example, during a prostatectomy, even when utilising nerve sparing techniques, damage occurs in the neurovascular bundle, interfering with the mechanisms necessary for erectile functioning (Darst, 2007). Some research has reported greater sexual recovery for nerve-sparing radical prostatectomy than non-nerve-sparing radical prostatectomy (Pardo et al., 2010). However, even with surgical technology
advancements using nerve-sparing techniques, incidence and severity of ED remains high (Briganti & Montorsi, 2006).

The onset and course of ED differs across both individuals and type of treatment undertaken. After surgery, ED occurs immediately and return of erections may take up to two years, if at all. In contrast, ED following radiation therapy is gradual, with symptoms peaking at approximately two years post-treatment (Anandadas, Davidson et al., 2011; Incrocci, 2005; Wittmann, Northouse et al., 2009).

Rates of ED have been evaluated by several researchers, either focusing on one treatment type for prostate cancer or across treatments. Penson et al. (2005) reported sexual outcomes for 1,288 men at baseline, and at follow up 6 months, 12 months, 24 months, and 60 months post-surgery. Baseline data were recalled retrospectively no more than 6 months after diagnosis. In terms of erectile function, the percentage of men reporting erections not firm enough for intercourse were 17% at baseline, 89% (6 months), 81% (12 months), 75% (24 months), and 71% (60 months).

A postal survey with 1,236 men treated for localised prostate cancer by either radical prostatectomy or radiotherapy, found that 79% reported ED within the past 6 months at a mean of 4.3 years post-treatment at the time of survey, with no significant differences between the two types of treatment (Schover et al., 2002a). Of the 21% who had functional erections, 38% were using an ED medical aid. Clinician reports of baseline ED prior to treatment were 36%, which was similar to patient retrospective reporting. Having good erections pre-treatment was predictive of functional erections post-treatment. In this study, although nerve sparing techniques showed a significant advantage, rates were still above normal rates of ED in the general population.
Other studies have found a difference across treatment types. For example, using a sample of 1,187 men, Potosky et al. (2004) found that 79% had ED after prostatectomy compared to a lower rate of 64% after radiation therapy at five years after diagnosis. At two years after diagnosis the difference was greater, with 82% reporting ED for the radical prostatectomy group and 50% for the radiation therapy group. The use of concurrent ADT with each of the treatments was associated with greater levels of ED at the five year time point.

One population-based prevalence study from the Netherlands compared erectile functioning of men (5-10 years post diagnosis) who underwent a range of treatments for prostate cancer, as well as a proportion who opted for watchful waiting, and compared this to the outcome data of a large sample of age-matched men without prostate cancer (Mols et al., 2009). Erectile difficulties were found in 74% (prostatectomy), 67% (radiotherapy or hormonal therapy), 40% (watchful waiting), and 18% (normative population sample).

While these studies demonstrate high rates of ED, they frequently employ comparisons between post-treatment functioning and retrospective reporting of pre-treatment functioning. As a result, there is some suggestion that the rates of ED reported in outcome studies mentioned previously are overstated, since pre-treatment erectile functioning is often not taken into account and is frequently low when considering the average age of patients (Monga, Kerrigan, Garber, & Monga, 2001). It is well known that erectile function declines with age and many men admit to problems with potency before prostate cancer (Boehmer & Clark, 2001).

In one prospective study by Jayadevappa et al. (2005), 40 men diagnosed with prostate cancer and treated by surgery were matched to 40 cancer free men. Health related QoL data, including sexual function, were taken prior to treatment, and at 3 months, 6 months, 12 months, and 24 months follow up. At baseline, prior to
treatment, 74% reported a good or very good ability to function sexually and at 24 months post-treatment only 28% reported this. Although a small sample size, this study was unique in that it provides evidence of declines in erectile functioning without retrospective reporting.

Other prospective studies have explored the recovery of potency from pre-operative erectile function, rather than reporting rates of ED specifically. An earlier study by Litwin, Melmed, and Nakazon (2001) used a prospective longitudinal design to assess sexual function outcomes for 247 men who underwent a radical prostatectomy taking baseline scores (before surgery) and every 3 months to a year post-surgery. About a third of the sample returned to baseline sexual function at one year, with the mean recovery time at 11 months. Tseng et al. (2006) measured sexual function at baseline (before surgery), and at six time points leading up to 18 months post-surgery with 90 men who underwent robotic radical prostatectomy (both nerve sparing and non-nerve sparing). Only 11.9% reported returning to baseline scores of sexual function at 12 and 18 months post-surgery. An analysis of 42 men who had erections firm enough for intercourse at baseline were found to return to pre-operative erections at a mean time of 13.5 months post-surgery.

Some more recent research has explored erectile function recovery also by assessing potency at baseline (pre-operatively) and at several time points up to one to two years post-surgery (Murphy, Kerger, Crowe, Peters, & Costello, 2009; Patel et al., 2011). Potency was measured on the Sexual Health Inventory for Men (SHIM) which focuses on the number and quality of erections. The percentage of men who returned to previous potency was found to be 62% (Murphy et al., 2009) and 89.8% (Patel et al., 2011) at 12 months follow-up post-surgery. The reason for these higher rates is likely to be a result of the inclusion criteria in these studies, which was men who had a certain level of potency prior to surgery and who underwent nerve sparing.
surgery. The use of PDE5 (phosphodiesterase type 5) inhibitor was also likely to play a major role in recovery with the majority of Murphy et al.’s (2009) sample using this aid.

The studies highlighted in this section reported rates of ED in these populations based on a definition of ED as the degree of ability to have an erection firm enough for intercourse (Penson et al., 2005; Potosky et al., 2004), or by using the erectile function specific scales (Murphy et al., 2009; Patel et al., 2011; Schover et al., 2002a), and the use of specific questions about the degree of erection problems (Moles et al., 2009). Other researchers have used scales including items focusing on erectile function in addition to desire and orgasm function (e.g., Litwin et al., 2001; Tseng et al., 2006) or a scale including questions about function and degree of bother by symptoms (e.g., Pardo et al., 2010). In these studies, without separation of subscales or items in analyses, reports of erectile function and more broadly sexual function were merged. Although measuring rates of actual erectile function are important, most researchers acknowledge that sexual function goes beyond the ability to be able to achieve an erection and emphasise the multidimensional nature of sexual function. Before covering this in more detail, the next section explores the role of urinary incontinence in prostate cancer treatment and its impact on sexual function and sexuality.

**Urinary Incontinence**

Urinary dysfunction refers to one’s “ability to maintain urinary control” (Litwin et al., 2000). Urinary dysfunction is also considered a difficult side effect of prostate cancer treatment to adjust to (Stanford et al., 2000). Surgery for prostate cancer is more likely to cause urinary dysfunction than radiation treatment (Litwin et al., 2000, p. 1973). Rates of urinary dysfunction vary in the literature and range from
5.8%-48% in samples of men with prostate cancer treated by surgery (Augustin et al., 2002; Burkhard et al., 2006; Mols et al., 2009; Penson et al., 2005). Such variations in rates of urinary dysfunction may be due at least in part to no clear consensus of the definition of urinary continence or incontinence (Bauer, Bastian, Gozzi, & Stief, 2009; Litwin et al., 2000). For example, definitions include “needing to wear pads” (Augustin et al., 2002) versus the level of reported control of leakage (Penson et al., 2005), both these factors together (Burkhard et al., 2006), or a measure of QoL in the urinary domain incorporating these factors (Mols et al., 2002).

Assessment time points varied in the above studies in terms of the time at which measurements were taken post-treatment. For example, Burkhard et al. (2006) measured function at one year post-surgery and Augustin et al.’s (2002) timeframe ranged from 12-78 months. Penson et al.’s (2005) study highlighted earlier measured urinary control for men treated for prostate cancer by surgery prior to diagnosis and at 6 months, 12 months, 24 months and 60 months post-surgery. While 87% of men reported “total control” of urinary function at baseline, rates were 23%, 35%, 39% and 35% at each of the post-surgery follow-up time points. This study demonstrated that urinary dysfunction remains for a long time post-surgery for many men. Gacci et al. (2009) explored factors contributing to urinary dysfunction and found a trend towards better urinary function after nerve sparing surgery; however, this was non-significant, highlighting that even with improved technology many men are still impacted by incontinence.

Although there has been a greater research focus on surgery outcomes, Litwin et al. (2000) compared urinary dysfunction in a cohort of 564 men who underwent surgery or radiation therapy within 6 months of diagnosis of localised prostate cancer. Surgery was found to have significantly worse urinary outcomes immediately following treatment compared to radiation therapy; however, urinary function
improved steadily during the first year post-treatment and rates of urinary function remained stable and comparable to radiation at one and two years post-treatment. Similarly, Anandadas, Davidson et al. (2011) found that men who had surgery for prostate cancer reported significant declines in urinary function compared to those who had radiation or brachytherapy, which improved over time but did not return to baseline levels. A prevalence study mentioned previously of longer term prostate cancer survivors after a range of treatments also found surgery to have significantly and clinically worse urinary function outcomes than other treatment, and all treatments were found to be worse than a normative control group (Mols et al., 2009). Urinary incontinence was found to be 48% (radical prostatectomy), 23-24% (other treatments), and 4% (age-matched normative population sample).

Even with inconsistent rates of urinary difficulties and incontinence, it appears that prostate cancer treatment impacts negatively on urinary functioning and that this is distressing for many men. Focus group research of men treated for prostate cancer has found that urinary dysfunction can cause both physical and emotional distress resulting in behavioural changes and difficulties (Clark, Bokhour, Thomas, Silliman & Talcott, 2003). Levels of urinary bother (impact and annoyance associated with urinary dysfunction) have been reported by Penson et al. (2005) to be highest at 6 months post-surgery (29% stated it was a moderate or big problem) compared to 3% at baseline. These rates improved over time but still remained elevated at 13% at 60 months post treatment. Litwin et al. (2000) also explored level of urinary bother and surprisingly found that at all time points urinary bother was higher for those who underwent radiation compared to surgery, even though surgery had higher post-operative urinary dysfunction rates. However, Mols et al.’s (2009) found no difference in levels of urinary bother across the different treatments for prostate cancer and in comparison to an age matched normative sample.
Urinary incontinence and sexuality. Urinary continence difficulties can negatively impact on sexual function and relationships. Pad use is frequently associated with urinary dysfunction and often makes a man feel embarrassed by wetness or unpleasant odours and this is thought to impact on a man’s sex life (Clark et al., 2003; Litwin et al., 2000; Penson et al., 2005). Incontinence can also directly impact sexual activity by occurring during arousal or orgasm (Mitchel, Jain, Laze, & Lepor, 2011). A recent study by Mitchell et al. (2011) found that 44% of men that had undergone a prostatectomy reported bother from incontinence specifically during sexual activity at 3 months post-surgery. Nilsson et al. (2011) explored orgasm-associated urinary incontinence in a large sample of men treated for prostate cancer by surgery and found 21% of men had experienced this type of incontinence in the past 6 months. Further, out of those men who were sexually active, those experiencing orgasm-associated incontinence were more likely to experience depressive and anxious symptoms and lowered sexual esteem.

Treatment of incontinence after surgery includes making lifestyle changes, use of physiotherapy including pelvic floor exercises and biofeedback, medication, and sometimes operative procedures (Bauer et al., 2009). Psycho-education and CBT based strategies are likely to assist men with anxiety associated with urinary dysfunction, especially around hypervigilance to bodily signals and social interactions, which is likely to also influence sexual function, and to assist with coping with uncertainty about the future.

Sexuality, Prostate Cancer and its Treatment

The physiology of erectile function plays an integral role in sexual behaviour (Beck et al., 2009). The alteration in sexual response for men after prostate cancer treatment means that the movement from desire to arousal within the excitement
phase is impacted as a result of physiological changes preventing erections (Wittmann, Northouse et al., 2009b). There may also be further physiological changes related to ejaculation and penile length. A recent study by Parekh et al. (2013) that a small percentage of men reported a reduction in penis size following prostate cancer treatment. Importantly these changes were found to be related to difficulties with close relationships and regretting cancer treatment type (Parekh et al., 2013). Radiation therapy can result in a reduction of ejaculation fluid which may even result in dry orgasms (King, 2010).

Just because a man’s ability to have an erection has diminished, it does not necessarily mean that other aspects of sexuality need to be impacted. For example, a man can still have an orgasm (dry orgasm) without an erection, and sexual desire and skin sensitivity remains (Schover, 1994). This is because the nerves are spared that provide transmission of sensations related to pleasure or orgasm (Schover et al., 1994).

Changes in sexual function after treatment for prostate cancer are considered to be multifactorial, including vascular, neurogenic and psychological factors (Dubbelman, Wildhagen, & Dohle, 2006). The changes in sexual desire, for example, evident in men treated for prostate cancer are complex and likely to be psychologically based, excluding the loss of desire associated with androgen deprivation therapy, which is related to hormone ablation (Wittman, Foley, & Balon 2011). Impact on other aspects of sexuality is likely to still occur for men treated for prostate cancer, either directly (through the impact on actual erectile function) or indirectly (e.g., from having cancer itself or relationship difficulties). Jakobsson, Lovén, and Hallberg (2001) suggested that psychological and somatic stress from surgery and other prostate cancer treatments could lead to a reduction in sexual desire and ability to perform.
Beyond erectile function, sexuality encompasses gender identity, sexual orientation, desire, intimacy, and reproductive processes, and expression of sexuality may occur through thoughts, attitudes, activities, roles and relationships (Knight & Latini, 2009; Wilmoth, 2006). More specifically, sexual functioning involves not only erectile function (quality and quantity), but sexual satisfaction, and interest or desire for sex (Boehmer & Clark, 2001; Schover, 1993). The impact of prostate cancer and its treatment on broader aspects of sexuality is considered below.

Sexual satisfaction, desire and orgasm function. Sexual satisfaction and erectile function are thought to be highly correlated (Nelson, Choi, Mulhall, & Roth, 2007). Nelson et al. (2007) conducted a cross-sectional study with 352 prostate cancer survivors and found that men reported low sexual satisfaction. The sample consisted of men treated for prostate cancer by a range of treatments. Although sexual satisfaction was reported to be lowered, no control group was used in this study. Nelson et al. also found erectile functioning, relationship closeness, and psychological distress (anxiety and depression) predicted sexual satisfaction in their sample of men with prostate cancer, the majority of whom had received a range of treatments. Therefore, it appears that treatment type, erectile functioning and psychological distress may contribute to a man’s sexual satisfaction in a complex interrelated process. Targeting all these areas may increase a man’s level of sexual satisfaction, whether or not he can have an erection.

In Schover et al.’s (2002a) outcome study, sexual satisfaction as measured on the International Index of Erectile Function (IIEF), was found to be significantly lower among men with prostate cancer, treated by radiotherapy or prostatectomy, compared to men from a normative sample with mixed types of ED. Jakobsson et al. (2001) used a cross-sectional design and compared pre-treatment and post-treatment satisfaction with sex life in 155 men treated for prostate cancer to 129 men from the
general population. While 12.4% of the general population reported they were “not at all” satisfied with their sex life in the general population, the response of men with prostate cancer to this question increased from 5.2% pre-treatment to 56.1% post-treatment.

Dahn et al. (2004) explored the relationships between sexual functioning, sexual desire and general QoL in a sample of men treated for prostate cancer, and found that both sexual function and sexual desire were necessary for optimal QoL. In Schover et al.’s (2002a) study, 45% of men treated for prostate cancer reported low sexual desire in the last 6 months, and 65% reported problems with achieving orgasm. Jakobsson et al. (2001) also found lower rates of sexual desire and pleasure among men treated for prostate cancer compared to the general population. While only 2.3% of the general population cohort reported never experiencing desire or pleasure, 43.2% of men post-treatment for prostate cancer reported never experiencing desire, and 29.7% never experiencing pleasure. Le et al. (2010) found that sexual desire out of several domains of sexual function declined by the least amount over time, suggesting that some level of desire remains intact compared to other sexual changes.

Changes in desire and orgasm have also been reported prospectively. In Jayadevappa et al.’s (2005) prospective study covered earlier, men treated for prostate cancer also reported poor sexual desire, and only 53% reported an ability to achieve orgasm compared to 79% prior to treatment.

These findings highlight that although ED is the most prevalent form of sexual dysfunction in men treated for prostate cancer, there are other areas of sexual functioning within the normal sexual response cycle that may be impacted.

**Sexual bother and distress.** The severity of reported symptoms of ED is not the same as the degree of symptom related bother (Gacci et al., 2009). Sexual bother
therefore refers to the degree of interference and impact of changes in sexual function. Gore et al. (2010) found that the relationship between sexual function and bother was weak in a sample of men treated for prostate cancer, highlighting the importance of separating these variables. Sexual bother is thought to encompass feelings of shame, embarrassment and may negatively impact general QoL (Nelson, Deveci, Stasi, Scardino, & Mulhall, 2010).

Research also suggests that ED causes more bother and distress than other side effects from treatment. For example, in a sample of 1,291 men who underwent surgery, only 8.7% were bothered by a lack of urinary control compared to 41.9% bothered by changes to sexual function (Stanford et al., 2000). Other research has found high rates of sexual bother. Litwin et al. (1995) found that 78% of men treated for prostate cancer, who had poor or very poor sexual function, viewed it as a “big problem”. Similarly, from a large sample of men who underwent surgery or radiation therapy, 61% reporting having been distressed by their ED (Schover et al., 2002a). In this study, 60% reporting distress related to desire issues and 64% distress in relation to orgasm difficulties (Schover et al., 2002a). Potosky et al.’s (2004) outcome study of men treated for prostate cancer, also broke sexual bother down into bother about several areas including lack of sexual interest, lack of sexual enjoyment, orgasm difficulty, and erectile difficulties. There was no significant difference between those who underwent surgery and radiation for sexual bother scores, and around 41%-63% of men were bothered by each of these domains. Steinsvik et al. (2012) found that one year post-prostatectomy 66% of men reported high sexual bother and that being sexually active pre-operatively was associated with greater bother.

Variability in levels of sexual bother has also been investigated across time. In Penson et al.’s (2005) five year outcomes study for men who underwent radical prostatectomy the level of perceived bother of sexual function declined over time,
however, 46% were still bothered by changes in sexual function at 60 months post-diagnosis. In Jayadevappa et al.’s (2005) prospective study, sexual bother peaked at 3 months, and began to improve at 24 months. However, the men remained statistically more bothered at 24 months compared to prior to treatment. Interestingly, in a recent study using a sample of men surgically treated for prostate cancer, even men with good erections post-operatively were found to have high sexual bother scores which remained stable from 12 to 24 months post-surgery (Nelson et al., 2010). This finding is important as it suggests that men may not adjust to changes in sexual function, even when erections improve. Similarly, Parker, Wang, He, and Wood (2011) found that sexual bother persisted across several time points (up to 60 months) post-surgery for localised prostate cancer. In this sample sexual function scores returned towards baseline in less time than sexual bother, providing further evidence that men struggle to adjust to the loss, even when some function returns.

**Sexual quality of life.** This chapter has covered changes as a result of prostate cancer and its treatment to erectile function, more broadly sexual function, and the degree of bother or distress associated with symptoms. Clark et al. (2003) suggested that the degree of symptom severity and associated bother does not encompass aspects such as sexual intimacy, sexual confidence, affection and masculinity. These are considered important facets of sexuality impacting a man, his partner and the relationship.

Bokhour et al., (2001) conducted a series of focus groups with prostate cancer survivors investigating the psychosocial issues surrounding sexual dysfunction. Results found that men spoke little of the mechanics of ED and focused instead on the wide reaching psychosocial impact on areas such as social relationships, including sexual intimacy in romantic relationships, sexual self-concept, difficulty engaging with a partner sexually, and ways in which they saw themselves as men.
One way to conceptualise the impact ED, as a result of prostate cancer and its treatment, has on men’s sexuality and sexual intimacy, is to acknowledge the potential threat ED has on a man’s sense of masculinity (Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002; Wootten, 2010). Hegemonic masculinity is used to describe the idealised form of masculinity within a given culture and time, encompassing characteristics such as independence, competence and virility (Gray et al., 2002). In a western culture, hegemonic masculinity is focused on the penis, specifically the size and associated performance, and this is considered an important factor determining one’s level of masculinity (Beck et al., 2009; Gray et al., 2002). Performance is favoured over emotional connections, which may limit the ways in which a man can express his sexuality (Brubaker & Johnson, 2008).

Both a prostate cancer diagnosis and its treatment can influence a man’s sense of identity and masculinity. Firstly, cancer itself can lead a man to be less independent in caring for himself, and secondly ED can directly impact on a man’s sense of masculinity (Beck et al., 2009; Conwell, Caine, & Olsen, 1990). An Australian qualitative study found that some men reported that changes to their bodies from surgery, weight gain, and genital appearance were difficult to adjust to and could impact a man’s sense of masculinity (O’Shaughnessy & Laws, 2009). In the face of prostate cancer, Helgeson and Lepore (2004) described how a man must adjust from the “healthy self” to the “chronically ill self” and that identification with male gender roles of control, independence and emotional inhibition may influence how one adjusts.

In terms of ED specifically, being able to have penetrative sex may be viewed as an essential part of sex and sexuality (Arrington, 2008) and of being a man (Fergus et al., 2002). If sexual performance and masculinity are greatly entwined, ED may serve as a major disruption to a man’s masculinity (Fergus et al., 2002).
Research has found that masculinity concerns are important factors at both pre-treatment and post-treatment time points for prostate cancer. Using semi-structured interviews with men prior to treatment for prostate cancer, men saw erectile function as an important dimension of their masculine identity (Boehmer & Babayan, 2004). Similarly, when using focus groups consisting of men who had undergone treatment for prostate cancer, Boehmer and Clark (2001) found that lack of sexual functioning threatened their masculinity, which impacted on a man’s relationships, his fantasy life, and their view of themselves as men, impacting both general and sexual confidence.

Consistent with the changes seen in men treated for prostate cancer across several domains of sexual function, Wittman et al. (2011) suggested that the loss men experienced may be related to desire, arousal or orgasm and that the consequence of such loss and changes to masculinity can be huge for some men. Motivation to engage in sexual activity may be impacted and avoidance behaviours related to anxiety can become prevalent, further complicating sexual function (Messaoudi, Menard, Ripert, Parquet, & Staeman, 2011; Wittman et al., 2011). In fact, when a man’s sexual capacity is no longer in line with his gender identity he may completely avoid any sexual activity (Fergus et al., 2002).

A man’s degree of conformity to masculine norms or scripts may determine how well he adjusts to ED. Successful adaption to erectile changes and associated sexual relationship changes may require a man to restructure his current definition of masculinity and broaden his understanding of sexuality to a much larger concept than erectile functioning (Fergus et al., 2002; Gray et al., 2002; Wittmann, Northouse et al., 2009). In achieving this restructuring, men may need to be reminded that sexual feelings, penile sensitivity, orgasm function and intimacy are still available (Wittmann, Northouse et al., 2009), and a loss of erectile functioning does not
necessarily need to result in a complete loss of enjoyment of sex and sexual intimacy (Schover, 1994).

Apart from qualitative research, research evaluating changes to masculinity related factors in the context of prostate cancer has only begun to be explored in recent years. Messaoudi et al. (2011) found that 61.9% of men reported loss of masculine identity in a sample of men who had predominately undergone surgery for prostate cancer. The impact on masculine identity was rated as overwhelming by 25.6% of men and partially overwhelming by 74.4%. Messaoudi et al. (2011) also found that 38.1% reported a loss of self-esteem. The measure used to assess masculine identity was one item from a questionnaire designed by the researchers, “Do you feel a loss of masculine identity since your operation?”

Clark et al. (2003) developed a QoL scale (Prostate Cancer-Related Quality of Life Scale) to address the gaps in the literature which fail to acknowledge and assess the emotional, behavioural and interpersonal dimensions of men’s experiences to prostate cancer and its treatment, including sexual intimacy, sexual confidence, and masculine self-esteem subscale. Clark et al. evaluated the scale on a sample of men predominately treated for prostate cancer with comparison group and found significantly poorer QoL across these sexuality variables.

Thornton, Perez, Oh, and Crocitto (2011) explored several dimensions of sexuality in a cohort of men treated for localised prostate cancer by prostatectomy, using Clark et al.’s (2003) QoL subscales of sexual intimacy, sexual confidence and masculine self-esteem. Thornton et al. (2011) found that sexual intimacy, sexual confidence and masculine self-esteem all decreased from pre-surgery to post-surgery time points. Using the same masculinity scale and a sample of men treated for prostate cancer on average 8.1 months prior, Zaider, Manne, Nelson, Mulhall and Kissane (2012) found that 30%-37% of men reported a loss of masculinity. Zaider et
al. found that the measure of masculinity was the strongest predictor of sexual bother out of other measures of sexual functioning including ED, desire and intercourse satisfaction. Importantly, the authors highlight the potential bi-directional relationship between masculinity and sexual bother.

While these studies demonstrate the importance of measuring masculinity and self-esteem changes in the context of prostate cancer, further research is needed using controls groups and follow-up time points.

**Summary and Treatment Implications**

ED is highly prevalent in men treated for prostate cancer, with rates ranging across studies, which is likely to be due to inclusion and exclusion criteria of men. Even though erections may return, many men experience ongoing erectile difficulties up to 4 to 5 years post-treatment (Penson et al., 2005; Schover et al., 2002a).

Although documenting the prevalence of the actual ability to have an erection is important, research suggests other aspects of sexual functioning may be affected by prostate cancer and its treatment, including sexual interest, sexual satisfaction, sexual desire, orgasm function, and sexual intimacy. Recognition of the importance of measuring and exploring these areas of sexuality is a result of an increasing awareness of the multi-dimensional nature of sexuality. Even more recent research has begun to acknowledge the psychosocial impact of changes to sexual function by exploring the role of factors such as sexual intimacy, masculinity, sexual confidence and motivation.

In terms of treatment it is clear that a holistic approach to sexuality is more appropriate and beneficial for sexual rehabilitation and assisting with the bother and distress associated with changes to sexual function. Implications for treatment also come from research which considers masculinity issues. Men may benefit from
assistance with grieving the loss of erectile functioning and spontaneity (Wittmann, Northouse et al., 2009), followed by psycho-education and open discussions about ways to express and fulfil sexual needs beyond intercourse (Oliffe, 2005).

Addressing urinary dysfunction may also assist men’s sexual functioning.

This chapter has explored how prostate cancer impacts on a man’s erectile function, his broader sexual function, and how this may impact on a man’s sense of self and his confidence. Both prostate cancer itself and the impact of treatment (sexual and otherwise) may have an influence on relationships and general psychological health. Focus group research suggests that in re-evaluating their sexual functioning, men need to explore how this relates to intimacy and their relationship (Bokhour et al., 2001). This suggests that a man’s partner and the dyadic relationship play a significant role in successful adaption to ED. This will be addressed in Chapter 4. The use of medical aids for ED will be covered in Chapter 6.

Psychological functioning and prostate cancer will be covered in the next chapter.
Chapter 3: Psychological Functioning and Prostate Cancer

Psychological implications of cancer have been well documented. A cancer diagnosis requires a patient, their partner and family to adjust to everything that a cancer diagnosis brings, including uncertainty about the future (Edwards & Clarke, 2004). Depression and anxiety have been previously viewed to be the most significant psychological comorbidity for cancer patients (Frick, Tyroller, & Panzer, 2007). This chapter discusses the rates of psychological distress in samples of men with prostate cancer, considers aetiological factors, explores the impact of psychological distress, and the implications for psychosocial treatment.

Psychological Distress and Prostate Cancer and its Treatment

Research exploring QoL of men with prostate cancer has been criticised for frequently focusing on the physical impact of prostate cancer and its treatment (e.g., sexual, urinary and other physical symptoms), while often ignoring psychological symptoms (Eller et al., 2006; Monahan et al., 2007). However, research investigating the impact of prostate cancer and its treatment on psychological well-being has increased over the last decade.

Several studies report levels of psychological distress, anxiety and depression, in a variety of prostate cancer samples using a range of scales evaluating levels of depressive and anxiety symptoms (e.g., Hospital Anxiety and Depression Scale-HADS; Brief Symptom Inventory – BSI). These studies have found rates of psychological distress in men with prostate cancer ranging from 17% - 38% (Balderson & Towell, 2003; Cliff & MacDonagh., 2000; Couper et al., 2006; Hervouet et al., 2005; Roth et al., 1998; Sharpley, Bitsika, & Cristie, 2009). Within the same studies, sample rates of anxiety tend to be higher than depressive symptoms (Bisson et al., 2002; Cliff & MacDonagh, 2000; Hervouet et al.; 2005; Roth et al.,
1998) and one study using a large sample found depression and anxiety comorbidity to be 16% (Sharpley, Bitsika & Christie, 2010). Research has found traumatic stress symptoms to be elevated in a sample of newly diagnosed men with prostate cancer (Bisson et al., 2002).

Elevated rates of psychological disorders according to the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, American Psychiatric Association, 2002) criteria or by clinical interview have also been found in men with prostate cancer. Couper et al. (2006) found rates of major depression to be almost twice that of previously reported general population rates (5.6% versus 3.0%). Pirl, Greer, Goode, and Smith (2002) found high rates of major depressive disorder for men receiving ADT for prostate cancer (12.8%). Roth et al. (1998) found that 47.1% of men who were above a specified cut-off point of distress on the HADS were consequently diagnosed by a psychiatrist with a psychological disorder based on the DSM-IV criteria. However, a significant proportion of Roth et al.’s sample had sub-clinical levels of depression, highlighting the importance of using different screening methods to identify psychological distress. Love et al. (2008) compared rates of psychiatric disorders across men recently diagnosed with early prostate cancer, advanced prostate cancer and a comparison group within the same study. Love et al. found little difference between the three groups; however, anxiety disorders were slightly higher in the prostate cancer groups.

Elevated levels of distress may have important implications. Suicide rates have been found to be elevated in older men with prostate cancer in population based samples (Bill-Axelson et al., 2010; Fang et al., 2010; Llorente et al., 2005). Llorente et al. (2005) reported that men with prostate cancer were over four times more likely to commit suicide than an age and gender matched cohort. A diagnosis of depression during the treatment phase for prostate cancer was found to be correlated with an
increased risk of death during later follow-up periods for men over 65 years (Jayadevappa, Malkowicz, Chhatre, Johnson, & Gallo, 2011).

Many studies reporting rates of psychological distress and psychological disorders frequently include samples of men with a variety of stages of disease, receiving different treatments for prostate cancer, and collecting data collected at different time points from diagnosis and treatment. Some researchers explored these factors in their analyses.

In relation to disease stage, Couper et al.’s (2006) sample consisted of men with both localised and metastatic disease, and contrary to expectations found no significant difference in levels of psychological distress associated with the level of disease. Similarly, Pirl et al. (2002) found no difference in levels of depression when comparing “stable” versus “progressive” disease stage.

In terms of treatment type, Hervouet et al. (2005) explored the rates of psychological difficulties in men treated for prostate cancer by radiotherapy, brachytherapy, and radical prostatectomy in 861 men who had been diagnosed within the past seven years. Rates of anxiety and depression were higher for men who underwent radiotherapy; however, the authors suggested that although statistically significant, the effect size was small. In a prospective study of men with prostate cancer, final treatment choice was found to be unrelated to psychological distress (Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2004). Couper et al. (2009) compared men who had radical prostatectomy, hormone therapy, other treatment (including radiation) or watchful waiting and found that those who underwent treatment for prostate cancer were more likely to experience symptoms of anxiety and depression at the time of diagnosis and treatment and 12 months later compared to those who opted for watchful waiting. However, only the hormone therapy group
had significantly greater levels of psychological distress than the watchful waiting group.

The samples in these studies varied greatly in terms of the time since diagnosis and/or treatment, both between studies and within studies. Bission et al. (2002) found that a sample of newly diagnosed men with localised prostate cancer, prior to treatment, only experienced mildly evaluated levels of psychological distress, suggesting that treatment for prostate cancer may be associated with increased psychological distress levels. Couper et al. (2006) found that psychological distress increased from the diagnosis point to 6 months post-diagnosis using a sample of men at different stages of disease and who had different treatments. Couper et al. (2006) found rates of psychiatric caseness (meeting criteria for a diagnosable psychiatric disorder) were 10% at the time of diagnosis and 15% at 6 months post-diagnosis.

Others have found that time since diagnosis was not related to anxiety and depression (Heurovet et al., 2005), however average time since diagnosis and treatment was quite long (30 months) and in a large sample of men diagnosed and treated for prostate cancer in the last one to eight years, depressive symptoms were not found to have lasting impacts on these men (Blank & Bellizzi, 2006). Similarly, Steginga et al. (2004) found that levels of psychological distress decreased from the time around diagnosis of localised prostate cancer to when men were surveyed again between 2 and 12 months post-treatment. These studies suggest that time from treatment for prostate cancer either has no impact or results in a decrease in symptoms.

Korfage, Essink-Bot, Janssens, Schroder and de Koning (2006) conducted a prospective, longitudinal study with 299 men treated for localised prostate cancer by surgery or radiation, measuring anxiety and depression at pretreatment (approximately 1 month), and 6 months, 12 months and 5 years follow up. At 6
months after treatment, levels of anxiety and depressive symptoms significantly improved and remained at longer term follow-ups. The authors in these studies suggest that most men show resilience to psychological distress in the face of prostate cancer and its treatment. However Korfage et al. (2006) did find that levels of anxiety and depression were elevated in comparison to the general population at baseline and emphasised that it was important for clinicians to identify a sub-group of men likely to continue to experience clinical levels of anxiety and depression.

**Factors that Influence Psychological Functioning in Men with Prostate Cancer**

There are many emotional and practical challenges associated with a diagnosis of cancer, including coping with the life threatening nature of the illness (Darst, 2007; Manne et al., 2010), which may impact on a man’s mental health. For prostate cancer there are specific challenges that explain the higher rates of psychological distress, and these can occur at different stages of the cancer journey. Men with prostate cancer often have the added distress of making difficult treatment choices when considering the potential impact of side effects, effectively being forced to make trade-offs between various levels of side effects and benefits from different treatments (Anandadas, Clarke et al., 2011).

Sharpley et al. (2009) highlighted that the withdrawal from unpleasant experiences related to diagnosis and treatment for prostate cancer, and losses related to changes in sexual function, fits a framework for psychological distress, particularly depression. Using an Australian sample, Sharpley et al. surveyed 150 men treated for localised prostate cancer and found significant links between depressive symptoms and the losses inherent in side effects of prostate cancer treatment. Some of the most common losses experienced by men in this survey were related to sexual function (ability and desire), disappointment, fatigue, memory
difficulties, sleeping problems, bowel changes, and inability to exercise as previously. Greater number of lifestyle changes and losses experienced were associated with greater levels of clinical anxiety and depression.

The side effects of prostate cancer treatment resulting in a functional loss (especially ED and urinary dysfunction) may be particularly challenging and pose a threat to a man’s psychological well-being and be associated with anxiety and depression (Manne et al., 2010; Sharpley et al., 2009). Research has investigated the relationship between psychological distress and erectile functioning, as well as sexual bother and sexual satisfaction. Using a sample of 70 men treated for prostate cancer by radiation therapy, Howlett et al. (2010) found that men without sexual problems before and after radiation therapy reported lower levels of anxiety and depression compared to men with sexual problems. Wootten, Burney, Foroudi et al. (2007) found that for those men treated for prostate cancer who demonstrated ongoing psychological difficulties, sexual bother was found to be a main variable associated with mood disturbance. Similarly, Nelson et al. (2010) found that poorer erectile function was associated with higher rates and severity of depressive symptoms in sample of men treated for prostate cancer. Finally, anxiety and depression rates have been found to be correlated with sexual satisfaction in a sample of men predominately treated for prostate cancer (Nelson et al., 2007).

The relationship between depression and anxiety, and sexual functioning is considered bi-directional, where psychological distress has also been implicated in the aetiology and maintenance of sexual difficulties (Althof et al., 2005). Sexual functioning may be impacted even before treatment of prostate cancer, as the fears, worries and stress associated with both the diagnosis and decision making may increase levels of psychological distress (Darst, 2007; Galbraith & Crighton, 2008; Schover, 1993). Post-treatment, the psychological and somatic stress as a result of
treatment may contribute to a reduction of sexual functioning, including sexual desire and potency (Jakobsson et al., 2001). Further, the process of dealing with the possibility of death and cancer recurrence and the psychological impact of the cancer itself are also likely to impact on a patient’s sexual functioning (Weber & Shervill-Navarro, 2005). Nelson et al. (2007) have commented that addressing psychological distress may be important when providing therapeutic assistance to men and couples to improve sexual functioning.

Other individual factors have been implicated in psychological distress and prostate cancer. Higher levels of psychological distress have been related to younger age (Bisson et al., 2002), pre-existing psychological symptoms (Pirl et al., 2002; Nordin et al., 2001), living in a rural location (Corboy, McLaren, & McDonald, 2011), lower levels of social support (Nelson, Mulhall, & Roth, 2009) and use of maladaptive coping styles (Blank & Bellizzi, 2006). In terms of factors buffering against depression, Sharpley, Wooten, Bitsika, and Christie (2013) found that psychological resilience, especially “confidence to cope with change”, was associated with lower levels of depression over time.

Research suggests that fear of cancer recurrence may also have an impact on psychological functioning. Fear of recurrence has been related to mental health related QoL in a mixed cancer sample (Crist & Grunfeld, 2012). The perceived lack of control and uncertainty related to a cancer diagnosis may also contribute to psychological distress (Cunningham, Lockwood, Cunningham, 1991). Even when in remission, men often undergo frequent PSA testing which is likely to provoke fear and anxiety especially when PSA levels are unstable (Chism & Kunkel, 2009; Roth et al., 2006). Changing PSA levels may lead to the need for further treatment which may increase psychological distress.
Treatment Implications

Depression and level of perceived stress contribute to the QoL of men with prostate cancer. Depressive symptoms have been found to be the strongest predictor of physical, emotional and functional well-being in a sample of men treated for prostate cancer (Eller et al., 2006). Depressive symptoms measured at 4 weeks post localised prostate cancer treatment have been found to predict a large number of disease specific and general QoL outcomes 4 months, 7 months, and 12 months post-treatment (Monahan et al., 2007). Not surprisingly, depression in men with prostate cancer has also been found to increase health resource utilisation (Jayadevappa et al., 2011).

Evaluation of psychological distress, and the use of strategies to treat depression and anxiety, may be of use if incorporated into a comprehensive psychological treatment program for prostate cancer survivors. Changes in psychological function as a result of the losses and changes in function and lifestyle inherent in prostate cancer and its treatment may be in part a normal and adaptive response rather being pathological (Sharpley et al. 2009). Men may benefit from assistance in managing their loss of function (e.g., sexual function) in reducing psychological distress (Sharpley et al., 2009). In addition, addressing the uncertainty associated with the future of having prostate cancer should also be targeted when aiming to prevent and decrease rates of psychological distress.

Kiss & Meryn (2001) suggested that psychological distress is too frequently ignored due to a belief that it is a normal response to having cancer. For some men, directly targeting psychological functioning may be of benefit, since for some men, distress, depression, and anxiety may be transient and decrease over time, while for others they may be sustained (Blank & Bellizzi, 2006). In addition, Roth et al. (1998) suggested that the use of educational and supportive type interventions as a
preventative measure to reduce distress and prevent development of psychological disorders.

Summary

Psychological implications of prostate cancer and its treatment are well documented. Some research has found that high rates of depression and anxiety have been found in samples of prostate cancer survivors, and there is some evidence that this has lasting effects. Mixed findings regarding the longer term psychological adjustment for men with prostate cancer highlight that potentially for some men distress improves over time, whereas for others it remains stable or increases. Adjusting to and managing some of the side effects of prostate cancer treatment, especially ED, is likely to influence a man’s psychological health. Several factors have been found and hypothesised to be implicated in the higher rates of psychological distress in men with prostate cancer and these factors should be integrated into psychosocial interventions. Such interventions should target both symptom management (e.g., sexual dysfunction) and psychological distress directly. Although rates of clinical depression are elevated in this population, lower sub-threshold levels of psychological distress in men are still likely to require psychological support and assistance, particularly as a preventative measure in protecting against the development of significant psychological distress including anxiety and depression.
Chapter 4: Relationship Functioning and the Role of the Partner

The patient and his partner are generally affected by the challenges of a cancer diagnosis together (Banthia et al., 2003; Galbraith & Crighton, 2008). In fact, prostate cancer has been referred to as the “relationship disease”, and the dyadic relationship is frequently framed as the “couple has cancer” (Badr & Taylor, 2009; Gray et al., 1999). This chapter outlines the theory and research relevant to relationship functioning, and the role of a partner with men who have prostate cancer. This section predominately focuses on men having a female partner. In this chapter, implications for psychosocial treatment for men with prostate cancer will also be evaluated. A core component of relationship functioning relates to intimacy. While sexual intimacy is covered in this section, the focus is on general intimacy which refers to the interpersonal process of expressing and responding to each other’s emotions within a relationship (Manne & Badr, 2008).

Relationship Functioning and Prostate Cancer

A cancer diagnosis can place significant strain on a relationship (Banthia et al., 2003; Galbraith & Crighton, 2008). A couple’s relationship may be impacted at various stages of the cancer journey, including at cancer diagnosis, when discussing and deciding on treatment options, when going through treatment, and when dealing with post-treatment side effects (Beck et al., 2009; Manne et al., 2010). Manne et al. (2010) found that how a couple manages the concerns regarding cancer recurrence and progression, as well as personal and relationship needs, can impact on relationship functioning, in particular, relationship intimacy.

At the same time, the nature of relationship functioning prior to diagnosis can impact on how the disease and side effects are managed and coped with. One of the most important influences the spousal relationship has on the reaction to the
introduction of cancer is social support (Banthia et al., 2003). A strong and
supportive relationship dyad can act as a buffer against distress (Banthia et al., 2003;
Maliski, Heilemann, & McCorkle, 2001) and the negative effects of sexual
dysfunction (Badr & Taylor, 2009) for both members of a couple.

On the other hand, the degree of social support given to a patient from his
spouse can be greatly reduced in a relationship which is under conflict and strain
(Banthia et al., 2003). A recent study by Zaider et al. (2012) actually found that the
diminishing relationship between sexual bother and masculinity was stronger for
those reporting lower marital affection. In terms of relationship satisfaction, Couper
et al. (2006) found that level of relationship satisfaction was different between
patients treated for prostate cancer and partners at 6 months post-diagnosis, with
partners displaying lower relationship satisfaction, while there was not difference at
time of diagnosis. This suggests that a couple’s relationship is negatively impacted
by prostate cancer and its treatment, and this may be experienced differently by each
member of the couple.

In addition, the level of support offered by a partner may be influenced by the
negative impact prostate cancer can have on the partner. For example, higher rates of
psychological distress have been found in partners of men diagnosed with prostate
cancer, with one study reporting partners’ levels of major depression as twice that of
a community sample (Couper et al., 2006). Levels of psychological distress have also
been reported to be higher in partners than men (Cliff & MacDonagh, 2000; Couper
et al., 2006). However, Ezer, Chachamovick, and Chachamovich (2011) found that
men were more emotionally distressed than spouses at pre- and post-prostate cancer
treatment and Eton, Lepore, and Helgeson (2005) found that there was no difference
between men and partners on a measure of depression. Eton et al. (2005) found that
while partners reported more distress than patients, this only applied to cancer-
specific distress and there was no difference between men and partners on depressive symptoms. These differences could be in part because the samples used in these studies varied greatly in terms of time since diagnosis and treatment and the type of prostate cancer.

The Partner, the Relationship, and Sexual Functioning

While a cancer diagnosis alone is stressful and may impact on relationship functioning, the side effects of prostate cancer treatment, such as incontinence and ED, may also have a direct impact on a couple’s relationship (Gray et al., 1999). ED, and its potential impact on sexual functioning and sexual intimacy, may in turn lead to severe disruption of the couple’s relationship in other areas (Beck et al., 2009; Giesler et al., 2005). This is why ED is often referred to as a shared problem for couples, as the side effects impact on the man, his partner, and the dyadic relationship. Not surprisingly, clinical research has found that sexual dysfunctions in either sex can be both a cause and a result of relationship problems (Althof et al., 2005). This may be particularly the case when many men react to ED by retreating from all physical contact or sexual intimacy, including touching, hugging and kissing, if intercourse is not possible (Boehmer & Clark, 2001; Galbraith & Crighton, 2008).

Research using interviews and focus groups has found that both members of a couple are concerned about how the loss of erectile function, and how the man’s ability to cope with this will influence the relationship (Boehmer & Babayan, 2004). Indeed relationship quality has been found to be correlated with sexual satisfaction in a sample of men predominately treated for prostate cancer (Nelson et al., 2007). However, research has found differences in the emphasis men and women in a relationship place on the importance of the loss of erectile functioning. Men have
been found to be more distressed than their partners across sexual relationship and sexual adjustment domains of functioning, which may threaten their identity (Ezer et al., 2011).

On the other hand, women have been found to place more importance on prolonging their partner’s life over maintaining sexual function (Boehmer & Clark, 2001; Petry et al., 2004), and to be less concerned with their partner’s actual sexual function compared to how their partner would cope with these changes and how these problems would impact on intimacy and relationship quality (Boehmer & Babayan, 2004; Petry et al., 2004). Women do not appear to be as focused on the necessity of an erection for sexual pleasure and satisfaction (Neese, Schover, Klein, Zippe & Kupelian, 2003; Wittmann, Northouse et al., 2009) and to be more focused on other dimensions of a relationship, such as companionship (Boehmer and Babayan’s, 2004).

Other research has found that female partners are concerned about the direct impact ED may have on their sexual relationship (Neese et al., 2003; Sanders, Pedro, Bantum, & Galbraith, 2006). Neese et al.’s (2003) focus group study with 164 female partners of prostate cancer survivors found that 38% were dissatisfied with their sex life and many were found to believe that seeking help for a sexual problem would be beneficial and should be a mutual decision (Neese et al., 2003). This suggests that while many women are supportive of their partners during cancer and its treatment, women are significantly impacted by the changes in their partner’s sexuality.

However, Neese et al. (2003) found that many female partners admitted to having no interest in getting help for sexual problems, and suggested that both the stress of the prostate cancer and the negative impact a man’s ED has had on the couple’s sexual relationship, may contribute to a partner’s loss in sexual desire and interest. Not surprisingly, female sexual dysfunction can be a further complicating
factor in sexual rehabilitation for men (Badr & Taylor, 2009; Schover et al., 2002a; Wittman, Montie, Hamstra, Sandler, & Wood Jr, 2009; Wittmann, Northouse et al., 2009). Partners’ sexual problems, often related to postmenopausal difficulties, can further contribute to a difficult time in adjusting to the changes of male sexual functioning, often provoking joint anxiety surrounding sexually pleasuring each other (Wittmann, Northouse et al., 2009). Hence, incorporating sexual therapy that aims to improve female sexual function may impact on sexual functioning for the male and the overall relationship. Research has also found that having a partner who still enjoyed and wanted sex was as an important factor in improving sexual rehabilitation outcomes (Schover et al., 2002b).

**Communication and Relationship Functioning**

A couple’s communication is thought to be especially affected by prostate cancer and its treatment, and poor communication by either partner can lead to misunderstandings (Galbraith & Crighton, 2008). Specifically, couples may not openly discuss their concerns regarding sexual dysfunction (Galbraith & Crighton, 2008), or the possibility of the man’s life being under threat (Manne et al., 2010). The Relationship Intimacy Model of Cancer (Manne & Badr, 2008) suggests communication can either be defined as relationship enhancing or relationship compromising. Relationship enhancing communication has a positive effect on the relationship functioning by improving aspects such as closeness, self-disclosure of cancer-related concerns and associated emotions. This model suggests that improving relationship communication may influence a couple’s psychological distress and adaption by its impact on relationship intimacy. On the other hand, relationship compromising communication and behaviour, for example, withholding
concerns and avoiding discussions, can reduce the level of relationship intimacy (Manne & Badr, 2008).

Research on men with prostate cancer and their partners has found couples struggle to disclose some information to each other and may use avoidant coping styles in discussing cancer related concerns and worries (Lavery & Clarke, 1999). Specifically, men have been found to have difficulty discussing physical changes, including erectile functioning, while women showed hesitation in sharing their emotional reactions to cancer and discussing their concerns (Boehmer & Clark, 2001). Research with couples has also found mutual avoidance communication style was associated with higher marital distress (Badr & Taylor, 2009).

In relation to ED, open sexual communication is considered imperative to the adjustment to sexual functioning changes after prostate cancer treatment (Incrocci, 2006b). Garos, Kluck, and Aronoff (2007) found that men with prostate cancer reported less frequent communication around sexual difficulties in comparison to a sample without sexual problems. Mutually avoidant communication has been associated with poorer erectile function (Badr & Taylor, 2009) and to inhibit sexual pleasure and emotional intimacy (Darst, 2007). Such a lack of communication may mean that men simply assume women are unaffected by changes in erectile functioning and associated intimacy, and coping mechanisms of avoidance and resignation are employed rather than actually having conversations with their partners (Boehmer & Clark, 2001).

**Treatment Implications**

Given the importance partners have in providing support for a man surviving prostate cancer, as well as the role that effective communication plays in relationship functioning, researchers have highlighted the importance of including the patient’s
partner in psycho-educational and counselling sessions regarding ED (Berterö, 2001; Neese, et al., 2003; Schover et al., 2002b; Wittmann, Northouse et al., 2009).

However, in Australia, Chambers et al. (2008) suggested that current medical and support services are largely focused on patient outcomes and do not take into account a couple’s relationship, as well as overlooking the female partners’ needs.

Research from focus groups mentioned previously would suggest it is particularly important to include partners when differing needs and levels of distress are apparent and at different times across the cancer journey. Different reactions and experiences to prostate cancer and its treatment, including sexuality and psychological functioning, suggest that interventions need to be sensitive to this information. For example, in regards to sexual functioning, Ezer et al. (2011) suggested that interventions should allow men to adapt to the loss of sexual function while encouraging women to support their men by providing reassurance about their masculinity. In addition, information provision to the couple about how their sex lives can be improved is also important (Ezer et al., 2011).

Targeting communication style could be one means to help address these differences. The impact of communication style on relationship functioning and sexual functioning, suggests that therapy should aim to address both general and sexual communication skills. Improved communication, both general and sexual, may play a role in allowing different ways of expressing intimacy (both sexual and non-sexual), and as a result may assist to maintain a couple’s relationship and facilitate both partners’ adaptation in the face of sexual dysfunction (Badr & Taylor, 2008). Specifically, improving knowledge of sexuality and developing sexual communication skills may result in improved communication, sexual relations, and intimacy potentially beyond pre-cancer levels (Darst, 2007; Wittmann, Northouse et al., 2009). Alternatively, avoidance will inhibit any potential sexual pleasure and
emotional intimacy and couples may withdraw from each other (Darst, 2007; Incrocci, 2006b).

One way to improve couples’ communication is to develop skills using role plays, followed by discussion in a counselling session (Galbraith & Crighton, 2008). Homework assignments and spending time identifying problematic sexual and intimacy areas may facilitate improvements in dyadic communication (Galbraith & Crighton, 2008). Researchers have also cited the importance for psychosexual counselling to encourage and expand physical sexual contact to other forms of pleasure, since sexual desire and skin sensitivity remain unchanged post-treatment (Berterö, 2001; Schover, 1994).

To date there has been limited literature focusing on the outcomes and relationship functioning for homosexual and bisexual men. It has been emphasised that homosexual men may have differing needs in the face of ED and relationship disruption, and that consideration of sexual preferences may be necessary when considering psychological treatment for this cohort of men (Latini, Hart, Coon, Knight, 2009; Kleinmann et al., 2012). The program developed in this thesis was open to men of any sexual orientation, however given the past research focus on heterosexual relationships the content was more appropriate for heterosexual men.

Summary

The impact that prostate cancer and its treatment can have on relationship functioning, as well as the impact of prior relationship functioning on management of symptoms is complicated. However, it is apparent that prostate cancer and the impacts of treatment, especially on ED, can have a significant effect on relationship functioning. There is also evidence for conflicting needs and opinions between men and women in dealing with erectile and sexual problems within a relationship, and
couples may often avoid discussing the impact of prostate cancer on their emotions and relationship. For some couples, communication needs to be addressed before sexual dysfunction improves, and general communication may need to be targeted prior to sexual communication specifically (Wincaze & Carey, 2001). Even if erectile function returns, men may be left with psychological and relationship distress and disruption, as a result of the loss of sexual function not being adequately addressed. As such, the importance of including the partner, and addressing general and sexual communication skills in treatment and intervention programs has been highlighted by several authors (Berterö, 2001; Darst, 2007; Incrocci, 2006b; Neese et al., 2003; Schover et al., 2002b; Wittmann, Northouse et al., 2009).

This chapter provided an overview of the research on the impact prostate cancer and its treatment has on a man, his partner, and their relationship. In order to establish a psychosocial treatment program for men with prostate cancer, research suggests that inclusion of the partner may be beneficial. The previous three chapters looked at sexual, psychological, and relationship functioning in men with prostate cancer. The next chapter will explore and evaluate treatment programs that have addressed these areas.
Chapter 5: Treatments for Sexual Functioning, Relationship Functioning, and Psychological Functioning in Prostate Cancer Survivors

This chapter examines and evaluates past research targeting sexual, psychological, and relationship functioning in men who have been treated for prostate cancer. Initially, the chapter considers medical treatments for ED in men treated for prostate cancer. This is followed by an evaluation of psychosocial based interventions that have been developed and evaluated, focusing on sexual, psychological, and relationship functioning. The findings of these studies are summarised and limitations of the intervention programs are provided.

Medical Treatments for ED

Medical treatments for ED vary in their level of invasiveness and efficacy. The most common medical options include oral medications, vacuum constriction devices, intracavernosal injection therapy, and penile implant surgery. These aids are commonly used in men treated for prostate cancer. For example, Bergman, Gore, Penson, Kwan, and Litwin (2009) reported that from a sample of 425 men treated for localised prostate cancer, 56% of participants used some form of erectile aid within the 4 years post-treatment, even though none of the men in this selected sample used these aids prior to treatment for prostate cancer. Not surprisingly, those who were significantly bothered by their ED were more likely to use an aid. A much lower rate of 15% was found by Mols et al. (2009) in a sample of men 5-10 years post diagnosis who underwent a range of prostate cancer treatments. Schover et al. (2002b) found that 30% of their sample was currently using and 59% had tried at least one medical treatment for ED previously.

Oral medications provide phosphodiesterase type 5 (PDE5) inhibitors in an easily utilised tablet form and are one of the most common forms of drugs used to
treat ED generally, as well as in men suffering ED as a result of prostate cancer treatment. PDE5-inhibitors, such as sildenafil, more commonly known as Viagra, produce their effects by relaxing the smooth muscles of the penis and increasing blood flow to the penis (Darst, 2007). Although oral medications are often a preferred treatment choice as they are not as invasive as other treatments, they generally have limited success in treating men with prostate cancer (Schover et al., 2002b). Perhaps partly as a result of PDE5-inhibitors’ reduced effectiveness in ED caused by prostate cancer treatment, men may be less likely to continue using these drugs compared to men with ED from other causes (Schover et al., 2002b).

Rates of success for erectile aids tend to vary. After undergoing surgery, researchers have found positive responses to sildenafil in their samples to be 29% (Zagaja, Mhoon, Aikens, & Brendler, 2000) and 31% (Blander, Sanchez-Oritz, Wein, & Broderick, 2000). In a review of studies, Montorsi and McCullough (2005) also found a greater response rate for successful use of sildenafil for nerve-sparing surgery (35%-75%) versus non-nerve-sparing surgery (0%-15%). After radiation therapy, positive erection response rates have been found to be between 71% (Kedia, Zippe, Agarwal, Nelson, & Lakin, 1999) and 91% (Valicenti et al., 2001). However, post-radiation (and pre-sildenafil), potency was comparably higher in Valicenti et al.’s (2001) study compared to Kedia et al.’s (2001).

There are some proponents for the use of intracavernosal injections at regular time points aimed at preventing tissue damage and increase recover of spontaneous erections (Mulhall & Morgentaler, 2007). While there are some promising results for this method there have been calls for further research supporting its efficacy (Mulhall & Morgentaler, 2007).

More invasive treatments for ED include penile injection therapy and vacuum constriction devices. Penile injection therapy is often used when drug therapy is
unsuccessful (King, 2010). Caverject™ or other pharmacy mixed injection medications, drugs containing prostaglandins, are injected directly into the penis to create erections (King, 2010). Injection therapy has more positive results within the initial months after surgery compared to other treatments, as intact penile nerves are not essential (King, 2010). Vacuum devices consist of a cylinder which is placed over the penis, creating a vacuum which increases blood flow to the penis, allowing an erection to be maintained for up to 30 minutes (King, 2010). Vacuum devices have been suggested to be gaining in popularity recently as an attractive alternative to PDE-5 inhibitors which may be ineffective or produce unwanted side effects (Pahlajani, Raina, Jones, Ali, & Zippe, 2012). These devices may also be used in combination with PDE-5 inhibitors (Pahlajani et al., 2012). Pahlajani et al. (2012) state that although there may be high initial dropout rates for vacuum devices’ use, the proportion of men who are satisfied typically continue with this option for the long-term. Earlier research found that men displayed preferences for injections over vacuum devices (Soderdahl, Thrasher, & Hansberry, 1997). Fifty men were randomised to use penile injections or vacuum constriction devices, and 57% of men preferred penile injections compared to 27% preferring vacuum devices (Soderdahl et al., 1997).

Penile prosthesis (implants) are frequently used when a positive result from other ED treatments cannot be achieved (King, 2010; Wittmann, Montie et al., 2009). While the implant is highly likely to provide a firm erection, the surgery is invasive and not usually performed until 2 years post-radical prostatectomy (King, 2010; Wittmann, Montie et al., 2009). Penile prosthesis have been found to have a more positive impact on sexual functioning than drug therapy such as sildenafil and to also have the highest rates of satisfaction (Schover et al., 2002b). Schover et al. (2002b) found that only 16% of men reported that sildenafil greatly improved their sexual
functioning, whereas 44% reported that the penile prosthesis greatly improved their sexual functioning. Penile prosthesis may be particularly beneficial for those men for whom spontaneity of erections remains an important factor (Wittmann, Montie et al., 2009).

**Limitations of medical treatments.** Although there are several medical treatments available to treat ED, there are large variations in reported efficacy rates. In addition, some men display a reluctance to use these treatments and men may also have unrealistic expectations of the efficacy of medical aids (Neese et al., 2003; Schover et al., 2002b). Research suggests that men want firm erections by non-invasive means (Neese et al., 2003). Even though invasive treatments for ED have demonstrated greater efficacy, men appear more reluctant to utilise these treatments (Schover et al., 2002b), and find them difficult and not worthwhile (Neese et al., 2003). Common complaints from men who use medical aids and reasons for reluctance to use these treatments include disruption in the spontaneity of sex (Mishel et al., 2002; Wittmann, Northouse et al., 2009) and fear of needles (Titta, Tavolini, Dal Moro, Cisternino, & Bassi, 2005). In Schover et al.’s (2002b) study, while 59% of men had tried one or more medical treatments for their ED, only 38% of these men actually found it helpful in improving their sex lives. In Potosky et al.’s (2004) large outcome study of men treated for prostate cancer by surgery or radiation therapy, the use of medical interventions for ED were not significantly correlated with ED at five years after diagnosis.

Bergman et al. (2009) stated that given the generally higher rates of ED reported within prostate cancer samples compared to the rates of erectile aid use, this would suggests that there are a proportion of men who do not use erectile aids in the face of sexual changes after prostate cancer treatment. There may be some men who would prefer to improve their sexual function and sex lives by other means, either
exclusively or in conjunction with medical aids. Even if erectile function returns, with or without the assistance of medical aids, many men experience sexual and relationship distress and disruption, and changes in self-confidence (Beck et al., 2009; Boehmer & Babyan, 2004; Bokhour et al., 2001; Schover et al., 2002a). These factors suggest that targeting sexuality, relationship functioning and psychological functioning through psychosocial interventions may be of benefit in conjunction to medically based interventions. In addition, such interventions may have a direct positive impact on erectile function, sexual function and sexuality more broadly, relationship function and psychological function.

**Psychosocial Interventions Targeting Sexual, Psychological, and Relationship Functioning**

There are a growing number of intervention studies in the literature targeting sexual, psychological and/or relationship functioning in men treated for prostate cancer. Identification of relevant studies was through a literature search using electronic databases: Medline, PsychINFO, PsycARTICLES and Cinahl. A variety of keywords were used to access psychosocial interventions and patient outcome variables and these were used separately and in combination. Keywords used to search title and abstract included *prostate*, *AND random*, *AND psychosocial intervention OR psychological intervention OR psychosocial support OR psychological support OR psychotherapy OR *education OR *education OR counseling OR counseling OR rehabilitation OR social support OR behaviour*. Abstracts of identified records were screened for relevance according to the inclusion criteria (see below). Considering that not all abstracts highlighted the use of sexual, psychological and relationship functioning strategies, short-listed papers were retrieved in full and method sections were examined against these criteria. The
reference lists of relevant papers were screened for identification of additional relevant studies that may have been missed using the search strategy listed above.

Retrieved studies were included if they were randomised controlled trials using samples of men diagnosed for prostate cancer of any stage, making up at least 80% of the sample (multi-tumour site interventions were included). Studies were required to have a psychosocial intervention in at least one arm of the study design, which had at least one strategy explicitly designed to address sexual, psychological and/or intimate relationship functioning difficulties. Interventions focusing exclusively on men with advanced prostate cancer or men who had not been treated for prostate cancer (e.g., decision making interventions) were also excluded. Studies were not retained if they included partners but did not also target sexual, psychological or relationship functioning. Finally, studies were not retained if they targeted partners only.

Types of measures used by the interventions covered in this section vary, however the majority used some form of quality of life (QoL) measure which frequently addressed disease symptoms, psychological distress, self-concept, coping, social functioning, and overall adjustment to cancer. Outcomes for partners are specifically excluded as this is not a focus in this thesis. Table 1 summarises each of the interventions covered in this section, and only lists those measures that are relevant to sexual, psychological, and relationship functioning, which will be the focus of this thesis. In particular sexual functioning in terms of erectile function, sexual function, and other variables related to sexuality or masculinity; psychological functioning in terms of measures of psychological distress; and relationship functioning in terms of communication, support and relationship satisfaction with an intimate partner. Table 1 can be found at the end of this chapter. This section
categorises studies based on intervention type: peer support based, supportive/educative, and counselling/skills based interventions.

**Peer support interventions.** Peer support is one means by which psychosocial issues in men surviving prostate cancer can be targeted. Support groups are thought to provide an opportunity to educate, explore and confirm specific opinions and issues that men find important or of concern (Weber et al., 2007). Two studies (Weber et al., 2004; Weber et al., 2007) implemented a dyadic peer support program where men recently treated for prostate cancer with surgery were paired with longer term survivors (3 or more years). Men were required to have sexual and urinary dysfunction in the anticipation that they would discuss these sensitive topics. Each dyad was required to meet eight times over eight weeks and were encouraged to discuss physical and emotional aspects of prostate cancer and treatment.

In Weber et al.’s (2004) study, 30 men were allocated to the one-on-one peer support program or a control group. A measure of depression, sexual function (erectile ability, sexual desire and orgasm function), and sexual bother was taken. The intervention significantly lowered depression scores at 4-weeks compared to controls; however these benefits were not maintained at 8-weeks. While the peer support program was not associated with any benefits in sexual function, sexual bother was significantly reduced for those who underwent the support program compared to controls at 8 weeks. Meetings typically went for around 60 minutes with the most popular topics discussed being incontinence, ED, and prostate specific antigen testing. While this study highlights the immediate change support can have, the sample size was very small.

Weber et al. (2007) extended upon this peer support program by training peer support partners to recognise signs and symptoms of clinical depression. Seventy-two men were randomly assigned to a control group or treatment group. Again, men
were encouraged to discuss thoughts and feelings associated with prostate cancer and the sexual and urinary side effects of treatment. It was found that the peer support group demonstrated significantly improved depressive scores from baseline and immediately following intervention (8-weeks), compared to controls. This study did not directly compare efficacy of intervention on sexual function.

Supportive/educative interventions. Several studies have used supportive and/or educative strategies to address sexual, psychological, and relationship functioning. Lepore, Helgeson, Eton, and Schulz (2003) randomly assigned 279 men treated for localised prostate cancer to a control, education or education-plus-discussion intervention group. Interventions consisted of six weekly 1-hour face-to-face lectures on a variety of topics including control of physical side effects, stress and coping, relationships and sexuality. These were run by experts in the area. The discussion group included an additional 45 minute weekly discussion on topics relevant to group members and female family members who attended separate group discussions. No treatment effects were found for sexual function or depressive symptoms. Lepore et al. (2003) found the education-plus-peer facilitated discussion arm of their intervention had a positive impact on sexual bother compared to controls, whereas education alone did not. Further analysis on the data from this study revealed significant moderator effects (Helgeson, Lepore, & Eton, 2006). Specifically, men with lower general self-esteem at baseline demonstrated greater improvement on psychological variables as a result of both of the interventions.

Berglund et al. (2007) compared the efficacy of education sessions in a group format compared to a control group. Berglund et al.’s sample consisted of 158 men who had been diagnosed with prostate cancer in the last 6 months, were at different stages of disease progression and had used a variety of cancer treatments. Men were randomised into seven weekly sessions of face-to-face group therapy in three
formats: physical training only, information only, physical training and information combined, or usual care. Physical training consisted of general fitness training and relaxation training. Information sessions included information about prostate cancer, associated treatment, and the common side effects (including incontinence and sexual function). Group participants were given the opportunity to discuss experiences with each other and group leaders. Outcome measures included variables for depression and anxiety. The authors anticipated that physical activity would be associated with improvements in depressive symptoms, and information giving would be associated with reductions in anxiety. However, the interventions were not found to have any effect on the outcomes measures of anxiety and depression. Although nurse-led education targeted several topics that are likely to be distressing for men, education around anxiety and depression was not provided directly which may not have provided men with the knowledge to implement strategies to deal with psychological distress.

Three other nurse run supportive/educative studies were conducted over the telephone. Firstly, Mishel et al. (2002) randomly assigned 239 men treated for localised prostate cancer into a control group or to an 8-week psycho-educational and support program delivered by trained nurses over the telephone. The intervention was given in one of two formats, with or without a significant other. The program targeted the specific needs of patients in relation to difficulties they experienced managing and coping with the impact of prostate cancer treatment. Although nurses were given a list of standardised topics to cover, semistructured interviews were conducted to assess areas of uncertainty and concern and men were encouraged to focus on topics important to them. Nurses assisted with providing information, problem solving, and communication, all relevant to specific problem areas. Strategies for ED included potency enhancement methods and information on
intimacy expression beyond penetrative sex. The most common problem areas identified were urine function, ED, communication with health professionals and general treatment side effects. This study found no effect of the interventions on erectile function or sexual satisfaction. Mishel et al. (2002) did find a moderator effect, where African American men displayed improved sexual satisfaction in the support group when a close family member was included compared to the control group.

Northouse et al. (2007) conducted a supportive/educative intervention comprising of a 10-week couple program incorporating three home visits and two telephone calls from nurses. The final sample consisted of 218 men newly diagnosed and treated for prostate cancer at various stages of disease. The intervention focused on communication about prostate cancer and providing support and symptom management. The study demonstrated no effect of the intervention compared to the control group for general symptom distress, or prostate cancer specific symptoms including sexual function. Communication about the illness was improved at a 4 month follow-up time point for patients; however, partner outcomes demonstrated improved communication at all three follow-up time points. Limited impact of this intervention on sexual function may be because, although symptom management was targeted, the program had limited material specific to sexual functioning.

McCorkle, Siefert, Dowd, Robinson and Pickett (2007) also investigated a supportive/educative program for couples, by evaluating the efficacy of an 8 week post-hospital standardised nursing intervention with men with a variety of stages of prostate cancer. Contact was equally divided by the nurses between telephone sessions and home visits. The program targeted sexual, relationship and psychological functioning in both men and their partners. This program provided information and medical symptom management during the initial recovery after
surgery. The intervention also focused on restoration of sexual function and increasing intimacy between partners. Both patients and partners completed measures of sexual function, martial interaction, and depressive symptoms at baseline and 1, 3, and 6 months post-surgery. For patients, the intervention did not impact on sexual, relationship, or psychological functioning measures. Although emotional distress was listed as a major aim on their intervention, specific education and strategies targeting psychological functioning were not covered in any detail.

In a comprehensive study of a supportive/educative intervention, Giesler et al. (2005) also addressed and measured aspects related to sexual, relationship and psychological functioning. Giesler et al. (2005) examined the efficacy of a 6-session computer-assisted-nurse-driven intervention with 99 localised prostate cancer survivors and their partners, where participants were randomised to the intervention or standard care group. Sessions were over over 6 months, twice in person and four times by telephone. Giesler et al.’s intervention was highly tailored to the needs of participants. The program was aimed at targeting symptom management and providing psycho-educational strategies for dealing with a variety of problems according to patients’ individual needs. While all participants were provided with information on bowel and urinary function problems and given a video with sexuality and relationship content, a computer-assisted program was used to identify problem areas for further exploration. Strategies for further assistance with ED and dyadic adjustment difficulties were provided, including information on ED medical intervention methods, as well as communication skills development, such as active listening and expression of feelings. Depression associated with the side effects of prostate cancer treatment was targeted by addressing cancer worry (anxiety over cancer recurrence).
At 4 months post-treatment, those who were in the intervention group reported significant improvements in sexual functioning. Although sexual bother was not reduced by their intervention, the degree to which activities were limited by sexual dysfunction improved in the intervention group at 7 and 12 month follow-ups (but not initial 4 month follow-up). The program did not impact on depression levels or dyadic adjustment scores. This study was particularly innovative in that computer assisted technology was utilised to provide the intervention information, and the study was also highly tailored to the needs of participants, including sexual needs. Lack of a treatment effect on relationship functioning measures may be because this was considered a more distal consequence of prostate cancer side effects, and not a major focus of the program. Further, the program was largely educational and no homework was given to consolidate new skills learnt.

**Skills based/Counselling interventions.** There have been a growing number of studies that have attempted to use skills based strategies in addition to psycho-education in addressing psychosocial issues in prostate cancer survivors. Campbell et al. (2006) compared the efficacy of a 6-weekly couple telephone based CBT Coping Skills Training intervention to a control group using a sample of African American men with localised prostate cancer. Sessions were run by psychologists for men and their partners. The sessions included education around involving partners; developing skills for managing cancer symptoms and emotional distress; developing problem solving skills; relaxation training; communication skills; cognitive restructuring; and coping maintenance planning. A variety of measures were taken including the EPIC (Expanded Prostate Cancer Index) – see Table 1 for details. There was an effect size of .45 for sexual bother but this was non-significant, and there was no treatment effect for sexual functioning. A measure of mood state or relationship functioning was not taken for the men. Although Campbell et al.
emphasised the importance of the partner and the relationship in the context of prostate cancer, there were limited specific strategies targeting sexual functioning for the man and the couple. Additionally, there was a small final sample size of 30 accounting for the non-significant moderate effect size found for sexual bother.

Stress management has been viewed as an appropriate intervention for improving psychological distress and other QoL domains in cancer survivors (Chism & Kunkel, 2009). A research group led by Penedo (Penedo et al., 2004; Penedo et al. 2006; & Penedo et al., 2007) conducted a series of RCTs (Randomised Controlled Trials) investigating the efficacy of a group-based Cognitive Behavioural Stress Management (CBSM) program using various populations of men with prostate cancer. The CBSM program was run over 10 weeks, led by a psychologist or graduate level psychologist, and focused on developing relaxation and cognitive behavioural approaches to stress management aimed at improving QoL in men with prostate cancer. The intervention included targeting distorted cognitions and communication skills training, in addition, some of the skills were designed to assist with the management of ED and spousal relations. Information was provided on ED and it was emphasised that prostate cancer is a couple’s disease. All three studies used the Function Assessment of Cancer-Therapy General Module (FACT-G) to measure QoL across four domains (physical, social and family, emotional, and functional).

Firstly, Penedo et al. (2004) investigated the efficacy of this program using an ethnically diverse sample of 91 men treated for localised prostate cancer and secondly Penedo et al. (2006) used a larger sample of 191 men treated for localised prostate. Both these studies did not take specific measures of sexual, psychological, or relationship functioning, and instead focused on general QoL as this was the focus of their intervention. Both studies found treatment effects for QoL.
Penedo et al. (2007) investigated the efficacy of the CBSM group intervention using a sample of Spanish Monolingual Hispanic men treated for localised prostate cancer. Penedo et al. (2007) analysed the emotional well-being subscale of the FACT-G separately and found that this improved for the intervention group relative to control group. Penedo et al. (2007) also obtained a measure of sexual functioning using the EPIC and found that overall sexual function improved for those in the intervention group compared to controls.

Molton et al. (2008) utilised a similar 10-session group-based CBSM program specifically aimed to improve sexual functioning as well as general psychosocial outcomes, using a sample of 101 men treated for localised prostate cancer. The comprehensive intervention program included psycho-education about sexual function restoration, relaxation exercises, challenging distorted cognitions surrounding sexual performance, redefining sexuality beyond intercourse, and developing sexual communications to use with partners. Participants who received the intervention demonstrated significantly better sexual functioning (quality and frequency of erections as well as desire) in comparison to participants who completed the control condition of a 4-hour workshop on stress management skills. Although a measure of sexual bother was taken, this was not detailed in the results. Men with higher interpersonal sensitivity (reflecting a tendency to be overly sensitive and more likely to see ED as a threat to their masculinity) demonstrated a significantly greater improvement in sexual functioning as a result of taking part in the CBSM intervention. This suggests that targeting masculinity as a part of psycho-education may be beneficial for improving sexual functioning. However, while Molton et al.’s program attempted to broaden men’s definitions of sexuality, psycho-education on masculinity was limited.
Three skill based studies used couple or individual therapy to assist with sexual and relationship difficulties as a major focus. Canada, Neese, Sui, and Schover (2005) and Titta et al. (2006) developed two couple focused face-to-face manualised interventions using strategies from CBT and sex therapy to address the complex relationship between sexual problems and relationship variables. Firstly, Canada et al. (2005) developed a manualised face-to-face sexual rehabilitation program for localised prostate cancer survivors that also targeted sexual and relationship functioning. Fifty-one men who had undergone surgery or radiation therapy were randomised to one of two intervention formats. This study also incorporated aspects of sex therapy, including sensate focus exercises, which aimed to expand physical and sexual contact. The program incorporated CBT techniques focused on negative beliefs surrounding cancer and sexuality; psycho-education on the impact of treatment on sexual function; assistance with medical treatments for ED; and skills training to improve general and sexual communication. Participants were required to complete behavioural exercises by themselves and with their partners. Measures of sexual, relationship, and psychological functioning were taken at baseline, post-treatment, and at three and 6 month follow-ups.

Canada et al. (2005) also aimed to directly assess the influence of including the partner in a treatment program by comparing the 4-session program in a couple versus individual format. Since no difference was found between the two interventions, the groups were merged for further analyses. Psychological distress improved across all time points relative to baseline, but was only significantly different at 3-month follow up. Both intervention groups demonstrated positive effects for erectile and orgasmic function, intercourse satisfaction, overall sexual satisfaction, and partners’ sexual function at 3 months; however, these gains regressed to baseline at 6 month follow up. The programs found reductions in
emotional distress at 3-month and 6-month follow ups. Positive effects were also found for use of medical treatments for ED, where the use increased from 31% at baseline to 49% at 6-months follow up. Those who completed their homework exercises were more likely to use ED treatments successfully, suggesting use of homework exercises can make an intervention more efficacious. The presence of a partner did not appear to influence outcomes and the intervention did not impact on dyadic adjustment scores. While this study uniquely compared the potential benefits of a partner, no control group was used. A further limitation of this study was the high level of non-compliance and a drop-out rate of 39%. Reason for dropping out included high marital distress and discomfort with explicit sexual topics.

Titta et al. (2006) investigated the effects of a couples’ sexual counselling intervention. While some studies have incorporated education about the use of ED medical treatments, Titta et al. directly compared a medical intervention for ED with and without counselling. Fifty-seven men who had been treated for localised prostate cancer by surgery or muscle-invasive bladder cancer by cystectomy, were randomised to receive intercavernosal injection therapy (ICI) or sexual counselling-plus-ICI. The sample was predominately prostate cancer survivors. Female partners were encouraged to attend therapy sessions. Although both intervention groups experienced improvements in erectile function over an 18 month period, the counselling-plus-ICI group reported comparatively higher erection function, sexual desire and satisfaction, and higher compliance with medical treatments. While this study did not use a control group, it highlights the potential positive influence counselling can have on medical treatment compliance. The counselling group demonstrated greater response to Sildenafil and greater satisfaction with injection therapy in an ICT-plus-counseling group as opposed to an ICT-only group. Also, participants who received the ICT-plus-counselling intervention demonstrated much
higher partner participation in the medical intervention than participants who received ICT-alone (89.6% versus 28.5%).

Both the Canada et al. (2005) and Titta et al. (2006) studies demonstrated improvements in several aspects of men’s sexual functioning, including erectile function. Importantly, these studies also provided support for the utility of sexual intimacy programs that assist with compliance of medical treatments for ED. It is important to note, however, that these findings were observed in studies with a small sample size (Canada et al., 2005, Titta et al., 2006), a mixed cancer sample (Titta et al., 2006), or no control group (Canada et al., 2005).

Finally, a recent study by Manne et al. (2011) investigated the impact of 5-sessions of couple based Intimacy Enhancement Therapy (IET). Sessions were run by psychologists for men diagnosed and treated for localised prostate cancer in the last year. The IET program aimed to improve couple’s ability to share thoughts and feelings regarding cancer, facilitate discussion of concerns, and improve overall emotional intimacy. There was in-session practice of skills (e.g., communication) and joint homework. A final 54 couples who completed the IET or usual care were compared across a variety of relationship quality, communication and psychological distress measures. The authors did not find any treatment main effects for psychological distress, dyadic adjustment or a variety of relationship communication outcomes, including level of disclosure, responsiveness, and use of mutually constructive communication.

However, Manne et al. (2011) found several moderator effects for patients. Those patients with lower levels of effective communication demonstrated significant improvements for each of those measures (including self-disclosure, perceived partner disclosure, and partner responsiveness) as a result of engaging in the intervention. While Manne et al. demonstrated that a couple focused intimacy
intervention can assist couples with more severe relationship difficulties, this intervention did not adequately address sexual function, which is known to influence relationship variables.

Most recently Collins et al. (2013) developed and pilot tested a 4 week face-to-face couple’s program for men recently diagnosed with localised prostate cancer called Cognitive Existential Couple Therapy. This intervention focused on the patient-partner relationship and aimed to reduce psychological distress, and enhance coping and relationship functioning. The program focused on several areas commonly viewed as a concern including dealing with uncertainty about the future, coping with diagnosis and treatment side effects while focusing on the impact on the couple’s relationship with an emphasis on sexual impact. Although the intervention was manualised, a questionnaire after the first session gave some direction on which concerns to address. The intervention was pilot tested on 12 men, with 10 men reporting outcome data. There was no significant effect on relationship function measures or depression and anxiety. There was significant improvements on a scale reporting psychological distress in relation to experience of traumatic events.

**Summary of psychosocial interventions.** Studies that have been evaluated in this section vary in terms of the use of platforms (telephone, face-to-face); strategy (group, supportive, educative, counselling); partner inclusion (no, requirement, or recommendation); the degree of assistance (self-management versus therapist assisted); and whether the intervention targeted a single problem or had a multi-problem focus. Some studies focused on sexual, psychological or relationship functioning as a minor focus within the context of general symptom or stress management focus, whereas others made these factors a major focus of the intervention.
The majority of reviewed studies targeted sexual functioning to some degree, with approximately half of these finding significantly positive effects for at least one arm of their intervention (Canada et al., 2005; Giesler et al., 2005; Molton et al., 2008; Penedo et al., 2007; Titta et al., 2006). There was a trend towards interventions that had sexual functioning as a major focus, and used more complex intervention strategies (psychological counselling or CBT), as opposed to supportive/educative strategies, being more effective in improving sexual functioning. Studies that used sex therapy techniques, aimed to broaden a man’s definition of sexuality and intimacy, engaged the partner in the intervention, and included information on ED medical aids appeared to be efficacious (Canada et al., 2005; Molton et al., 2008; Titta et al., 2006). One study using a supportive/educative strategies had a positive effect on overall sexual functioning (Giesler et al., 2005), and this study was also highly tailored to the needs of participants, including sexual needs, suggesting some level of choice may be important when engaging and addressing men’s difficulties.

Several studies took a measure of sexual bother; only four studies analysed this in the results and only half found a positive effect. Some form of peer discussion was involved in those interventions that found a positive effect (Lepore et al., 2003 and Weber et al., 2004), suggesting that this may reduce a man’s feelings of bother around sexual problems. However, only four studies measured sexual bother, with half finding no effect of the intervention on sexual bother, making it difficult to draw any conclusions.

Although several studies reported used a measure of psychological functioning, only three found a positive treatment effect in this area (Canada et al., 2005; Weber et al., 2004; Weber et al., 2007) and a further study found improvements for psychological distress related to traumatic events (Collins et al., 2013). Some studies reported that this may be because psychological functioning was low at baseline
(Canada et al., 2005; Lepore et al., 2003). Two of the studies that did find a positive influence on psychological functioning were peer support programs which found improved levels of depression (Weber et al., 2004; Weber et al., 2007). One study that had a positive influence on psychological distress largely focused on sexual and relationship functioning, suggesting that aiming to improve those areas can have an impact on psychological distress (Canada et al., 2005).

For relationship functioning outcomes, the reviewed interventions provided limited evidence for the efficacy of interventions in improving relationship functioning for men, in terms of dyadic adjustment, marital distress, and communication. This was found across two supportive/educative interventions (McCorkle et al., 2007; Gieser et al., 2005) and three counselling/psychological therapy interventions (Canada et al., 2005; Collins et al., 2013; Manne et al., 2011). The only positive effect found for relationship functioning was improvements in men’s communication with their spouse about their illness (Northouse et al., 2007).

Even though a number of studies included a partner as an essential or recommended part of treatment (Campbell et al., 2007; Canada et al., 2005; Collins et al., 2013; Giesler et al., 2005; Lepore et al., 2003; Manne et al., 2011; McCorkle et al., 2007; Mishel et al., 2002; Northouse et al., 2007; Titta et al., 2006), only two studies directly compared the efficacy of an intervention with and without an intimate other (Canada et al., 2005; Mishel et al., 2002), with only one study having this person exclusively as a romantic partner (Canada et al., 2005). Both studies did not find a benefit from including a partner (Canada et al., 2005) or close family member (Mishel et al., 2002). However, Mishel et al. (2002) did find a moderator effect, where African American men displayed improved sexual satisfaction in the support group when a close family member was included. The lack of evidence for
the benefits of partner inclusion is consistent with a past review (Cockle-Hearne &
Faithfull, 2010).

Given the suggestion that both a patient and partner may benefit from an
intervention with partner inclusion (Berterö, 2001; Darst, 2006; Neese et al., 2003;
Schover et al., 2002b; Wittmann, Northouse et al., 2009), it is surprising that more
studies have not investigated this variable. While no other study directly compared
the efficacy of an intervention with and without a partner, Titta et al. (2006) found
that participants who received the ICT-plus-counseling intervention demonstrated
much higher partner participation in the medical intervention than participants who
only received ICT-only.

**Limitations of psychosocial interventions.** Several limitations need to be
taken into account when interpreting the findings from these studies. Firstly, the wide
variety of approaches to address sexual, psychological, and relationship functioning
made interpretations of the findings difficult. As well as differences in the
overarching strategy and theory, intervention techniques differed in terms of format
and delivery, the use of homework, discussions, and in-therapy practice. Given that
many interventions covered a range of areas in their intervention protocol, details
about the specific nature of strategies for sexual, psychological and relationship
functioning were sometimes limited.

In terms of the content of interventions, although several interventions stated
that their specific aims were to address areas of sexual, psychological and
relationship functioning, some studies did not adequately address these areas. For
example, they provided information on ED side effects without further strategies and
skill development in the broader area of sexual functioning. For psychological
functioning, the programs frequently targeted psychological distress and included an
outcome measure on this, but failed to specifically address anxiety and depression,
instead focusing only on other areas that may indirectly influence these outcomes. Given the complex relationship between psychological functioning and sexual function, including intimacy and a man’s sense of manhood, it may be beneficial to target both areas directly.

There were also limitations related to overall study design and characteristics. The heterogeneity of study characteristics, represented by differences in the duration of intervention, timing of interventions, follow-up times, measures used and sample characteristics (e.g., stage of disease), made it difficult to draw many definitive conclusions as to whether particular study design features were associated with greater efficacy. Control groups varied from non-specific interventions to basic information only. A further limitation was the use of small sample sizes and high dropout rates in some studies, making generalisability of any significant findings difficult.

Although there was some consistency in the type of sexual, psychological and relationship functioning measures employed in the studies, single item measures were frequently used and several studies did not separate subscales on sexual, relationship, and psychological functioning for analyses (often within QoL scales). Separation of subscales in analyses is beneficial when comparing actual erectile function changes against other sexual functioning measures, and between sexual functioning and bother associated with sexual problems. The importance of this is highlighted in the results of the studies that found a positive impact on sexual bother (Lepore et al., 2003; Weber et al., 2007) but did not have an impact on other sexual functioning measures.

Further, typical prostate cancer QoL measures have been criticised for failing to assess the complexity of sexual functioning and call for the inclusion of aspects such as sexual self-concept and masculine identity in addition to symptom severity.
and bother (Clark et al., 2003). Only two studies explored broader sexual QoL measures including interpersonal sensitivity (linked to masculine identify) (Molton et al., 2008) and activity limitations brought on by sexual changes (Giesler et al., 2005). In order to expand our understanding of sexual functioning after prostate cancer, researchers need to utilise measures that assess all aspects of sexual functioning including intimate activities, sexual bother, the use of therapeutic aids, and psychosexual constructs such as masculine identity and self-esteem. Recent research has emphasised the important of masculinity in men treated for prostate cancer (Messaoudi et al., 2011, Thornton et al., 2011; Zaider et al., 2012).

Finally, participants were frequently heterosexual, partnered, Caucasian men from Western countries. There was only one study that acknowledged homosexual men by asking about sexual orientation (Manne et al., 2011). Latini, Hart, Coon and Knight (2009) has previously emphasised that homosexual men may have differing needs in the face of ED and relationship disruption. Demographic information provided from several studies in this review, suggests that around 20% of samples consist of single men. However, no study addressed the particular needs a single man may have in relation to his sexuality and thoughts around future relationships.

**Summary and Conclusion**

This chapter focused on reviewing psychosocial interventions addressing sexual, psychological and relationship functioning for men treated for prostate cancer. It was found that there is considerable variability in the attention to these aspects and in the types of psychosocial interventions used. The chapter highlighted the range of strategies that can be used to assist men and their partners cope with sexual, psychological and relationship functioning difficulties in the context of prostate cancer and its treatment. In summary, interventions where sexual
functioning was a major focus and where more complex strategies were employed (e.g., CBT and sex therapy), demonstrated some benefits for improving sexual functioning for men treated for prostate cancer. There is not yet sufficient evidence to determine whether psychosocial interventions are efficacious in improving sexual bother, psychological functioning, patients’ relationship functioning, or whether inclusion of an intimate partner improves treatment outcome. Any significant effects found in these studies should be treated with caution in the light of the methodological issues highlighted previously.

These limitations indicate the need for further research to clarify whether psychosocial interventions improve sexual, psychological, and relationship functioning for men treated for prostate cancer. Limitations included poor use of measures (including failure to explore sexual bother separately from sexual and erectile function), lack of control groups, and failure to adequately address sexual, psychological and relationship functioning in the intervention protocol of these studies. Only three studies have addressed and measured all three areas of functioning.

Past treatment approaches outlined in this chapter have predominately focused on the use of face-to-face, telephone, or a combination of face-to-face and telephone modalities, either in individual, couple or group format, and each with a moderate to high level of assistance and direction. Less is known about the use of largely self-directed psychosocial treatment programs for men with prostate cancer. The following chapter introduces the internet as a platform for delivery of psychosocial interventions and the potential for this to be used in a self-directed manner for men with prostate cancer.
Table 1

**Characteristics and Outcomes of Included Studies**

<table>
<thead>
<tr>
<th>Study / Year</th>
<th>Intervention</th>
<th>Treatment Groups</th>
<th>Sample size and characteristics</th>
<th>Aspects of intervention related to SF, PF, RF</th>
<th>Outcome measures related to SF, PF, RF</th>
<th>Assessment times</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Berglund et. al., 2007 (Sweden)</td>
<td>7 weekly sessions of face-to-face group therapy.</td>
<td>(1) Physical training (2) Information (3) Physical training and information (4) Usual care (printed leaflets and opportunity to call nurse)</td>
<td>Patients within 6 months of PCa diagnosis. Range of treatments and disease progression. M_{age} = 69 N(rand): 211 N(base): 194 N(comp: 158</td>
<td>Two sessions led by psychologist on side effects (including sexual dysfunction). Information on sexual aids, solving problems related to sexual related side effects, and opportunity to discuss experiences with participants and group leaders.</td>
<td>No EORTC - several subscales related to functioning and symptoms, however no questions regarding sexual function directly. HADS – depression &amp; anxiety subscale.</td>
<td>Baseline, 6m and 12m post-intervention</td>
<td>No treatment effect on anxiety or depression.</td>
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<tr>
<td>Campbell et. al., 2006 (USA)</td>
<td>6 weekly sessions telephone based CBT sessions.</td>
<td>(1) Coping Skills Training. (2) Usual care (routine care)</td>
<td>African American men with localised PCa (beyond the acute phase and treatment).</td>
<td>Session 1: Information on how PCa affects relationship and the need to include partner. Session 3:</td>
<td>Partner encouraged to listen to phone conversations.</td>
<td>Baseline and post-intervention</td>
<td>No significant impact on sexual function or sexual bother.</td>
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<tr>
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<td>Canada et al., 2005 (USA)</td>
<td>4 face-to-face sessions of sex therapy</td>
<td>(1) Counseling without partner. (2) Counseling with partner.</td>
<td>Men with localised PCa treated with surgery or radiation therapy in the previous 3-60 months. Sample 88% Caucasian; 4% African American; 8% Hispanic. M&lt;sub&gt;age&lt;/sub&gt; = 65.5 N(rand) = 84 N(comp) = 51</td>
<td>Major focus on both relationship and sexual function. Obtained a relationship and sexuality history and set goals. Provided education around PCa and sexual dysfunction, information on medical treatments and troubleshooting problems with these. Communication strategies to improve discussions about cancer related emotions and sexual problems. Provided ways to increase intimacy and enjoy</td>
<td>Criteria were man to be married/defacto and partner willing to participate. M&lt;sub&gt;age&lt;/sub&gt; = 61.8</td>
<td>IIEF: subscales for erectile function, sexual desire, orgasm function, intercourse satisfaction, overall satisfaction, and overall function. Also measured ED medical treatment use. DAS: relationship quality and satisfaction. BSI: global distress score, and depression, anxiety subscales.</td>
<td>Baseline, post-treatment, and follow-ups at 3 and 6 months.</td>
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<tr>
<td>Collins et al., (2013)</td>
<td>Cognitive Existential Couple Therapy (6 weekly couple face-to-face sessions)</td>
<td>Pilot study – intervention only.</td>
<td>Men undergoing treatment for PCa. Final sample 60% surgery, 40% radiation, hormone, surgery combinations Median age = 64 N(enrolled) = 12 N(comp) = 10</td>
<td>Exploring psychological changes and impact on couple’s relationship including sexual; major focus on exploring and promoting open communication and mutual support, including partner’s perspective.</td>
<td>Criteria to be married/defacto for at least 1 year and partner included throughout.</td>
<td>MHI: overall mental health and subscales for depression and anxiety. IES-R: psychological distress related to traumatic life events. FRI: relationship function, expressiveness and conflict resolution. CSI: perceived level of support regarding PCa.</td>
<td>Baseline and immediately post-test</td>
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Giesler et al., 2005 (USA)

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<th>Study</th>
<th>Intervention</th>
<th>Treatment Groups</th>
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<tbody>
<tr>
<td>Giesler et al., 2005 (USA)</td>
<td>Computer assisted symptom management program, 6 monthly sessions (2 face-to-face, 4 phone)</td>
<td>(1) Intervention (2) Usual care (not specified)</td>
</tr>
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</table>

Sample size and characteristics:
- Diagnosed with localised PCa and scheduled to have or had surgery, radiation, brachytherapy. Sample 87% Caucasian; 8% African American; 2% other. 
- $M_{age} = 63.8$. 
- $N(\text{rand}) = 99$ 
- $N(\text{comp}) = 85$

Aspects of intervention related to SF, PF, RF:
- At 1st visit all patients were given a video on PCa, managing symptoms, and sexuality and relationships. Program was then tailored to individual needs and sexual and dyadic adjustment concerns were in top three areas covered for tailored interventions. 
- Sexual function - teaching dyadic communication skills, providing information about medical ED interventions. Relationship function - teaching active listening and how to express feelings to partner. Depression – one of Criteria for man to have spouse/partner who was willing to participate.

Partner inclusion:
- PCQoL: sexual function, sexual bother, activity limitation by sexual dysfunction.
- DAS (cohesion and satisfaction subscales only).
- CESDS – depression.

Outcome measures related to SF, PF, RF:
- Baseline, follow-ups at 4, 7, and 12 months post-intervention.

Assessment times:
- Intervention displayed improved sexual function at 4m and sexual limitation improved at 7m and 12 m follow up. No treatment effect on sexual bother or on dyadic satisfaction or cohesion. No main treatment effect for depression.
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<td>Lepore, 2003</td>
<td>6 weekly group lectures.</td>
<td>(1) Education (2) Education-plus-discussion (3) Usual care (not specified)</td>
<td>Men with localised PCa treated in last month (range of treatments). Sample: 90% Caucasian; 9% African American; &lt;1% other. M(rand) = 65.07 N(rand) = 279 N(comp) = 250</td>
<td>One education session on stress and coping and on relationships and sexuality taken by a psychologist. Education-plus-discussion arm included an additional 45 minutes of facilitated group discussion. Female partners who attended lectures had separate discussions. Patient was encouraged to attend lectures with a significant other.</td>
<td>UCLA-PCI: Sexual function (erectile ability, sexual desire &amp; orgasm function) and sexual bother. CESDS – depression.</td>
<td>Baseline, 2 weeks, 6m, 12m post-intervention</td>
<td>Men in the education-plus-discussion intervention were less bothered by sexual problems than controls. Did not report how significant changes occurred over time. No treatment effect on sexual function. No treatment effects for depression.</td>
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<tr>
<td>Manne et al., 2011</td>
<td>5 couple sessions of manualized therapist IET (Intimacy-Enhancement Therapy)</td>
<td>(1) IET (2) Usual care (potentially a social worker visit and referral to psychologist/psychiatrist). Men diagnosed localised PCa in last year and treated by radiation therapy, surgery or hormone therapy. Sample 88.7% Caucasian and</td>
<td>IIT aimed to improve couples ability to share thoughts/feelings regarding cancer, facilitate discussion of concerns, and improve emotional intimacy. In-sessions Criteria for man to be married/defacto and include partner. M age = 55.7</td>
<td>DAS: marital quality and satisfaction. PAIR: relationship intimacy. Communication measures (self-disclosure,</td>
<td>Baseline and post-intervention.</td>
<td>No effect of intervention on relationship satisfaction, intimacy, communication, or psychological functioning.</td>
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| McCorkle et al., 2007 (USA)| 8 weekly post-hospital standardized nursing intervention (SNIP) with 16 contacts (50% home and 50% telephone). | (1) SNIP  
(2) Usual care (as specified by urology clinic). | Men with variety of diagnoses (including metastatic PCa). Sample 86% Caucasion.  
M\(_{age}\) = 60  
N(rand) = 126  
N(comp) = 107 | Patient, spouse and couple content focusing on reinforcing open communication, ways to coney love and support, exploring areas of conflict, and sharing concerns about intimacy. Booklet provided containing information on common myths, | Criteria for man to be married or in a committed relationship and to include partner.  
M\(_{age}\) = 56 | CARES: Sexual function (sexual interest, sexual dysfunction) Marital interaction (affection, overprotection by partner, and neglect by partner). CESDS: depression. | Baseline and 1, 3, and 6m post-surgery. | Intervention did not impact on sexual, psychological or relationship functioning. |

11.3% non-white.  
M\(_{age}\) = 60  
N(rand) = 71  
N(comp) = 54  
skill practice and homework.   
responsiveness)  
CPQ: Mutually constructive and demonad-withdrawn communication.  
MHI: psychological distress and psychological well-being subscales.
<table>
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<tr>
<th>Study</th>
<th>Intervention</th>
<th>Treatment Groups</th>
<th>Sample size and characteristics</th>
<th>Aspects of intervention related to SF, PF, RF</th>
<th>Partner inclusion</th>
<th>Outcome measures related to SF, PF, RF</th>
<th>Assessment times</th>
<th>Findings</th>
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<tbody>
<tr>
<td>Mishel et al., 2002 (USA)</td>
<td>8 weekly telephone calls for uncertainty management.</td>
<td>(1) Telephone support (2) Telephone support and family member support. (3) Control (usual care &amp; printed health information materials unrelated to PCa).</td>
<td>Men with localised PCa with 2 weeks postcatheter removal after surgery and/or 3 weeks into current radiation therapy. Sample 56% Caucasian and 44% African American. ( M_{age} = 64 ) ( N(\text{rand}) = 252 ) ( N(\text{comp}) = 239 )</td>
<td>Information on potency enhancement methods, ways of expressing intimacy in other ways than intercourse, and general problem solving.</td>
<td>Criteria for man to include family member (most were partners.)</td>
<td>SDS: erectile function and sexual satisfaction.</td>
<td>Baseline, 2m and 5m post-intervention.</td>
<td>No effect of interventions on erectile function or sexual satisfaction. Significant moderator effect for African American men where sexual satisfaction improved at 2 month follow-up in the telephone support and family member support intervention group compared to control.</td>
</tr>
<tr>
<td>Molton et al. 2008 (USA)</td>
<td>10 weekly group CBSM sessions focusing on promotion of sexual</td>
<td>(1) Intervention (2) Control (4 hour workshop on stress management skills).</td>
<td>Men recovering from surgery for localised PCa within 18 months. Sample 43% non-hispanic white;</td>
<td>Promotion of sexual functioning by providing information on treatment options for ED, broadening definition of</td>
<td>No</td>
<td>UCLA-PCI: Sexual function (erectile ability, sexual desire, orgasm function) and sexual</td>
<td>Baseline and post-intervention</td>
<td>Improved sexual function in intervention group. Did not report sexual bother scores. Moderator effect also</td>
</tr>
<tr>
<td>Study</td>
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| Northouse et al., 2007 (USA)  | 10 weekly couple FOCUS sessions (3 home visits and 2 telephone calls).       | (1) FOCUS (2) Usual care (standard clinic care and support).                                         | 38% Hispanic; 18% African American.  
  $M_{age} = 60$.  
  N(rand) = 121  
  N(comp) = 101 | sexuality, developing skills to discuss ED with partners, and challenging distorted cognitions around performance. |  
  Criteria for man to have a spouse/partner willing to participate.  
  M age = 59. |  
  EPIC: erectile function, desire, orgasm, and sexual bother.  
  FACT-G: 1 item related to satisfaction with sex life and 1 item related to closeness with partner.  
  MISS: communication with partner around illness. | Baseline, and 4, 8, 12 months post-intervention. | found where those with greater interpersonal sensitivity demonstrated a greater increase in sexual function. |
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<tr>
<td>Penedo et al., 2004 (USA)</td>
<td>10 weekly group-based CBSM sessions.</td>
<td>(1) CBSM (2) Control (half day education seminar on stress management skills).</td>
<td>Men with localised PCa treated by surgery or radiation in past 18 months. Sample 35% non-hispanic white; 34% Hispanic; 22% African American; 9% other. ( M_{age} = 63.1 ) ( N(\text{rand}): 92 ) ( N(\text{comp}): ) not specified</td>
<td>Focus on relaxation skills with cognitive-behavioural approaches to stress management, including communication training. Skills were partially designed to assist with management of ED and spousal relations. Also provided some information on the mechanics and treatment for sexual dysfunction. PCa as a couple’s disease was emphasised.</td>
<td>No</td>
<td>FACT-G: 1 item related to satisfaction with sex life and 1 item related to closeness with partner.</td>
<td>Baseline, 2 to 3 weeks post-intervention.</td>
<td>While overall QoL improved for those in intervention group, no analysis for sexual function separately.</td>
</tr>
<tr>
<td>Penedo et al., 2006 (USA)</td>
<td>10 weekly group-based CBSM sessions.</td>
<td>(1) CBSM (2) Control (half day education seminar on stress)</td>
<td>Men with localised PCa treated by surgery or radiation therapy in past 18 months, and 45+</td>
<td>Focus on relaxation skills with cognitive-behavioural approaches to stress management, including</td>
<td>No</td>
<td>FACT-G: 1 item related to satisfaction with sex life and 1 item related to closeness with</td>
<td>Baseline, 2 to 3 weeks post-intervention.</td>
<td>While overall QoL improved for those in intervention group, no analysis for sexual function separately.</td>
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<tr>
<td>Penedo et al., 2007</td>
<td>10 weekly group-based CBSM sessions.</td>
<td>(1) CBSM (2) Control (half day education seminar on stress management skills).</td>
<td>Men with localised PCA treated by surgery or radiation therapy in past 21 months. Sample Hispanic monolingual men. M_{age} = 65.5 N(rand) = 93 N(comp) = 71</td>
<td>Focus on relaxation skills with cognitive-behavioural approaches to stress management, including communication training. Skills were partially designed to assist with management of ED and spousal relations. Also provided some information on the mechanics and treatment for sexual dysfunction. PCa as a couple’s disease was emphasised.</td>
<td>No</td>
<td>EPIC: sexual function (erectile function, sexual desire, orgasm function), sexual bother, and sexual total score. FACT-G: 1 item related to satisfaction with sex life and 1 item related to</td>
<td>Baseline, 2 to 3 weeks post-intervention.</td>
<td>Improved sexual function for the intervention group compared to control group. Did not report sexual bother scores.</td>
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<td>Titta et al., 2006 (Italy)</td>
<td>Short-term psycho-dynamic counseling aimed at increasing use of erectile medical aids.</td>
<td>(1) Intercavernosal injection therapy (ICT)-plus-counseling, (2) ICT-only</td>
<td>88% of sample consisted of men treated for PCa with surgery. M_{age} = 63.5 N(rand) = 57 N(comp) = 49</td>
<td>Couple's sexual history taken and a therapeutic alliance was formed between partners during counseling. Used sexual therapy techniques to consider couples' sexual behaviour and relationship and facilitate couples' communication about sexual problems. Investigate and assist with any fears &amp; difficulties with ICT.</td>
<td>Female partners encouraged to attend counseling therapy sessions and assist with ICT.</td>
<td>IIEF: erectile function desire, orgasm function, intercourse satisfaction, overall satisfaction. Measured level of responsiveness to Sildenafil.</td>
<td>Prior to surgery, post-surgery, and 3, 6, 9, 12, 18 follow-up post-intervention.</td>
<td>Sexual function improved in both groups. At 18 month follow-up (significance not reported at other months) ICT-plus-counseling group demonstrated greater improvements in erectile function, intercourse satisfaction, and desire than ICT-only group. ICT-plus-counseling group were also better responders to sildenafil and demonstrated higher partner involvement</td>
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<td>Weber et al., 2004 (USA)</td>
<td>Dyadic peer support program. Met 8 times in 8 weeks.</td>
<td>(1) Peer support (2) Control (usual care - not specified what this involved).</td>
<td>Men with localised PCa recruited 6 weeks after surgery which resulted in urinary and sexual dysfunction. Sample 83% Caucasian; 13% African American; 2% Hispanic. M_age = 58 N(rand) = 32 N(comp) = 30</td>
<td>Recent patients were paired with long term survivors (3+ years) who had surgery that resulted in urinary and sexual dysfunction. Encouraged to talk about sensitive topics including sexual dysfunction.</td>
<td>No</td>
<td>UCLA-PCI: sexual function (erectile ability, sexual desire, orgasm function) and sexual bother. GDS: depression.</td>
<td>Baseline, 4 weeks (middle of intervention) and 8 weeks (end of intervention).</td>
<td>Peer support group was not associated with any benefits in sexual function, however less sexual bother was found for the peer support group. Lowered depression at 4 weeks for intervention group, but not maintained at 8 weeks.</td>
</tr>
<tr>
<td>Weber et al., 2007 (USA)</td>
<td>Dyadic peer support program. Met 8 times in 8 weeks.</td>
<td>(1) Peer support (2) Control (usual care - provided by their urologists)</td>
<td>Men with localised PCa recruited 6 weeks after surgery which resulted in urinary and sexual function.</td>
<td>Recent patients were paired with long term survivors (3+ years) who had surgery that resulted in urinary and sexual function.</td>
<td>No</td>
<td>UCLA-PCI: Sexual function (erectile ability, sexual desire, orgasm function) and sexual bother.</td>
<td>Baseline, 8 weeks (end of intervention).</td>
<td>Improved depressive symptoms in intervention group. Did not directly compare efficacy of intervention on sexual function.</td>
</tr>
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</table>
### Study Intervention Treatment Groups Sample size and characteristics Aspects of intervention related to SF, PF, RF Partner inclusion Outcome measures related to SF, PF, RF Assessment times Findings

- **dysfunction.**
  - Sample 83% Caucasian; 11% African American; 2% Hispanic; 1% Asian.
  - $M_{age} = 60$
  - $N_{(rand)} = 81$
  - $N_{(comp)} = 72$
  - Support partners trained to recognize clinical depression.
  - Encouraged to talk about sensitive topics including sexual dysfunction.
  - GDS: depression.

**SF** = sexual functioning; **PF** = psychological functioning; **RF** = relationship functioning; **PCa** = Prostate Cancer; **N_{(rand)}** = number participants randomized; **N_{(comp)}** = number participants completed; **EORTC** = EORTC Quality of Life Questionnaire; **HADS** = Hospital Anxiety and Depression Scale; **EPIC** = Expanded Prostate Cancer Index; **IIEF** = International Index of ED; **DAS** = Dyadic Adjustment Scale; **BSI** = Brief Symptom Inventory; **MHI** = Mental Health Inventory; **IES-R** = The Impact of Events Scale-Revised; **FRI** = Family Function Index; **CSI** = Cancer Support Inventory; **PCQoL** = Prostate Cancer Quality of Life Scale; **CESDS** = Center of Epidemiologic studies- Depression Scale; **UCLA-PCI** = UCLA Prostate Cancer Index; **PAIR** = Personal Assessment of Intimacy in Relationships; **CPQ** = Communication Pattern Questionnaire; **MHI** = Mental Health Inventory; **CARES** = Cancer Rehabilitation Evaluation System; **SDS** = Symptom Distress Scale; **CASF** = Concern about sexual functioning; **FACT-G** = Functional Assessment of Cancer Therapy; **MISS** = Lewis Mutuality and Interpersonal Sensitivity Scale; **GDS** = Geriatric Depression Scale.
Chapter 6: Internet-Based Treatment

This chapter introduces the internet as a platform for providing psychological treatment for men with prostate cancer and their partners. In general, internet-based treatment for psychological difficulties and health problems are thought to have many advantages. These include the ability to provide psychological services to those who are geographically isolated with limited options for face-to-face treatment, to those with time constraints, and to those who prefer to work at their own pace, to their own needs and be able to review material as desired (Chambers, Baade, & Pinnock, 2010; Cuijers, Van Straten, & Andersson, 2008; Spek et al., 2007). The internet may also overcome any stigma and uncertainty in accessing mental health support services (Gega, Marks, & Mataix-Cols, 2004; Klein et al., 2009). Although the internet may not be appealing or helpful to everyone, the internet may capture those people who previously would not have accessed treatment (Spek et al., 2007).

Internet-based treatment has been growing in many areas in the past 15 years, and more rapidly in the past 10 years. The following sections will outline and review the types of internet-based treatment used for mental health, health behaviour, and chronic illness, followed by a focus on the use to date of internet-based interventions for cancer with a specific focus on any interventions specific to prostate cancer. Throughout this chapter, research which has identified which structural or content related components of an intervention are likely to be effective will be highlighted.

Internet-Based Treatment for Mental Health

Internet-based psychological treatment has been used for a range of psychological disorders including panic disorder (e.g., Klein, Richards, & Austin, 2006), post-traumatic stress disorder (e.g., Lange, van den Ven, Schrieken, &
Emmelkamp, 2001), and depression (e.g., Cristensen, Griffiths, & Jorm, 2004). More recently internet-based psychological treatment has been applied to maternal depression (e.g., Sheeber et al., 2012), bipolar disorder (e.g., Smith et al., 2011) and eating disorders (e.g., Pretorius et al., 2009).

The most common strategies used in internet-based psychological treatment for mental health has been Cognitive Behavioural Therapy (CBT). CBT is thought to be particularly amenable to the internet due to its structured format and ability to be converted to text (Cuipers et al., 2008; Ritterband, Thorndike, Cox, Kovatchev, & Gonder-Frederick, 2009; Spek et al., 2007). The rapid increase in internet-based treatment has resulted in some recent comprehensive reviews and meta-analyses.

Firstly, Spek et al. (2007) reviewed RCTs evaluating the efficacy of internet-based CBT programs for mood and anxiety disorders. Spek et al. (2007) included studies with no therapist assistance or minimal assistance, while specifically excluding studies where there was high level of support and where a relationship between therapist and participant developed. Measures included self-rating and clinican rating of depression and anxiety symptoms. Overall meta-analytic results of the 11 treatment studies found a large mean effect size, with a small mean effect size for depression and a large mean effect size for anxiety. Drop out rates for reviewed studies were between 3% and 24%. Spek et al. (2007) conducted further analyses comparing the studies based on level of support or assistance, categorised as having minimal support (e.g., feedback and monitoring emails or telephone calls) or no support. Those studies that incorporated minimal support found a large effect size compared to a small effect size when no support was given.

A second recent review paper by Griffiths, Farrer, and Christensen (2010) investigated the efficacy of CBT internet-based intervention targeting depression and anxiety. Studies included were also self-help websites or websites that had a self-help
component. Studies were excluded that had an active treatment control group (e.g., peer support, medication, or other form of therapy). The review included eight studies targeting depression, 16 targeting anxiety, and two targeting both. Recruitment of participants varied greatly from formal diagnosis of a mood or anxiety disorder, use of screening self-report clinical screening tools, or participants’ self-selection. Studies also varied in terms of level of therapist assistance/support, with two out of eight of the depression studies having therapist support, and the majority of the anxiety trials having support. Median therapist time for the interventions was 155 minutes.

Overall, Griffiths et al. (2010) found that 23 of these trials reported some evidence of effectiveness. The effect sizes found for anxiety and depression were at least as large as the effect sizes of previously reported face-to-face treatment. Effect sizes for depression were also comparable to anti-depressant medication. Although not statistically evaluated, the authors reported that this review suggests that internet-based treatment can be effective without therapist input. This review was also limited in that it excluded studies that had an active treatment control group and only made comparisons of effect sizes to face-to-face treatment of previously reported statistics within past research.

The comparative efficacy of face-to-face treatment to internet-based treatment is an important research question. Although no review paper has directly made this comparison, Cuijpers et al. (2010) conducted a systematic review and meta-analysis of studies that directly compared the effectiveness of face-to-face therapy to guided self-help therapy for depression and anxiety disorders. The review covered guided self-help interventions including the internet, and also the use of booklets, computer programs, and audio recordings. Cuijpers et al. found that guided self-help and face-to-face treatments did not differ significantly, and these findings were sustained at
longer term follow-ups of up to a year. The authors also found no difference in drop-out rates across the two treatment modalities.

Barak, Hen, Boniel-Nissim and Shapira (2008) conducted a broader meta-analysis exploring the effectiveness of internet-based psychological interventions for a range of identified problem areas. Problem areas ranged from weight loss, stress, smoking cessation, to anxiety and depression across a total of 92 studies. Overall, across all dependent measures included in these studies, the effect size was found to be medium. Barak et al. (2008) also made comparisons across problem type and found that strongest effect sizes were for internet-based programs targeting anxiety disorders and the smallest were for weight loss. Barak et al. also found CBT to be significantly more efficacious than psycho-education or behavioural therapy. Although Barak et al. evaluated a large number of studies, they did not isolate the effects specific for psychological problems and physical problems clearly. The following section explores the use of internet-based treatment for health behaviour and chronic illness specifically.

**Internet-Based Interventions Targeting Health Behaviour and Chronic Illnesses**

Self-management approaches for health conditions have long been advocated (Bodenheimer, Lorig, Holman, & Grumbach, 2002; Coleman & Newton, 2005). In terms of chronic illnesses, a self-management approach details the requirement for the individual to “manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition” (Barlow, Wright, Sheasby, Turner, & Shapira, 2002, p. 178). Barlow et al. (2002) extends on this to suggest that effective self-management requires an individual to monitor their condition and influence cognitive, behavioural and emotional contingencies in order to maintain a high QoL. In a review of RCTs and non-RCTs
(i.e., within-group changes) targeting self-management strategies for a variety of chronic health conditions, Barlow et al. found support for the use of a variety of formats (e.g., booklets, lectures, audiotapes, buddy system, internet) in terms of increasing knowledge, promoting self-management behaviours, self-efficacy and health status. Interestingly, although few trials targeted psychological well-being, those that did found a greater improvement in mood. This review found support for self-management strategies, however, the internet was not a focus in this review as a limited number of studies had used internet-based treatment as this point in time.

Given the need for promotion of self-management strategies in the area of health behaviour change and management of medical illnesses, it is not surprising that the internet has been growing as a platform to provide this service. Although most health based internet sites focus on information provision, there has been an increase in evidenced based strategies directed towards behaviour change in the context of health and illness. Using the internet to target such health psychology areas is thought to be highly useful considering the typically structured nature of the treatment approaches in these areas (Ritterband et al., 2003).

Cuijpers et al. (2008) systematically reviewed RCTs or comparitative trials focusing on internet-based treatment for health problems, while excluding studies focusing on mental disorders. Included studies used CBT to target behaviour change with participants who had existing physical disorders or health problems. The final study number was 12, and the included health conditions varied from chronic pain, insomnia, chronic diseases (heart, lung, or diabetes), to tinnitus. Included trials varied greatly from self-help material over the internet with and without minimal support (emails or telephone calls), and predominately online contact with a therapist or moderator (in group or individual format). The content of the interventions typically included psycho-education, cognitive restructuring, relaxation techniques
and social skills training. Finally, the interventions varied in length, ranging from 4 to 20 weeks.

Effect sizes for studies targeting pain were moderate to large, and small effect sizes were found for headaches, and these findings were comparable to previously reported face-to-face treatment. For other health problems, results could not be grouped, and the effect sizes for these ranged from small to moderate. Several limitations of reviewed studies were reported, including: limited use of control groups other than wait-list controls; and none compared internet-based treatments directly to face-to-face or other treatments.

In addition to chronic illness, internet-based treatments have also targeted behaviour change including smoking, alcohol, other substance abuse, weight loss, and HIV risk behaviours. Webb, Joseph, Yardley, and Michie (2010) systematically reviewed studies that compared a treatment condition that promoted some form of health behaviour change to a control condition or comparison group. Included studies were required to have a measure of behaviour related to health (e.g., alcohol consumption and physical activity). Importantly, Webb et al. (2010) also aimed to explore and identify which characteristics of internet-based interventions were related to significant positive health behaviour changes.

Webb et al. (2010) found an overall small effect size found with great variability in the level of effect between 85 included studies. The most commonly used behaviour change techniques included information provision, self-monitoring, and problem solving (includes identifying barriers). Although not used in many interventions, the use of stress management and communication skills training had the largest effect sizes. There was also greater benefit for the use of more strategies in a single intervention.
Webb et al. (2010) developed a coding system in order to explore the different modes of internet-based treatment delivery. Each type of delivery mode was divided into three categories: (i) automated functions – use of an enriched environment (e.g., videos, games), automated tailored feedback, automated follow-up reminders (e.g., tips); (ii) communicative functions – access to an advisor for advice, schedule contact with advisor (including emails); and (iii) supplementary modes – email, telephone, Short Messaging Service (SMS), CD-room, or videoconferencing. Studies using automated tailored feedback and an enriched online environment had small and significant effects on behaviour change, whereas automated follow-up reminders did not have a significant effect. For communicative functions, there were small to medium effects found for provision of access to an advisor and small effects for scheduled contact or peer-to-peer access. For supplementary modes – SMS had large effects, telephone use small-to-medium, and use of email had small effects.

**Internet-Based Treatment for Erectile Dysfunction**

Internet-based psychological treatments have also been developed for sexual dysfunction, including ED. A small number of programs have been developed and evaluated in populations of men without prostate cancer. Firstly, Leusink and Aarts (2006) developed a website providing basic behavioural exercises and information on pharmaceutical treatment for ED with the option of a prescription for PDE5 inhibitors. Use of the website by 98 men resulted in 81% of the participants reporting that their erections improved as a result of website use. However this study did not use a control group, as such it cannot be determined if erections improved spontaneously. The focus of this website was for men to initiate seeking help from a professional for their ED, and the website also focused heavily on medical treatment for ED.
Other researchers have developed specific internet-based psychological interventions and evaluated these in comparison to some form of an intervention group. McCabe, Price, Piterman and Lording (2008) and McCabe and Price (2008) developed a five module (over 10 weeks) internet-based CBT program for men suffering from ED called Rekindle aimed at targeting the psychological and interpersonal contributors to ED. The program consisted of sensate focus, communication exercises, and unlimited email contact with a therapist, and partners were heavily involved in the treatment process. Modules were covered in sequential order and were fed as each module was completed.

Firstly, Rekindle was evaluated by McCabe and Price (2008) by comparing Rekindle on its own to Rekindle in conjunction with oral medication for ED in a sample of 12 men with ED. Results found that both groups improved across measures of sexual functioning, relationship functioning (relationship satisfaction) and personal well-being. Therefore, the use of medication in addition to psychological internet-based treatment did not seem to have any additive benefit to sexual function. Although the sample size for this pilot study was very small, McCabe and Price highlighted many benefits for men with ED, including those facing time constraints and embarrassment about accessing help. The authors also highlighted such a program may only be suitable for men who are motivated and committed.

McCabe et al. (2008) compared Rekindle to a control group with a total of 31 men. Findings revealed improved erectile functioning and sexual relationship satisfaction and quality for men who completed the program, and improvements were maintained over the 3-month follow up. However, other areas of sexual function, orgasmic function, sexual desire and overall satisfaction did not improve and while sexual relationship satisfaction improved, general relationship satisfaction
did not. The authors suggest that this is because the program used did not directly target general relationship functioning. While this study demonstrated benefits in erectile function from this program, targeting general relationship functioning may impact on other areas including sexual desire and overall satisfaction. This may be particularly relevant for a prostate cancer sample, where gains in actual erectile function may be limited by the impact of cancer treatment.

A more recent study by Andersson et al. (2011) evaluated another internet-based CBT program for ED using a sample of 78 men randomised to receive the treatment or a control condition. The 7 week CBT program provided a series of modules covering the biospsychosocial information on ED in terms of aetiology and maintenance, relationship exercises, exposure tasks, relaxation strategies, and relapse prevention. Therapists’ assistance via emails provided support, clarified information, and reviewed participants progress through feedback. The control group had access to an anonymous forum with weekly topics added by a moderator. Results found that the treatment had a significantly positive impact on erectile performance in comparison to the control and this difference increased at the follow-up assessment point. There were no treatment effects for anxiety and depression.

**Internet use for Cancer Patients**

The types of internet health resources available for cancer patients have been divided into three categories: basic information, various types of social support and evidenced based interventions (Leykin et al., 2011). While the use of internet-based interventions has grown in both the mental health and general health setting, it has received relatively limited attention in the cancer setting, although in recent years growth in the cancer setting has started. Internet-based resources for cancer have been criticised for frequently consisting of support sites and provision of information
(Chambers et al., 2010; Leykin et al., 2011). While these sites play a role in assisting cancer patients, they fail to actually treat and decrease psychological symptoms, for example anxiety and depression (Leykin et al., 2011). In addition to information provision and support, evidence based internet interventions aim to engage participants in learning and practicing methods of behaviour change that are empirically supported (Leykin et al., 2011). This section will firstly briefly highlight the use of online support groups in cancer followed by internet-based psychological interventions.

**Online support groups and forums for cancer patients.** Although it is widely accepted that the online environment may be used by cancer survivors to share information and provide support, often in the form of online support groups, few researchers have investigated the efficacy of such groups. Three studies exploring the efficacy of online support groups are briefly outlined below.

Winzelberg et al. (2003) investigated the efficacy of an internet support group for women with breast cancer, aimed at assisting women to develop new strategies to cope with their diagnosis. Seventy-two women were randomised to receive either a 12 week internet-based social support group moderated by a mental health professional or a wait-list control group. Participants in the support group could read personal stories from survivors, were encouraged to share their personal experiences, and use a personalised and private web-based journal, with new topics introduced each week. Positive treatment effects were found for depression, cancer-related trauma, and levels of stress, but not for anxiety and other measures of coping. Satisfaction and acceptability with the support group was also reported to be high and participants logged into the site around three times per week. Although Winzelberg et al. (2003) found some evidence for the utility of online support groups for women with breast cancer, this study design did not allow for comparison to
another treatment group (e.g., face-to-face support group, information provision or psychological internet-based intervention).

Salzer et al. (2010) explored the efficacy of an internet peer support program compared to a internet-based educational control condition using a RCT for 78 women recently diagnosed with breast cancer. Limited details of the support program were given, other than that it was unmoderated and unstructured. The intervention resulted in declines across QoL and psychological distress in comparison to the control condition, while there was no differences for perceived social support and self efficacy. In contrast, acceptability and perceived benefit of the support program was rated as high, suggesting the women did receive some benefit from the intervention. The authors suggest that declines in QoL may be influenced by the sample consisting of newly diagnosed women with limited opportunity to receive advice from women with more experience.

Finally, Wiljer et al. (2011) explored the utility and efficacy of a 12-week internet-based support group (forum) for women with gynecologic cancer focusing on psychosexual distress by randomising 27 women to a wait-list control condition or the intervention. Moderators posted weekly topics to encourage discussion and women were encouraged to post other discussions relevant to them. This was a pilot study and the authors explored the efficacy and feasibility of the program through semi-structured interviews and found that women reported several benefits from the support program including increased emotional well-being, positive outcomes for body image and sexuality. Women reported finding the online environment beneficial for discussing sexual concerns.

Internet-based interventions for people with cancer. Two studies, using cancer samples, have developed interventions using a mixture of social support and
information provision or coping skills training. Firstly, van den Brink et al. (2003) developed an electronic health information support system for head and neck cancer patients in the Netherlands. The intervention group were loaned a computer with internet access for a period of 6 weeks after being discharged from hospital. Patients could communicate with hospital staff, gain information, monitor symptoms and have contact on an online forum with fellow patients.

Subsequently, van den Brink et al. (2007) evaluated the program with a cohort of head and neck cancer patients treated by surgery and the majority were men. The authors reported that patient use and satisfaction with the program were very high. Patient age was not a barrier (mean age 59 years and range 38-78) and nor was limited experiences with computers. Although the program demonstrated improved QoL outcomes compared to a control group, several QoL subscales were not significantly different to the control group, and only one of the improved outcomes remained at a 12 week follow-up.

Owen et al. (2005) evaluated the efficacy of a 12 week online self-guided coping skills group in a peer based format using 62 women with early stage breast cancer. Participants were randomised into either a wait-list control group or the online intervention providing a bulletin board for asynchronous group discussion, a medical dictionary, a series of useful resources, information and coping advice for the management of physical symptoms, and six CBT-based coping skills training exercises. Automatic emails were sent as reminders to engage in exercises and the forum. Fifty-three women completed post-test measures at 12 weeks from baseline. Although there were no main effects across QoL variables for the intervention group compared to the control group, Owen et al. found that women with lower self-perceived health status improved on this variable across time as a result of being in the intervention group. Although this program offers some support for combining
CBT based strategies with peer support, the study design did not allow for evaluation of these aspects in isolation.

**Internet use for Prostate Cancer Patients**

The internet as a medium has been viewed as offering a unique opportunity for provision of psychosocial interventions and social support in prostate cancer survivors (Chambers et al., 2010). In seeking support for psychosocial issues related to prostate cancer and its treatment, there have been several potential barriers implicated, and many of these barriers may be overcome by internet-based treatment. In addition to those benefits of internet-based options highlighted at the beginning of this chapter, the common morbidities of prostate cancer for which men may need assistance (e.g., sexual problems and incontinence) may increase stigma that men associate with seeking help. Specifically, it has been suggested that men may not be comfortable requesting information or assistance for managing ED (Wootten, Burney, Foroudi et al., 2007). In fact, both men with prostate cancer and health professionals may display discomfort and embarrassment with discussing sexual and intimacy issues (Galbraith & Crighton, 2008; Incrocci, 2006b). The anonymity and convenience of the internet means that discussion about often embarrassing and sensitive issues such as sexual dysfunction can be easier to disclose (Hall, 2004).

The internet has also been found to be an attractive means to obtain medical information for prostate cancer survivors, especially information surrounding sexual rehabilitation (Davison, Keyes, Elliot, Berkowitz, & Goldenberg, 2004; Neese et al., 2003). Participants in this research generally had a positive view of using the internet (Davison et al., 2004; Neese et al., 2003). Schover et al. (2004) found that help-seekers for sexual problems were more likely to be distressed about ED and have
more positive attitudes regarding help seeking and have lower sexual satisfaction. These are the kinds of men that could be targeted in an internet-based intervention.

**Online support groups and forums for prostate cancer patients.** Social support has been advocated for people with cancer because of its potential positive impact on QoL. In particular social support is thought to be beneficial for mental and physical health, in addition to helping adjustment to a diagnosis of cancer and what it entails (Lepore & Revenson, 2007). Face-to-face support groups for prostate cancer are common in Australia and have been found to provide men with information and emotional support while reducing feelings of social isolation (Steginga, Pinnock, Gardner, Gardiner, & Dunn, 2005). The online environment may provide additional benefits. Chism and Kunkel (2009) suggested that social networking sites and online groups can offer a non-threatening space for men to explore and express difficulties and concerns.

It is generally acknowledged that online support groups for men with prostate cancer exist in the form of both information and support. Most research has focused on evaluating the content of messages of already running online groups, with limited research detailing specific trials evaluating the efficacy of online support groups for men with prostate cancer. Blank, Schmidt, Vangsness, Monteriro and Santagata (2010) recently explored the content of messages over a 1 month period on prostate and breast cancer groups’ websites. Two internet resources were included, WebMD and Google Groups. Both of these are free and individuals can create comments and respond to topics as they choose. Interestingly, 80% of posts were from cancer survivors compared to those newly diagnosed. Blank et al. (2010) further categorised the content of messages into several categories and sub-categories. Although women’s messages were more likely to offer emotional support, men were more
likely to post messages related to intimacy issues, with 77.6% of intimacy classified posts for men with prostate cancer being related to sexual performance. This suggests that men may find a forum or bulletin board as a valuable to explore intimacy issues.

Consistent with Blank et al.’s (2010) findings, others have suggested that women are more emotionally expressive and men prefer to share information (Kiss & Meryn, 2001; Zakowski et al., 2003). Zakowski et al. (2003) also stated that although men tend to seek support primarily from their partners, compared to multi social supports that women access, there is little evidence that men do not want to engage in support groups. The lack of empirically developed support groups, including online, for men with cancer means that men may be disadvantaged, especially single men who lack support from a partner. The groups that do exist that have been evaluated in Blank et al.’s (2010) study have not been designed specifically for evaluation and do not have a particular moderator who posts comments, as seen in previous studies using support groups for women (Salzer et al., 2010; Wiljer et al., 2011; Winzelberg et al., 2003). It could be that a moderator forum increases engagement and the benefits men may receive from online support groups.

**Internet-based treatment for prostate cancer patients.** Although there have been several studies exploring the efficacy of internet-based programs to assist with screening and treatment decisions (e.g., Berry et al., 2006; Frosch, Bhatnagar, Tally, Hamori, & Kaplan, 2008), to date there have only been two psychological internet-based interventions targeting men with prostate cancer dealing with survivorship issues. Firstly, Kazer, Bailey, Sanda, Colberg, and Kelly (2011) developed an intervention to assist men with the uncertainty that comes with having prostate cancer treated by active surveillance. This 5 week program included general
information about prostate cancer and active surveillance, cognitive reframing, self-care management strategies (e.g., weight loss, exercise, smoking cessation), and tailored emails addressing specific problems or issues relevant to individuals (e.g., disease progression or relationship concerns). Kazer et al. evaluated the program using a single-subject design using nine men and found eight out of 12 measures of QoL demonstrated improvements at 5 weeks, but returned to baseline or below at the follow-up time point (e.g., emotional health and sexual function). Acceptability rates were quite high (e.g., satisfaction with information and ease of use of website), suggesting further investigation of this program using a more rigorous trial is warranted.

There has been one internet-based study that has used a sample of men treated for localised prostate cancer using active treatment. Schover et al. (2012) designed an internet-based version of Canada et al.’s (2005) couples’ sexual rehabilitation treatment program, and compared this to a 3-session version of the face-to-face counselling program. Initially, 121 couples who underwent surgery or radiotherapy in the past 3 months to seven years were randomised into a wait-list control group or one of two intervention conditions: face-to-face counselling versus internet-based counselling with email contact with a counsellor. An internet-based replication trial was used for 71 couples who lived too far away from the study site to be randomised into the face-to-face intervention. Couples were recommended to complete the internet-based program in 4 to 8 weeks, however up to 12 weeks was accepted. As well as covering most aspects of the face-to-face program reported in Canada et al.’s study (see in previous chapter) focusing on sexual functioning, the internet program incorporated a videotape of couples’ personal experiences, and behavioural homework with feedback. Both groups were given telephone check-up calls. The researchers attempted to keep the face-to-face and internet versions of the
intervention similar by streamlining homework tasks. Sexual functioning and relationship functioning measures were taken, at baseline, post-intervention and at 3 months, 6 months, and 12 months post-intervention.

Schover et al. (2012) found that the internet-based program was as effective as a brief traditional face-to-face sexual therapy program. Outcomes across all measures for participants in the wait-list control condition did not change over the 3 month waiting period. When the two internet-based programs were combined, the strongest gains found in sexual function and sexual satisfaction were for couples who changed from not using ED medical treatment or oral medication only to a more invasive option. No gains were found for relationship functioning, however scores were high across all groups at baseline. Interestingly, recruitment into the second internet-based intervention was much faster than the randomised trial, suggesting that internet-based programs are appealing for couples. Despite the benefits of this innovative study, drop-out rates across all three groups were still high, ranging from 25-39%.

**Summary and Conclusions**

The internet is growing as an acceptable platform for delivery of psychological treatment programs for a variety of psychological disorders and medical conditions including cancer. The internet has been viewed as having many advantages, including breaking down the barriers that many people face in terms of accessing support, both in terms of available resources and in terms of stigma, fear and uncertainty in accessing mental health services, factors that deter many people in accessing support (Gega et al., 2004; Klein et al., 2009). Additionally, psycho-education and self-directed therapeutic techniques can easily be formatted onto an online format. In particular, the structured nature of CBT, with weekly cognitive and behavioural strategies with homework, appears to be particularly amendable to the
internet, and programs are sometimes developed from face-to-face therapies and adapted to the internet.

Comprehensive reviews and meta-analyses suggest that for CBT at least, internet-based treatment is as effective as face-to-face for anxiety and depression (Barak et al., 2008; Griffiths et al., 2010; Spek et al., 2007) and for chronic illness and health behaviour change (Barak et al., 2008; Cuijpers et al., 2008; Webb et al., 2010).

The use of internet-based treatment in cancer is still in its infancy. Most research has focused on developing and evaluating peer support based programs with mixed outcomes, and there have been a small number of studies that have used peer support in conjunction with other intervention strategies demonstrating some promising results. Only one study (Owen et al., 2005) used more complex intervention strategies that were seen in previous internet-based research for mental health and other health conditions for women with breast cancer. Although emerging evidence suggests some utility for the use of peer support programs or peer discussion in conjunction with other psychological treatment, further research is needed to clarify this and no studies have evaluated the use of developed peer support or forums using prostate cancer samples.

There has only been one study to date investigating the efficacy of an internet-based psychological intervention for men treated for localised prostate cancer (Schover et al., 2012). While this study found that an internet-based version of a couple’s sexual counselling program was as effective as brief traditional face-to-face program, this program was heavily therapist assisted and focused predominately on sexual rehabilitation. To date, no internet-based, self-directed, with minimal support, intervention has been developed and evaluated for men treated for localised prostate cancer with a focus on a range of identified problem areas. The next chapter provides
further rationale for the current study and outlines the development of an internet-based program for men treated for prostate cancer.
Chapter 7: Rationale for Future Research and Development of an Internet-Based Program

This chapter firstly outlines the rationale for the current study, followed by a description of the various components of a psychosocial internet-based program for men treated for localised prostate cancer. Secondly, it outlines the development of the program with a detailed overview of the content and structure of the program. The processes involved in the development of this program and the specific program modules are discussed in detail in the current chapter.

Rationale for the Current Study

The primary aim of the present study was to develop and evaluate a treatment program designed to address the psychosocial functioning of men who have been treated for localised prostate cancer. From the review of literature covered in the previous chapters, it is clear that the impact of prostate cancer and its treatment on a man and his partner’s life is well established. Prostate cancer is a life changing experience which is likely to influence a man’s sense of self, his emotional health, his physical health and his relationships with others. Although survival rates for prostate cancer are high, treatment for prostate cancer typically results in several major morbidities, including incontinence of bladder and bowel, sexual dysfunction, and psychological difficulties. Partners are likely to be influenced by prostate cancer and its treatment, and the couple’s relationship may be negatively impacted.

Research has indicated that men with prostate cancer have many unmet needs. An Australian population-based study explored the needs of men who had been diagnosed with prostate cancer between three and 12 months after diagnosis (Smith et al., 2007). The majority of the sample had localised prostate cancer and about half
had undergone surgery at the time of data collection. Smith et al. (2007) identified that 74% of men reported some form of unmet support need in relation to their prostate cancer diagnosis. The most common reported unmet need was psychological support, where 54% of men expressed that they felt they had some level of unmet psychological support (Smith et al., 2007). Forty-seven percent of men reported sexuality to be an area in need of some assistance or support. Not surprisingly, having surgery predicted needs in the sexuality domain. Similarly, Stegina et al. (2001) reported that approximately a third of men reported unmet needs in the sexuality and psychological health domain in a sample of men who had been treated for prostate cancer and who were members of a support group.

The current health care system in Australia provides no standard model of care in terms of accessibility of appropriate and timely psychosocial support services for men with prostate cancer. This is a common theme worldwide (Holland et al., 2011). In Australia, rural and regional patients may have the most difficulty accessing appropriate support (Clinical Oncological Society of Australia, 2006), even though people in these areas have been identified as having a disadvantage in terms of mental health outcomes (Burris and Andrykowski, 2009). Around one third of Australian’s live outside Australia’s major cities in rural and regional areas (Australian Institute of Health and Welfare, 2007). The psychosocial services that are available often have long waiting lists and involve out-of-pocket costs and other restrictions (COSA, 2006). Research has found that telephone and internet-based support are particularly important for men with cancer, predominately prostate cancer, living outside metropolitan regions in Australia (Corboy et al., 2011). Klein et al. (2009) also highlighted that rural and regional areas also lack access to general mental health treatment, which suggests that men with comorbid mental health issues in these areas may be particularly vulnerable.
Although there are several support group options through organisations such as The Cancer Council and the Prostate Cancer Foundation of Australia, these do not provide specific psychosocial interventions aimed at reducing distress. Smith et al. (2007) strongly recommended access to the spectrum of support services for prostate cancer patients, including nursing specialists, psychological counselling, peer support groups and consumer information. In Australia, Chambers et al. (2008) suggested that current medical and support services are largely focused on patient outcomes and do not take into account a couple’s relationship, as well as overlooking the female partners’ needs.

The medical model also focuses on care at diagnosis, where there is a tendency to focus on prognosis and treatment (Incrocci, 2006b). However, some men may not be fully aware of the potential side effects and difficulties faced post-treatment until sometime after treatment (Beck et al., 2009). Men have different needs at different times. Although it has been suggested that men have information needs at diagnosis and when considering treatment options (Beck et al., 2009), Incrocci (2006b) suggested that at this time there may be a tendency to focus on prognosis and treatment, with little time to appreciate the importance of sexual function. Symptom distress may increase post-treatment when some of the discussions and stressors have subsided. As such, men may not be aware of the impact ED has on their lives and underestimate the ease of use of medical treatments. Beck et al. (2009) suggested that even if men are well informed of the potential side effects and difficulties faced post-treatment, there are always some men who do not believe they will experience these side effects or overestimate their ability to adjust to side effects.

The internet has been emerging as a platform for e-health in recent years and research has found support for the effectiveness of internet interventions in a variety of psychological disorders, health conditions, ED in the general population, and in
cancer. As highlighted previously, the internet has been viewed as particularly attractive for men treated for prostate cancer given the anonymity involved when discussing sensitive topics such as sexual problems. An internet-based intervention may enable some of the unmet needs of men treated for prostate cancer to be addressed, including providing services to those in geographically isolated locations or those who prefer not to seek treatment via other formats or those with sub-clinical levels of mental health problems.

Although internet-based treated has been advocated in the area of cancer (including prostate cancer), there has been very little empirical research, with only one study addressing the needs of men treated for localised prostate cancer which focused on sexual rehabilitation (Schover et al., 2012). The cost effectiveness of internet interventions is frequently cited as a reason to use the internet as a delivery platform (Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006). Given the prevalence of prostate cancer in Australian men, a more self-directed program may be able to assist a greater number of men in the long term, and address a broader set of needs than can be addressed in face-to-face treatment. A self-directed internet-based program is also likely to improve accessibility to men located in rural and regional areas who have been highlighted by COSA (2006) as having limited support and service options for cancer.

**Description of Components of an Internet-based Program for Men Treated for Prostate Cancer**

The following section outlines a justification for the various components of a psychosocial internet-based treatment program for men treated for prostate cancer. This is based on past research and recommendations from authors working in this area.
Theoretical framework for program. The internet-based psychological intervention that was developed and evaluated in this thesis was predominately CBT based. CBT is an evidenced-based psychological therapy aimed at treating a range of problems including mental health, interpersonal difficulties, adjustment and personal problems (Sheldon, 2011). CBT assists people to understand the relationship between their thoughts, feelings and behaviours. In doing this, the underlying premise of CBT is that thoughts and feelings influence behaviour and that cognitions can be altered (Taylor, 2006).

CBT is thought to be helpful for those with medical illnesses because it addresses the stressors associated with such an illness, associated psychological distress and other QoL concerns (Taylor, 2006). For many, cancer can be a threat across several areas of a patient’s life, and thus may trigger cognitive beliefs related to illness, oneself, others and the world (Mooer & Greer, 2010). In addressing the difficulties and unmet needs of men treated for prostate cancer, a CBT approach aims to promote active problem solving and alter cognitions and behaviours. Since CBT can also be used to assist clients to test fears or avoidant behaviours through behavioural experiments, it may be particularly helpful when addressing some of the sexual difficulties seen in prostate cancer. Typical techniques in CBT include psychoeducation, relaxation, thought monitoring, cognitive structuring, behavioural experiments, problem solving, and activity scheduling.

As highlighted previously, CBT is thought to be particularly amendable to the internet due to its structured format and ability to be converted to text (Cujpers, 2008; Ritterband et al., 2009; Spek et al., 2007). In addition, Ritterband et al. (2009) stated that promoting cognitive and behavioural change is a common goal for internet-based interventions. As such, it appears CBT is well suited to help men
adjust to the psychological, physical and social difficulties associated with prostate cancer and its treatment.

The majority of internet-based research covered in the previous chapter for psychological and physical health problems were CBT based, and one review study found that CBT demonstrated greater efficacy than psycho-education or behavioural therapy (Barak et al., 2008). In terms of prostate cancer, the use of CBT has been found to have benefits in face-to-face, telephoned based formats and internet formats (Canada et al., 2005; Molton et al., 2008; Penedo et al., 2007; Schover et al., 2012). CBT internet-based programs have also been used to treat ED in the general population (Andersson et al., 2011; McCabe & Price, 2008; McCabe et al., 2008).

Psychological distress has been identified as a risk factor for men with prostate cancer. As highlighted previously, past research has failed to adequately address this, instead often focusing exclusively on general symptom or stress management. CBT based strategies in the current project were able to assist men treated for prostate cancer by identifying symptoms and building skills and strategies to improve any psychological distress. A CBT based program could also assist with education and development of communication skills for men to use with health professionals, friends, partners, and other family members. The relationship with an intimate partner was particularly targeted, where general communication and sexual communication would be specifically targeted as suggested by past researchers (Wincaze & Carey, 2001) and integrated into successful programs (Canada et al., 2005; Schover et al., 2012).

Interventions targeting sexual difficulties in populations with and without prostate cancer have also incorporated strategies from sex therapy (e.g., sensate focus). Such programs have been found to be effective in assisting men treated for prostate cancer in face-to-face formats (Canada et al., 2005; Molton et al., 2008; Titta
et al., 2007) and internet format (Schover et al., 2012). Sex therapy works to address the emotional, cognitive and interpersonal aspects of ED. Specifically, it was found in Chapter 5 that those who used sex therapy strategies were more likely to have a positive influence on sexual function outcomes. Strategies were also be included in the proposed program that aimed to broaden a man’s concept of sexuality and masculinity, which has been suggested by others to be useful for sexual rehabilitation (Fergus et al., 2002) and used successfully by previous RCTs (Canada et al.; 2005; Molton et al.; Schover et al., 2012). In addition, the use of medical aids in conjunction with psychological strategies has been suggested to be of benefit (Canada et al., 2005; Fergus et al., 2002; Schover et al., 2012; Titta et al., 2007) and was included in the program.

Although the focus of the program and this thesis was on sexual, psychological, and relationship functioning, a comprehensive program needed to also address other problems and difficulties that men treated for prostate cancer typically experience. Psycho-education and CBT based strategies were used to assist men with anxiety associated with urinary dysfunction, and to assist with coping with uncertainty about the future.

**Level of therapist assistance.** In light of the rapid increase of psychological internet-based interventions, researchers have begun to explore the utility of different components of such treatment. Although most internet-based treatment is generally described as self-help, one of the major ways that psychological internet-based treatment can vary is the level of contact/support by a therapist or advisor (Cuijpers et al., 2008; Spek et al., 2007). This can vary from no assistance, automatic emails, minimal personalised or tailored emails, therapist assisted tailored emails to telephone calls (Cuijpers et al., 2008; Spek et al., 2007). At the extreme end, therapists may provide individual or group therapy at a specified time, at a level of
therapist assistance comparable to face-to-face therapy (Cuijpers et al., 2008; Spek et al., 2007).

Spek et al. (2007) found a greater overall effect when minimal support was provided in comparison to no support for interventions targeting anxiety and depression and Webb et al. (2010) found greater treatment effects for automated tailored feedback compared to automated follow-up reminders. One group of researchers who had previously identified that the use of emails enhanced outcomes for a self-directed behavioural based internet intervention for obesity/weight loss (Tate, Jackvony, & Wing, 2003), later found automatic tailored emails was as effective as personalised human emails for a similar intervention, and both were more effective than no emailing (Tate, Jackvony, & Wing, 2006).

Although the exact optimal level of therapist assistance may not be known, it seems reasonable that some level of minimal assistance is appropriate and beneficial for programs that are in a self-directed format. In particular, some sort of weekly feedback in the form of email contact is thought to increase accountability and enhance responsiveness (Tate, 2011). This was integrated into the current program.

**Structural components.** Leykin et al. (2011) made several recommendations when calling for the need for more methodological rigorous trials for psychosocial internet-based interventions for patients with cancer, many of which were incorporated in the proposed program.

Leykin et al. (2011) highlighted that an important decision for online intervention developers is whether to use a sequential flow of lessons where subsequent lessons are gated or an adaptable structure where individuals can choose the order of lessons. For this study the second option was taken to increase engagement and sense of control for men, while potentially reducing attrition rates. Research using formats other than internet in prostate cancer that have been highly
tailed have allowed men to identify problem areas such as ED and relationship concerns (Giesler et al., 2005). In addition to an open gated program, the use of a log book was implemented to allow the program to have some level of personalisation.

The use of an interactively enriched environment (e.g., use of audio, video) has been found to contribute to more effective internet-based programs (Barlow et al., 2009). Webb et al. (2010) also suggested that these programs should be as interactive as possible with the use of online exercises and videos, while using limited amounts of text on each screen shot. The current program used videos, audios and online exercises while incorporating components of CBT including offline exercises (i.e., homework) in order to practice and consolidate new skills. Based on past recommendations for internet-based treatments for cancer patients, a mood monitor was included as a form of self-monitoring (Leykin et al., 2011).

**Forums/online support.** A forum was developed for men treated for prostate cancer. Social support may come from peers, moderators or other men on some form of online forum, either in isolation or conjunction with internet-based interventions. An online forum was developed for those treated for prostate cancer based on an asynchronous format where weekly topics are given by a moderator. This was based on research using such forums in samples of women with cancer. Similar the study by Wiljer et al. (2011), posts were put up weekly by the moderator to encourage discussion.

**The Current Project**

There is a clear need for psychosocial assistance for men treated for prostate cancer. Although there is some emerging research providing evidence for the benefit of various programs, further research is required concerning psychosocial treatments. Very few interventions have aimed to target sexual, psychological and relationship
functioning in a comprehensive program, and no research that the author is aware of has addressed these factors in a comprehensive internet-based intervention. Further, no psychosocial internet-based program for men treated for prostate cancer has been developed in a self-directed format with minimal assistance. While this program was designed to be largely self-directed, past research clearly suggests that some level of contact or assistance may be necessary. We aimed to create a program with minimal support with the intent to develop a program that could be disseminated effectively and efficiently at minimal cost in the future.

In an attempt to address the gaps in the research, the current study aimed to develop and evaluate the efficacy of a manualised CBT internet-based program aimed at improving sexual, psychological and relationship functioning, among men treated for prostate cancer. The program was designed to target men who were married or single and had been treated for localised prostate cancer in the last five years. This timeframe was selected since past research has found many men struggle with the impact of prostate cancer and its treatment (e.g., erectile dysfunction) up to five years post treatment. Partners were encouraged to be involved in the treatment process. Even though intervention research has not yet clearly found support for the inclusion of partners, quantitative and focus group research highlight the importance of partner inclusion.

The first part of the empirical investigation of this thesis involved the development of the program for men treated for prostate cancer. The content of the program aimed to overcome some of the limitations of past research by including psycho-education plus skill-based strategies; addressing the complex multi-dimensional nature of sexuality; acknowledging the couple’s relationship and including the partner; and targeting psychological distress directly. A summary of the main strategies identified to form a comprehensive psychosocial intervention are
outlined below. These are incorporated into specific modules that are outlined in
detail later in this chapter.

- Psycho-education for psychological functioning in relation to cancer and
treatment.
- Exploring the overall impact of prostate cancer (including aspects such as
urinary difficulties).
- Sexual problems and cancer and the impact of ED and cancer on the
relationship.
- Education and assistance with the use of medical aids.
- Targeting negative cognitions surrounding cancer and ED/sexuality.
- Skills training in general and sexual communication.
- Broadening definitions of sexuality and sexual range of sexual activity.
- Addressing masculinity and identity issues.
- Addressing worries and concerns about the future.

The second part of the empirical investigation of this thesis involved an
evaluation of the internet-based psychosocial program for men treated for prostate
cancer using a RCT. The program included a control group and comprehensive
measures addressing the multi-dimensional nature of sexuality were used. A variety
of outcomes measures were used to adequately cover sexual, psychological and
relationship functioning. Data were collected at pre-test and post-test. Three
treatment groups were formed in this study: (i) access to the online modular program
(Modules-only); (ii) access to the online modular program plus the online forum
(Modules-plus-Forum); (iii) access to the online forum only (Forum-only).

This study design was chosen to evaluate the online modular program in
comparison to a more basic level of care, which in this case was peer support. Past
RCTs have used a variety of control conditions from wait-list control groups, care as usual, or some basic information provision. Cuijpers et al. (2008) has criticised past internet-based RCTs for failing to use control groups beyond wait-list control, since there may be an overestimation of intervention efficacy when those in a wait-list control condition are unlikely to make self-directed steps to improving their situation if they are “waiting”. Basic moderated forums have been used in previous studies as a control group as a means to control for spontaneous improvement or to control for the general attention and the possible beneficial effects from sharing one’s distress with others (e.g., Andersson et al., 2011; Hesser et al., 2012). Since online support groups may themselves have positive effects for people with cancer (e.g., Wiljer et al., 2011 and Winzelberg et al., 2003) it was thought that the use of three groups (Modules, Modules-plus-Forum, and Forum) would allow for exploration of the benefit of combining the internet psychosocial intervention with peer support (forum).

**Development of an Internet-based Program for Men Treated for Prostate Cancer**

An internet-based CBT program was developed to assist men who have been treated for localised prostate cancer. The processes involved in the development of this program and the program modules are discussed in detail in this section. An overview of the program and its components is provided before detailing participant’s experience of entering the program and each of the modules.

**Program aims.** There were several aims which informed the development of the online self-directed psychosocial intervention for men with prostate cancer including: (i) attempting to overcome the barriers for men in accessing appropriate support (e.g., rural communities, anonymity for ED); (ii) targeting the common
problems men experience after treatment for prostate cancer, including psychological adjustment difficulties, management of side effects, relationship and sexuality concerns; (iii) creating a universal program that can be used by partnered and single men; and (v) providing both education and therapy in an attempt to improve the wellbeing and address the needs of men treated for localised prostate cancer.

Program development. A variety of sources were used to guide the development of both the content and structure of the internet program titled My Road Ahead. Firstly, previous research providing information about the psychosocial needs and problems of men and their partners, and research evaluating the efficacy of psychological treatments for men with prostate cancer, was used to guide the content for the program. Secondly, the development of the content of the program was assisted by a CBT group-based psychotherapy program developed by Melbourne Health called Below the Belt. This program is currently being evaluated through an unpublished RCT (A. Wootten, personal communication, November 25, 2010).

Thirdly, the program content was guided by clinical practice. Specifically, a Clinical Psychologist who has provided face-to-face individual and group therapy for men who have been treated for prostate cancer over the past seven years played an integral role in My Road Ahead’s development. The structure of the program was largely guided by a multimedia company, Web Elements, and research detailing the use of internet-based treatments in other settings. Key learnings from a well-established mental health online intervention platform, Anxiety Online, were also integrated into the development of My Road Ahead.

The actual website was created by the research team in consultation with a multimedia company. In addition to building the My Road Ahead website, two owners of this company were prostate cancer survivors who also provided creative input that assisted in making My Road Ahead appealing to men with prostate cancer.
Finally, the program was pilot tested by several researchers and eight prostate cancer survivors.

**Overview of program.** *My Road Ahead* was developed as a 6-module self-directed program to assist men with many of the typical difficulties faced after prostate cancer and its treatment. The program was called *My Road Ahead* to reflect the cancer journey that many men with prostate cancer describe, emphasising a process and the need to take a number of steps along a path that eventually leads to psychological adjustment. *My Road Ahead* was largely CBT based, incorporating aspects of sex and relationship therapy.

The program was designed with the following requirements in mind. *My Road Ahead* was a program for men who had received treatment for localised prostate cancer in the last five years. The program was open to men who did and did not have a partner and who were any sexual orientation. In order to get the most out of the program, men were required to be able to regularly commit at least one hour per module. However, it was expected that more than one hour would be necessary for some modules, particularly if a man was interested in or found particular benefit from a module. Modules were designed to take approximately one and a half weeks to complete. Many of the skills learnt in earlier modules were used in subsequent modules and were sometimes expanded on across modules. Therefore, men were informed that they should complete the modules in the designed order. However men were also informed that they could opt to access any of the modules they found relevant or interesting at any point in time. Men could only access the beginning of each module.
Program components. The following section outlines the major components of My Road Ahead. These components form the basis of the modules. The modules are covered in detail after this section.

Partner involvement. As mentioned previously, My Road Ahead was designed for men who do and do not have a partner. Men who had a partner were frequently encouraged to discuss the information they learnt from the program with their partners. Partner involvement was voluntary. At the beginning of Module 1 there was a video which encouraged men to bring their partner to the computer screen and listen to the video. There were handouts for men to print for their partners at the end of each module. These information sheets were generally 2-3 pages long and summarised the major components of each of the modules the men completed (Appendix A). The partner information sheets contained some specific exercises for partners that mirrored the exercises men completed and joint exercises for partners to complete with men.

Single men. For men who did not have a partner, they were encouraged to use a close friend or family member to complete some of the online and offline exercises. Throughout the program alternative diagrams and examples were provided specifically for single men and their needs in mind.

Videos. Men were recruited for videos through three different urologists’ patients and public patients from the Royal Melbourne Hospital and the Willian Buckland Radiation therapy centre. Of the 151 patients who were sent letters, 16 offered their services, and a final 9 were selected based upon availability. Videoing took place over two days by a Clinical Psychologist using a semi-structured interview.

There were two to four online videos in each module from various health professionals and prostate cancer survivors. Each video ran for between 1 and 3
minutes. A Clinical Psychologist was featured throughout *My Road Ahead*, providing information and advice about using the program, relevant psycho-education and summaries of module key points. At the end of each module, the Clinical Psychologist summarised the module, provided an overview of the offline exercises and encouraged men to practice skills newly acquired. When relevant, these videos also encouraged men to include their partners, highlighting the importance of communication and organising time to work through things together. Where applicable, other health professionals participated in the videos.

Videos reporting prostate cancer survivors’ experiences formed an important feature of *My Road Ahead*. Each module commenced with an edited video with four or more men discussing their own experiences and thoughts relevant to that specific module. Placement of these videos at the beginning of each module was hoped to normalise men’s experiences and demonstrate that *My Road Ahead* has been developed in consultation with men who actually have prostate cancer.

**Online exercises.** In an attempt to make *My Road Ahead* as interactive as possible and provide men with an opportunity to develop specific skills throughout the modules, there were several online exercises throughout the program. Men were requested to type their responses directly into online worksheets which were then stored in their own personal logbook. Many online exercises were expanded and developed upon across each of the modules. For example, initial CBT exercises involving thought monitoring later involved challenging thoughts.

**Offline exercises.** Men and their partners were asked to complete a range of activities in-between modules to assist them develop and practise the skills learnt throughout the program. Offline exercises were generally relevant to the content and skills learnt in the immediately preceding module. Men had the option to download the offline exercises in paper form or log their work in the logbook online.
Offline exercises were reviewed by participants before commencing the next module. This involved a series of questions related to the outcomes of the offline exercises and consideration of any difficulties completing this. Example questions included – “How did sharing this exercise with your partner go?” and “What was learnt from this exercise?”

_Mood monitor._ Throughout _My Road Ahead_, men were given the opportunity to track their mood at the beginning and end of each module. Mood was measured across five different continuums: (i) “sad” to “happy”; (ii) “anxious” to “relaxed”; (iii) “angry” to “calm”; (iv) “confused” to “informed”; and (v) “lost” to “in control”. Users were able to drag a tab along five different points on each of the mood continuums. The mood monitor was recorded into each participant’s logbook and produced a graph over time which men could view at any point. The mood monitor was anticipated to increase awareness of the relationship between actions and wellbeing, and increase engagement in the program.

_Personal logbook & bookmarks._ Responses men entered into the online worksheets and offline exercises were entered into a personalised logbook that men could visit at any point. Upon program completion men could use the logbook as a resource for reflection and as a summary of what they have learnt and achieved. Men could also use the logbook for recording and developing future orientated goals. Additionally, participants were able to bookmark any specific pages or subjects of interest, for example, a particular diagram related to sexual function.

_Moderated forum._ This forum was developed to offer men the opportunity to share experiences, ask questions and share information. This was a space to share thoughts, ideas, tips or information with other men who might be going through similar experiences. There was a separate forum for those men who had access to the modules and those that did not.
**Website set-up earlier pages.** Before consenting to participate in the study and program, men obtained some background information on the program from the home screen. The “What is My Road Ahead” tab provided some basic background information about the program and a video of David Parkin introduced *My Road Ahead*. David Parkin was a high profile ex-footballer who had prostate cancer. There was also a “FAQ” tab which has 10 questions related to the program, research and privacy. A tab titled “Seek help” directed men to emergency contacts, support contacts, and useful websites.

**Program entry.** The start-up pages for *My Road Ahead* can be found in Appendix B. Once participants selected the “sign up” option they were taken through a series of pages which summarised the program and the research. This section also covered expectations of participants and required men to tick three statements related to their commitment to the program and agreement to complete the questionnaires. This was aimed at increasing motivation and commitment, similarly to a therapeutic contract drawn during face-to-face therapy. On the following page, men were requested to download the consent form and give consent to participate in the research. Once they had consented, participants were asked to form an account creating a username (which was used on the forum if they have access to this) and password. Due to the sensitive and private nature of the program, passwords were necessary to ensure security of website users. After creating an account, men were immediately sent an email requesting that their *My Road Ahead* account was validated. Once validating their accounts men are asked to complete the first set of questionnaires, a series of demographic questions and questionnaires. Immediately following questionnaire completion participants were informed which treatment condition they had been randomised to: the Modules only, the Modules-plus-Forum or Forum only.
Men were then provided with sliding screen shots relevant to which of the
three groups they had been randomised to (see Appendix C). Each group received a
screen shot covering information on completing questionnaires and a remainder that
access was only for 10 weeks. Those with access to the modules were given sliding
screen shots on an overview of modules; program features including video content,
online exercises, offline exercises, book marking topics of interest, logbook, mood
monitor; and partner or close friend/family member’s involvement. Those with
access to the forum were given three sliding screen shots recommending participants
“share their experiences”, “help others by providing support” and “ask questions”.
Participants who had access to the modules also received a video from a Clinical
Psychologist explaining the main aims of the program and how to get the most out of
the program.

**Specific treatment modules.** *My Road Ahead* consisted of 6 modules, with
earlier modules designed to provide a “stepping stone” for the next module. Each of
these modules is described below. Some example pages from these modules are in
Appendix D. Appendix D also displays the home screen seen by participants who
have access to the modules, the logbook and an example of the mood monitor. Login
details to review the modules are: username (healthprovider) and password (health).
The website is www.myroadahead.org.

**Module 1: Prostate cancer and you.** The purpose of Module 1 was to provide
an overview of how prostate cancer and its treatment can affect the different areas a
man’s life, and to address some of the common emotional reactions that accompany
prostate cancer and its treatment. On completion of this module it was anticipated
that men would begin to understand and explore how prostate cancer impacts
different aspects of their lives and emotions. The module also aimed to provide some self-care strategies.

Module 1 commenced with a video of prostate cancer survivors discussing their reaction to cancer diagnosis and treatment, including emotional reactions such as depression, anxiety and anger. This was immediately followed by a video from a Clinical Psychologist emphasising the importance of physical, social and emotional changes associated with prostate cancer and its treatment and that these areas would be addressed in *My Road Ahead*. This video also emphasised the need to acknowledge the impact prostate cancer has on both the man and his loved ones.

This module moved into further education around emotional reactions to prostate cancer and treatment. Emphasis was placed on normalising reactions and highlighting that there is no normal or correct way to feel, and that emotions can vary across the different stages of a cancer journey. While a variety of emotional reactions were presented, anxiety, grief/sadness, and anger were covered in more detail. A diagram was used to demonstrate the common and unique symptoms of anxiety and depression using some prostate cancer specific examples. An online worksheet exercise requested that men consider what factors have been leading to worry in their lives. This exercise was anticipated to encourage men to begin self-reflection.

Further psycho-education on anxiety, using a flow diagram, explained the flight, fight, or freeze response. This was used to highlight the difference between low levels of anxiety (which may be beneficial) and high levels of anxiety which may occur in the absence of any real significant danger. The cognitive behavioural model of anxiety was introduced using a diagram to explain how cognitions, emotions and behaviours can form a vicious cycle. Finally, examples of when worry and anxiety become signs of concern were provided to assist men to gauge their level of anxiety.
Psycho-education around depression was covered next, beginning by differentiating between depression and normal feelings of sadness. Participants were able to complete a depression checklist and if a certain pattern of symptoms was selected, suggestions were given to make contact with health professionals for an accurate diagnosis or assistance. Psycho-education ended with information on anger, normalising this as a common emotion. Additionally, men were encouraged to further explore any symptoms of anger as this may encompasses other emotional reactions.

Module 1 covered guided suggestions for taking care of one’s self. A video from a Clinical Psychologist made suggestions such as exercise, finding ways to let off steam, writing things down, and talking to others. The importance of talking to others was further stressed by emphasising the benefit of sharing feelings with partners and close friends or family. Men and significant others were encouraged to express their feelings and thoughts without the need to make changes or take responsibility for the problems or emotions of others.

For offline exercises men were requested to download a “My feelings about prostate cancer” worksheet which asks participants to write down some feelings they have experienced with regards to their prostate cancer journey. Men were asked to share this with their partner or someone close to them, requesting that the confidant attempts to neither help nor change how they feel. If men had a partner, the partners were asked to complete a similar exercise. The closing of Module 1 entailed a video from a clinical psychologist summarising the module and encouraging participation in offline exercises.

**Module 2: Tools for effective communication and helpful thinking.** Module 2 covered strategies to assist men to cope with the challenges that prostate cancer and
its treatment often brings. Specifically, the purpose of this module was for men to
learn how communication plays a role in coping with prostate cancer and for men to
begin to develop assertive communication skills which can aid communication about
sensitive and personal topics. Secondly, in Module 2 men were further educated
about the connection between cognitions, emotions and behaviour.

Module 2 commenced with a video entailing prostate cancer survivor’s stories
relevant to the importance and difficulties involved in communicating. This was
followed by an explanation of the benefits of communication and highlighting some
common times when communication can be difficult during the cancer journey (e.g.,
with medical staff or discussing sex with partners). The importance of effective
communication with a partner was also emphasised.

Module 2 progressed to educating men about the definition of communication,
also covering some common unhelpful communication strategies. The first online
exercise for Module 2 requested men brainstorm what communication means to them
and list some of the ways they communicate. This exercise was immediately
followed by a list of several common communication mistakes and men were
requested to select whether they used any of these. After selecting an option an
explanation was provided as to why each communication style was ineffective.

Module 2 continued to assertiveness skills training. Initially three main
communication styles, passive, assertive, and aggressive, were described and an
explanation of the benefits of the assertive style was highlighted. An online exercise
requested that men enter the details of a particular time they found communication
difficult. This exercise encouraged men to consider whether any emotions interfered
with their ability to communicate and any factors that could have improved
communication. It was anticipated that men would also begin to acknowledge that
people tend to communicate differently about prostate cancer. Participants then
progressed to a three step process for communicating assertively which uses a prostate cancer specific example. Men were given the opportunity to practice the assertive communication technique using an online worksheet and were encouraged to use this in a variety of contexts.

The next section of Module 2 continued with socialisation on CBT and men were introduced to the power of “thoughts”. Flow charts, using prostate cancer specific examples throughout, demonstrated how cognitions can influence emotions with subsequent charts integrating behaviours and physical sensations. A video from a Clinical Psychologist normalised the experience of negative thoughts associated with prostate cancer and secondly explained when and how negative thoughts can become a problem. The psychologist also provided education on how balancing negative thoughts with more positive ones can improve one’s ability to cope. Men were then asked to identify unhelpful thoughts and were introduced to a thought monitoring sheet identifying situations/triggers, unhelpful thoughts, feelings, physical sensations, and behaviours/actions.

Module 2 offline exercises encouraged men to continuing assertiveness practice and thought monitoring using two record sheets. If participants had a partner they were asked to practice assertive communication with their partners. Module 2 closed with a video with a Clinical Psychologist recapping the module and encouraging homework completion. Again, couples were encouraged to work through the module and exercises together and single men were encourage to find a significant other to communicate with.

**Module 3: Coping with physical changes.** Module 3 aimed to provide an overview of the physical changes that typically occur as a result of prostate cancer and its treatment. This module focused on incontinence and aimed to provide
strategies to manage this, while encouraging men to use these strategies for other physical changes.

Module 3 began with a video of prostate cancer survivors discussing the impact on incontinence on their lives and some coping strategies they have used. A diagram of a man was presented to highlight the different areas of the body that are affected by prostate cancer and its treatment, including the head and brain, shoulders, arms and legs, chest, stomach and abdomen, groin, the urine system, and the sexual system. The major role stress plays in influencing each of these body parts was covered, for example, the impact of stress on breathing for the chest region.

Following this overview, Module 3 considered tools and strategies for coping with some of these physical changes, with a focus on incontinence in this module. After providing brief information around the nature of incontinence in prostate cancer, the range of emotions associated with incontinence was normalised. Participants were introduced to the anxiety-avoidance cycle by completing an online exercise requesting they identify a recent situation when incontinence led to worry or anxiety. Further education on the anxiety-avoidance cycle, with the assistance of diagrams, described how emotions and thoughts surrounding incontinence can lead to activity avoidance (e.g., sexual contact or social situations) due to fear of leakage or losing control.

Men were then directed to learn tools and strategies for managing incontinence. This commenced with a video from a urology nurse presenting some tips for managing incontinence successfully, including pelvic floor exercises and incontinence pads. After the video, four specific tools were covered to assist in breaking the anxiety-avoidance cycle. Firstly men were taught how to identify and challenge their automatic thoughts related to incontinence. Using an online worksheet, men were encouraged to note any thoughts during a specific situation
identified earlier in this module. Men then attempted to challenge these thoughts with the assistance of an illustrated example.

The second tool was risk assessment. An online worksheet asked men to answer a series of questions to assist in developing a more accurate assessment of a situation and potentially lower subsequent levels of anxiety. Example questions include – “what is the worst thing that could happen?” and “what is the likelihood of that happening?”

The third tool was relaxation. The benefits of relaxation and some tips for practising relaxation were covered first. Three downloadable MP3 audio files were provided, covering different relaxation scripts: a simple breathing relaxation covering abdominal breathing, progressive muscle relaxation, and visualisation with a guided imagery on a boat aimed at relieving stress. By covering three different types of relaxation it was hoped that men would find at least one beneficial.

The final tool was worry exposure, where men were encouraged to confront their worries. It was suggested that men visualise their specific worries until their worry begins to reduce. A specific example was used to illustrate this and a video from a clinical psychologist was used to further explain how exposure can help break this cycle.

For Module 3 offline exercises encouraged men to use each of the four tools covered in this module to address any worry or anxiety they may have about incontinence. Again, men were also encouraged to share what they had learnt with their partner or close friend. Module 3 concluded with a summary of the module from a clinical psychologist.

**Module 4: Sexuality and masculinity.** The aim of this module was to educate men and their partners about ED and prostate cancer. Module 4 also aimed for men
to consider how ED impacts on their sense of masculinity and sexuality. By the end of Module 4 it was anticipated that men would learn about the broader impact of ED, learn about traditional male role norms about sexuality and masculinity, and be able to identify and challenge thoughts around sexuality and masculinity.

The module began with a video from prostate cancer survivors describing their personal experiences with ED and what types of strategies they have used to cope (including medical aids). Background information about ED and prostate cancer treatment was provided via a video from an urologist and screen text. The urologist focused on medical explanations for ED with pictures of men’s sexual organs. The urologist also highlighted other potential physical changes men might expect in this bodily region and the likelihood of performance anxiety occurring.

Module 4 briefly covered the male typical sexual response cycle. This model was used to emphasise how a lack of an erection may lead to changes in sexual behaviour, leading to further decreases in arousal, highlighting to men that they can still actually enjoy arousal and experience an orgasm without an erection. Men were also educated about the overall impact of ED, the benefits of sex and sexual intimacy, and the reasons why changes to sexual intimacy should be addressed. Although intimacy and communication were addressed in more detail in Module 5, Module 4 briefly explained the impact of ED on intimacy and relationships, highlighting the importance of including their partner when addressing sexual problems.

Module 4 then covered acknowledging and accepting the loss associated with changes to sexual function. To assist this process, an online exercise requested that participants consider how ED has impacted their lives. Another online exercise asked men to brainstorm norms or stereotypes in society surrounding manhood and sexuality. Men were then asked what “being a man” means to them. Subsequently,
men were provided with a list of masculinity stereotypes – for example “physical strength” and “not being emotional”. A video from a clinical psychologist listed the different sources people typically develop sexual beliefs and myths from. The clinical psychologist continued by explaining how the thoughts that were identified in previous exercises can be used as clues for personal beliefs about sex and intimacy. Following this a list of eight common myths related to sex, ED and prostate cancer were presented. For example, “a man wants sex anytime with anybody”. Once men selected whether they held that belief or not, they were provided with an explanation as to why each statement was a myth.

Men were encouraged to use an online worksheet to explore any unhelpful thoughts about ED and sex. A four step process asked participants to identify a recent situation where they felt anxious, upset or concerned about their sexual ability. This required detailing the events of the situation, identification of any emotions, thoughts and subsequent actions/behaviours. Men were also encouraged to challenge any thoughts or beliefs by attempting to consider alternative perspectives of the situation. A video from a clinical psychologist assisted with this process by providing a list of questions used to challenge negative thoughts/beliefs. Example questions included “What evidence do I have to support this idea?” or “What would you say to someone else who had this thought?” The clinical psychologist also worked through an example related erection failure.

For offline exercises, men were asked to continue to identify and challenge their thoughts related to ED and masculinity. If men had a partner they were encouraged to share their responses to the first online exercise from this module with each other. Partners were also asked to complete this exercise using their personal downloadable partner information sheet. Couples were encouraged to share any thoughts and thought disputation they had achieved with regards to ED, sex and
masculinity. Finally, couples were encouraged to undertake a joint activity during the coming week, suggestions were given. Single men were encouraged to pick an area of their lives they feel sexual function has impacted and were challenged to make a difference to this area through their behaviour or thoughts (e.g., meeting new people if they had been avoiding social situations). Module 4 concluded with a summary video from a clinical psychologist.

**Module 5: Sexual and intimacy.** Module 5 followed on from Module 4, by aiming to assist men to enjoy intimacy and sexual interactions in the absence of erections or compromised sexual function. This module aimed to encourage men to consider how their thoughts and beliefs about masculinity, ED, and sexuality, identified in the previous module, can influence their intimate behaviour, and consequently impact on their relationship. Strategies targeted to meet these gains included challenging thoughts, communication, broadening definitions of sexuality, and the use of medical aids.

Module 5 commenced with a video of prostate cancer survivors describing how ED has affected their relationships and ability to be intimate. Some men highlighted that intimacy had become more important to them, while the importance of sexual intercourse had diminished. This video was immediately followed by a video from a clinical psychologist discussing how ED affects men’s relationships with their partners as well as other people, often resulting in withdrawal. It was anticipated that this introduction would prompt men to consider how intimacy had been impacted in their lives.

Module 5’s first online exercise involved a worksheet requesting men contemplate a time when they had difficulty obtaining an erection, and identify any thoughts, emotions, and behaviours associated with this situation. It was anticipated
that a subsequent series of flowcharts would educate men about the impact of positive or negative evaluation of a sexual stimulus on arousal, through the pathway of negative thoughts and emotional responses. Additionally, the direct impact that stress and tension has on adrenaline and arousal was acknowledged. The second online exercise requested men think of a situation when specific thoughts interfered with intimacy, while acknowledging associated emotions and behaviours. A diagram was used to display common thoughts men have that can impact on sex and intimacy (e.g., “I can’t satisfy my partner”), along with common emotions and behaviours.

The impact of previously identified patterns on partners and other people was highlighted. Partnered men were asked to consider what impact changes in sexual functioning have had on their partner from their perspective and from their partner’s perspective. A description of some of the typical partner reactions was given in conjunction with a video of a prostate cancer survivor’s partner. This partner highlighted how females typically place less emphasis on sexual intercourse than males, and the ways intimacy with her partner has been maintained and actually enhanced post-prostate cancer treatment.

Module 5 progressed to developing strategies assisting men to broaden their definition of sex and sexuality. An online worksheet requested men brainstorm what good sex means to them. Following this, various ideas to assist men to broaden their definition of sex were covered including oral stimulation and exploring different positions. Another online worksheet requested men elicit a description of a good sexual experience, and secondly broaden the description with consideration of the aims of the sexual experience. Further strategies to assist with broadening the definition of what good sex means were provided including creating a positive sexual environment by minimising disturbances, bringing the focus to here and now, and focusing on things that trigger arousal.
Communication was the focus of the next section of Module 5, beginning with a video from a clinical psychologist stressing the importance of communication in the face of ED. The clinical psychologist also discussed what single men could consider when entering a new relationship. Following the video, a series of communication pointers were provided for use when talking about sex (e.g., “Discuss what you like and don’t like”). The differences between males and females were highlighted again, emphasising that women are often less interested in sex when their emotional needs are not being met. The application of assertiveness skills developed in Module 2 was encouraged by applying these to a situation or topic related to sexual intimacy for discussion with their partners. This online exercise also required men to consider what they would like to know from their partner, and how they may be able to improve the situation. An example was provided to assist men with this exercise.

Finally, Module 5 covered erectile aids. A video from a urology nurse practitioner discussed the different ED medical aid options using visual examples of these aids. The nurse begun with the most simple aid (Viagra) and progresses towards more complex and invasive procedures (injections). A link was provided to a TreatED booklet supported by the Prostate Cancer Foundation of Australia and Impotence Australia. Following this, an online exercise suggested that partnered men select an erectile aid for potential use and consider the aid’s pros and cons and how potential difficulties using this aid may be overcome. Finally, the limitations of erectile aids were highlighted, emphasising the benefits of applying the strategies learnt in this module in conjunction with any medical aid use.

Offline exercises for Module 5 included using each of the strategies covered to address sexuality and intimacy difficulties or concerns. These included continuing to monitor and challenge thoughts related to intimacy and sex; using assertive
communication style to address issues around sex and intimacy with their partners; and working on creating a positive erotic or sensual focus.

**Module 6: Planning for the future.** The final module for *My Road Ahead* aimed for men to explore the impact of cancer on their personal beliefs about death and mortality. Module 6 also aimed to assist men to develop strategies to cope with fear of cancer recurrence. Finally, Module 6 provided a conclusion and summary of *My Road Ahead* aimed at consolidating the skills learnt during the entire program.

Module 6 commenced with a video of prostate cancer survivors’ experiences related to coping with uncertainty and their experiences of anxiety in relation to cancer recurrence. This module continued into normalising the range of thoughts and emotions that typically arise in response to a cancer diagnosis, especially related to feelings of vulnerability and mortality. Warning signs related to depression in relation to living with uncertainty were provided, for example, recurring very dark thoughts about the future. An online exercise asked men to list thoughts related to fear and uncertainty they have experienced, while considering any emotional responses.

After covering thoughts and feelings around mortality, Module 6 addressed fear of cancer recurrence. This response was normalised in relation to frequent PSA tests and anxiety. A video from a clinical psychologist discussed the difficulties with living with uncertainty and strategies that may assist including challenging negative thoughts and taking action to overcome worry (e.g., seeking GP advice). The clinical psychologist worked through a particular example in this video. An online exercise required men to identify any instances when they experienced fear of cancer recurrence, assisting men to challenge any thoughts by reality testing.
Mindfulness was introduced as a tool to assist with coping with uncertainty and fear of cancer recurrence. After providing some background on mindfulness, three basic mindfulness exercises were suggested: (i) noticing five things that can be seen, heard, and physically felt; (ii) noticing every detail while completing a daily chore such as dish washing; and (iii) mindfulness of the breath.

The final component of Module 6 summarised the learning achievements throughout My Road Ahead. An online exercise suggested that participants consider the thought processes they had developed to manage stress and difficulties in their lives. Additionally, men were asked to identify their emotions and behaviours that may be viewed as warning signs for becoming stressed or worried.

A video from a clinical psychologist encouraged men to, when possible, have a positive outlook even though the prostate cancer journey is often described as one of the hardest times of a person’s life. The psychologist listed some of the benefits and positive changes prostate cancer has brought to the lives of some men. The video also suggested men contemplate plans and goals for the future. Following this suggestion, an online exercise encouraged men to think about short-term, medium-term and long-term goals.

In an attempt to mirror the maintenance of treatment gains sessions that frequently occur in face-to-face therapy, the final online exercise asked men to contemplate what they have learnt during the program, followed by consideration of any positive things that may have come about as a result of having cancer. My Road Ahead concluded with two videos. Firstly, David Parkin thanked participants and encouraged men to seek further support if required. Secondly, a clinical psychologist provided an additional thank you, and suggested men reflect on where they have come from and their level of satisfaction of where they were presently. Participants
were also encouraged to use their logbooks for reflection and to create future orientated goals using an action plan.

**Website construction and set-up.** After an electronic document detailing the content for modules was developed, a multimedia company was employed to assist with construction of the website. As sections of the *My Road Ahead* website were constructed, regular testing and reviewing took place by IT professionals, researchers, and psychologists, which in turn lead to program refinements.

When designing the website, several end use factors were taken into consideration. The program was aimed to be appealing to men through the use of images and icons that were designed to be attractive and engaging to men. Ease of use was also an important priority in the development of *My Road Ahead*. This was achieved by placing limited information on each website page with arrows allowing men to proceed to the next page or take a step backwards. In addition, videos, diagrams, tables, and flowcharts were used wherever possible.

In order to create the idea of a “journey” the home screen consisted of a pathway that lit up in different colours as men progressed through the modules. As mentioned previously, although it was recommended that men complete the modules in sequential order, they could access the beginning of each of the six modules in any point in time. This option was chosen as a means to increase motivation and decrease attrition rates. When completing the questionnaires or modules, a line across the top of the website represented the portion of questionnaire or module completed. On the main screen a percentage of the entire program that had been completed was clearly visible down the bottom of the screen which also detailed the amount of time left to access the program.

There were several tabs across the top of the website screen allowing men to access the components of the program previously mentioned (e.g., mood monitor,
logbook). In addition participants could continue to access the overview information, FAQ, and seek help information.

**Chapter Summary**

The first part of this chapter outlined the rationale for the current study, which was the development and evaluation of a self-directed CBT internet-based psychosocial intervention for men treated for prostate cancer. A rationale for the various structural and content components of the proposed program was also provided. The second part of this chapter detailed the processes involved in the development of an internet-based CBT program for men treated for prostate cancer. The program, entitled *My Road Ahead* was developed from a variety of sources. In addition an online moderated forum was also created during the development phase of this study. The next chapter discusses the hypotheses and method of the study. Chapter 9 and 10 reports on the results of the evaluation of My Road Ahead, and an overall discussion of the research project is provided in Chapter 11.
CHAPTER 8: Hypotheses and Method of Study

The purpose of this study was to evaluate the efficacy of *My Road Ahead*, an internet-based program for men treated for prostate cancer utilising a RCT. This involved comparing the outcome measures of participants undertaking the online intervention (Modules group and Modules-plus-Forum group) with the group that only had access to the forum (Forum-only group). The Forum-only group was considered the control group. Details about these three groups are outlined in the procedure section. The efficacy was examined by comparing pre-test and post-test changes in sexual function (including sexual QoL), psychological function, and relationship function across the three groups. This chapter outlines the method for this study.

**Hypotheses**

The present study hypothesised that men who are allocated to the Modules-plus-Forum group would demonstrate significantly greater improvement than the Modules only group, which in turn both would demonstrate significantly greater improvement than the Forum only group, from pre-test to post-test for each of the following variables:

1. Sexual function (including sexual QoL).
2. Psychological function.
3. Relationship function.

A secondary aim was to explore and evaluate feasibility and acceptability of *My Road Ahead* in terms of retention rates, degree of program completion, and module and forum satisfaction feedback.
Method

Participants. Eligibility criteria for participation consisted of the following: (1) treatment for localised prostate cancer in the last 5 years; (2) being aged 18 years or over; (3) willingness and ability to commit at least 1 hour per week, for a minimum of 10 weeks; and (4) regular access to the internet. Men who were unable to meet the above criteria were excluded from the study.

The study was open to men located within Australia. Participants were recruited from April 2012 to August 2012 through a number of mediums. Firstly, a database of men treated for prostate cancer at the Royal Melbourne Hospital were sent a letter of invitation and a postcard size advertisement to participate in the research project (Appendix E). Urology centres, private hospitals, and some physiotherapy centres and sexual rehabilitation specialists across Australia were sent a general letter and postcard flyers and larger size advertisements to place at their worksites. Advertisements were included in these mail outs with varying levels of detail using postcards, A3 sized posters, and A4 sized flyers (see Appendix F). Health professionals were also sent a flyer with information about the features of My Road Ahead, an outline of the research, and test login details to view the website. Finally Men’s Sheds groups across Australia were sent five postcards each to distribute to any interested men. It was anticipated that this would allow them to gauge the applicability and usefulness of My Road Ahead for their patients. An advertisement was placed on the Prostate Cancer Foundation of Australia and Beyondblue websites (see Appendix G). In addition a male specific magazine called Man’s Space made reference to My Road Ahead in a journalist’s article about the impact of prostate cancer. All of these services and professionals contacted were informed that they could contact the research team if wanting more advertising material.
A power analysis was conducted to estimate the target sample size using G*Power 3.1.3 software. In order to detect medium effect sizes (.30) at alpha ≤ 0.05 with power set at 80%, a sample size of 111 is needed. This means we aimed to collect pre-test and post-test data from 37 men in each group. Considering attrition rates for self-directed online programs are moderate to high, this was also taken into account when aiming for certain sample size.

Figure 1 represents the time line for evaluating the efficacy of *My Road Ahead*. This figure includes the time line for the larger project of which the current thesis was part of.
Figure 8.1. Outline of recruitment and enrolment into *My Road Ahead*.

*Note.* Boxed area highlights the timeline for this thesis.
**Measures.** Questionnaires were used to assess changes over time in sexual function, psychological function, and relationship function. Questionnaires were completed at pre-treatment and immediately post-treatment (10 weeks post-treatment). The following section outlines each of the measures used to evaluate this program. These measures and the associated dependent variables are outlined in Table 8.1. Questionnaires were identical for each testing time point, and for each treatment group. However, pre-treatment questionnaires also included demographic questions and the post-treatment questionnaires included satisfaction and feedback questions for the forum and modules. See Appendix H for the complete questionnaire, with demographic questions and post-treatment satisfaction questions. These questions were answered online and have been converted to a word document for the Appendices.

**Demographics.** Demographic details requested included age, date of birth, ethnic background, relationship status and duration of relationship, sexual orientation, education, employment status, gross annual income, prostate cancer date of diagnosis, date of treatment, type of treatment, and incidence of other health conditions (both physical and mental). Information on prior access to support was also collected, including access to support groups and psychologists as well as accessing information from the cancer council or other online resources. Specific questions were also asked about past sessions with specialists for sexual rehabilitation, and the degree of use and satisfaction with erectile function medical aids.
Table 8.1

*Measures Used to Assess Changes in Psychological Function, Sexual Function, and Relationship Function*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Author</th>
<th>Dependent variable</th>
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<tbody>
<tr>
<td><strong>Sexual function:</strong></td>
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</tr>
<tr>
<td>Erectile function domain – International Index of Erectile Function (IIEF)</td>
<td>Rosen et al., 1997</td>
<td>Erectile function</td>
</tr>
<tr>
<td>Sexual desire domain – International Index of Erectile Function (IIEF)</td>
<td>Rosen et al., 1997</td>
<td>Sexual desire</td>
</tr>
<tr>
<td>Intercourse satisfaction – International Index of Erectile Function (IIEF)</td>
<td>Rosen et al., 1997</td>
<td>Intercourse satisfaction</td>
</tr>
<tr>
<td>Orgasm function – International Index of Erectile Function (IIEF)</td>
<td>Rosen et al., 1997</td>
<td>Orgasm function</td>
</tr>
<tr>
<td>Overall satisfaction – International Index of Erectile Function (IIEF)</td>
<td>Rosen et al., 1997</td>
<td>Overall sexual satisfaction</td>
</tr>
<tr>
<td>IIEF total score</td>
<td>Rosen et al., 1997</td>
<td>IIEF total score</td>
</tr>
<tr>
<td>Sexual intimacy – Prostate Cancer Quality of Life Scale (PCQoL)</td>
<td>Clark et al., 2003</td>
<td>Sexual intimacy</td>
</tr>
<tr>
<td>Masculine self-esteem – Prostate Cancer Quality of Life Scale (PCQoL)</td>
<td>Clark et al., 2003</td>
<td>Masculine self-esteem</td>
</tr>
<tr>
<td>Sexual confidence – Prostate Cancer Quality of Life Scale (PCQoL)</td>
<td>Clark et al., 2003</td>
<td>Sexual confidence</td>
</tr>
<tr>
<td><strong>Psychological function:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress – Depression Anxiety Stress Scale (DASS)</td>
<td>Lovibond &amp; Lovibond, 1995</td>
<td>Stress</td>
</tr>
<tr>
<td>Anxiety – Depression Anxiety Stress Scale (DASS)</td>
<td>Lovibond &amp; Lovibond, 1995</td>
<td>Anxiety</td>
</tr>
<tr>
<td>Depression – Depression Anxiety Stress Scale (DASS)</td>
<td>Lovibond &amp; Lovibond, 1995</td>
<td>Depression</td>
</tr>
<tr>
<td><strong>Relationship function:</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kansas Marital Satisfaction Survey (KMSS)</td>
<td>Schumm et al., 1986</td>
<td>Overall relationship satisfaction</td>
</tr>
<tr>
<td>Marital affection – Prostate Cancer Quality of Life Scale (PCQoL)</td>
<td>Clark et al., 2003</td>
<td>Marital affection</td>
</tr>
<tr>
<td>General communication – Communication Patterns Questionnaire (CPQ)</td>
<td>Christensen &amp; Heavey, 1990</td>
<td>General communication</td>
</tr>
<tr>
<td>Sexual communication – Dyadic Sexual Communication Scale (DSC)</td>
<td>Catania, 1986</td>
<td>Sexual communication</td>
</tr>
</tbody>
</table>
Depression, Anxiety and Stress Scale (DASS-21). Psychological function and distress was measured using the Depression Anxiety and Stress Scales (DASS-21) short version (Lovibond & Lovibond, 1995). The DASS-21 consists of 21 items with seven items allocated to three different negative emotional states (depression, anxiety and stress). The depression scale measures dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia and inertia. The anxiety scale measures autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The stress scale assesses difficulty relaxing, nervous arousal, and being irritable and impatient. Respondents were asked to indicate the extent to which a statement applied to them in the last week on a 4-point Likert scale covering the response categories: 0 = did not apply to me at all; 1 = applied to me to some degree, or some of the time; 2 = applied to me to a considerable degree, or a good part of the time; and 3 = applied to me very much, or most of the time. Higher numbers reflect greater applicability of statements to ones behaviour and emotions. Final scores were multiplied by two and scores ranged from 0 to 42 for each of the three subscales, with a higher score indicating greater levels of stress, anxiety, or depression. An example of an item from each of the subscales is depression (‘I felt down-hearted and blue’); anxiety (‘I felt close to panic’); and stress (‘I found it hard to wind down’).

The DASS-21 has been found to have psychometric properties equivalent to the full version (42-items) (Henry & Crawford, 2005). Additionally, Henry and Crawford (2005) found evidence for good construct validity by demonstrating that the DASS-21 measures three separate scales with an underlying common factor. The DASS-21 has also been found to demonstrate sound internal consistency. With reliabilities for each of the subscales using a large adult population at; depression ($\alpha = 0.88$), anxiety ($\alpha = 0.82$), and stress ($\alpha = 0.90$) (Henry & Crawford, 2005). Antony,
Bieling, Enns, and Swinson (1998) also found high levels of internal consistency using a clinical and community sample: depression (\(\alpha = .94\)), anxiety (\(\alpha = .87\)), and stress (\(\alpha = .91\)). Antony et al. (1998) also found that the DASS-21 demonstrated good concurrent validity, through correlations with other measures of anxiety and depression. For the current study, good reliability was found for each of the subscales: depression (\(\alpha = 0.96\)), anxiety (\(\alpha = 0.89\)), and stress (\(\alpha = 0.93\)).

**Prostate Cancer Quality of Life Scale (PCQoL).** The impact of prostate cancer and its treatment on sexuality, confidence, masculine identity and marital affection was measured using the Prostate Cancer Quality of Life Scale (PCQoL) (Clark et al., 2003). This scale focuses on the behavioural, interpersonal and emotional changes that patients attribute to prostate cancer. The PCQoL scale was developed in an attempt to create a scale that addresses the complex psychosocial consequences for men treated for prostate cancer, rather than the focusing on severity and associated bother of symptoms, as other prostate cancer QoL scales do. The domains of sexual intimacy, sexual confidence and masculine self-esteem encompass many of the items found in common subscales of sexual bother and sexual satisfaction in a more in depth way. For example items such as “I feel good about the way I deal with my own sexual needs and desires” and “Trying to have sex is too complicated” cover items found in the Prostate-Health Related Quality-of-Life Questionnaire used by Nelson et al. (2009) and implicitly provide information of the degree of bother associated with sexual symptoms found in the EPIC or UCLA-PI (see Table 1).

The PCQoL scale was developed from focus groups with 130 men (≥ 50 years old) who had been diagnosed with early stage prostate cancer 12-24 months previously (39% treated with prostatectomy, 39% treated with radiotherapy, 8% treated with hormone therapy, 5% brachytherapy and 9% chose watchful waiting) (Clark et al., 2003). The entire scale contains 84 Likert type items that fall into 11
scales including: 1. Urinary control (behavioural and interpersonal implications of impaired control of one’s bladder); 2. Sexual intimacy (ability to perform sexually and feelings of frustration, embarrassment or failure); 3. Sexual confidence (confidence and anxiety about intimate activity and sexual thoughts); 4. Marital affection (misgivings about demonstrations of affection with one’s spouse), 5. Masculine self-esteem (negative evaluations regarding ones level of perceived masculinity); 6. Health worry (uncertainty about one’s health); 7. PSA concern; 8. Cancer control; 9. Informed decision; 10. Regret; and, 11. Positive outlook. Since evaluation of My Road Ahead forms part of a larger evaluation, men were given the entire PCQoL scale. However, for this thesis only subscales number 2, 3, 4, and 5 were used. An example of an item from each of the subscales is: sexual intimacy (‘I’m worried that I might embarrass myself if I try to have sex’); sexual confidence (“I’m confident in my sexual ability’); marital affection (‘My spouse or partner seems cool and distant from me’); and masculine self-esteem (‘I’m not the man I used to be’). These four subscales were computed by adding item responses and transforming into scaled scores of 0 to 100.

Clark et al. (2003) evaluated the psychometric properties of the scale during its development. Using a sample of 742 men with and without prostate cancer the internal consistency was found to range from .77 to .93 for most scales, with .60 for the PSA Concern subscale. Validity was assessed by evaluating correlations between each of the subscales and by correlating the subscales with the Mental Component Summary of the SF-12. Subscales generally correlated more strongly with the Mental Component Summary of the SF-12 than the Physical Component Summary, providing evidence that the PCQoL was accessing aspects of prostate cancer QoL beyond physical symptomatology. Evidence for discriminant validity for the PCQoL
was found by the scale’s ability to discriminate between men who did and did not have prostate cancer on each of the scales that were not specific to cancer.

For the current study good reliability was found for each of the subscales used: sexual intimacy ($\alpha = .95$); sexual confidence ($\alpha = .87$); marital affection ($\alpha = 0.85$), and masculine self-esteem ($\alpha = .94$). For the purpose of this study “marital affection” relates to relationship functioning and “sexual intimacy”, “sexual confidence” and “masculine self-esteem” relate to sexual QoL fitting under the broader term of sexual functioning.

The International Index of Erectile Function. The International Index of Erectile Function (IIEF) is a widely used 15-item self-report measure that was developed to assess sexual function among men with ED (Rosen et al., 1997). The IIEF attempts to assess the multi-dimensional nature of sexual functioning in men and produces scores on five domains of sexual function as well as a total score. The domains include: erectile function, orgasm function, sexual desire, intercourse satisfaction, and overall satisfaction (Rosen et al., 1997). The IIEF instructs respondents to answer items according to functioning during the past 4 weeks. Items are rated on a 5 or 6-point Likert scale where the categories change slightly depending on the item. Higher scores generally represent a more favourable outcome. Responses to items are summed to determine the total IIEF score (range 5–75). Scores ranges for individual domain scores are erectile function (1–30), orgasm function (0–10), sexual desire (2–10), intercourse satisfaction (0–15), and overall satisfaction (1–10). Example items for each of the subscales are: erectile function (‘How often were you able to get an erection during sexual activity’), intercourse satisfaction (‘How much have you enjoyed sexual intercourse’), sexual desire (‘How often have you felt sexual desire’), orgasm function (‘When you had sexual
stimulation or intercourse, how often did you ejaculate’) and overall satisfaction
(‘How satisfied have you been with your overall sex life’),

The IIEF was initially developed after it was recognised that there was a need
for better efficacy instruments for ED, particularly for clinical trials. After the initial
development of the questionnaire through consultation with male patients and their
partners as well as a review of literature, a panel of international experts further
refined and validated the IIEF. The IIEF is internationally recognised and has been
converted to many languages; as such the IIEF’s psychometric properties have been
reviewed in a variety of populations.

During the development of the scale the psychometric properties of the IIEF
were evaluated (Cappelleri et al., 1999; Rosen et al., 1997) using a mixture of
samples including men involved in a clinical trial for sildenafil and aged matched
men without ED. Across three studies, Rosen et al. (1997) reported a high internal
consistency using Chronbach’s alpha across the total IIEF scale (.91 - .96), erectile
function (.92 - .96), orgasm function (.92 - .99), sexual desire (.77 - .91), intercourse
satisfaction (.73 - .88), and overall satisfaction (.74 - .87). Test-retest reliability was
also accessed using a 4 week interval. Test-retest reliability was found to be total
IIEF scale ($r = .82$), erectile function ($r = .84$), orgasm function ($r = .64$), sexual
desire ($r = .71$), intercourse satisfaction ($r = .81$), and overall satisfaction ($r = .77$).

Construct validity was also found for the IIEF by Rosen et al. (1997). In this
study evidence for discriminant validity was found by the outcomes for clinically
documented men with ED to an age matched control group. Significant differences
were found across each of the domains. Evidence for convergent validity was found
by significant positive correlations between each of the IIEF domain scores and
blinded clinician ratings of sexual function.
The psychometric properties of the IIEF have been reported in studies consisting of prostate cancer survivor samples. For example, Schover et al. (2002a) using a sample of men with localised prostate cancer found the reliability of the IIEF to be high using Cronbach’s alpha: total IIEF scale (.97), erectile function (.98), orgasm function (.87), sexual desire (.93), intercourse satisfaction (.94), and overall satisfaction (.89). Schover et al. also reported means and standard deviations on each of the domains for their prostate cancer sample which were IIEF scale (M = 27.8, SD = 21.6), erectile function (M = 9.7, SD = 10.4), orgasm function (M = 3.6, SD = 3.7), sexual desire (M = 5.3, SD = 2.5), intercourse satisfaction (M = 3.8, SD = 4.8), and overall satisfaction (M = 5.0, SD = 2.8). Schover et al. reported that scores on the orgasmic function, sexual desire, and intercourse satisfaction were significantly lower than those means reported by Rosen et al.’s (1997) study with 111 men with ED, indicating that men with prostate cancer may report lower sexual functioning than men with ED and no prostate cancer.

For the current study, good reliability was found for each of the subscales: total score scale (α = .95), erectile function (α = .96), orgasm function (α = .70), sexual desire (α = .89), intercourse satisfaction (α = .87), and overall satisfaction (α = .90).

**Kansas Marital Satisfaction Scale.** The KMSS (Schumm et al., 1986) is a common measures of relationship satisfaction. It is a 3-item self-reported questionnaire measuring general relationship satisfaction. The questionnaire requires respondents select a response along a 7-point scale of: extremely dissatisfied, very dissatisfied, somewhat dissatisfied, somewhat satisfied, very satisfied, and extremely satisfied. Final scores on the KMS scale range from 3 to 21, with higher scores indicating higher relationship satisfaction. An example item is “how satisfied are you with your partner as a spouse’.
The construct validity of the KMS scale has been evaluated. Schumm et al. (1986) explored the concurrent validity of the KMS scale against two other measures of marital adjustment, the Dyadic Adjustment Scale (DAS) and the Quality of Marriage Index (QMI). Support for the concurrent validity of the KMS scale was found by strong correlations with the DAS ($r = .83$) and QMI ($r = .91$) (Schumm et al., 1986). Similarly, Crane, Middleton, and Ben (2000) found evidence for construct validity by strong correlations between the KMS scale and the DAS, with comparatively greater correlations with the DAS Satisfaction subscale. Additionally, Schumn et al. found support for discriminant validity by assessing the relationship between the KMS scale and a variety of unrelated measures of satisfaction with factors such as local weather and local politics, with correlations ranging from $r = -.10$ to .37. Crane et al. (2000) also found that the KMS scale could identify relationship distress by using scores of 16 or below to demonstrate marital distress using a sample of 486 clinical and non-clinical married individuals.

A recent meta-analysis of 398 articles evaluated the reliability of seven different relationship satisfaction measures using Cronbach’s alpha estimates (Graham, Diebels, & Barnow, 2011). The authors found the KMS scale to be the strongest overall measure based on reliability alone with an average of $\alpha = .95$ across studies. Although initially designed for married couples, Graham et al. (2011) found that the KMS was slightly more reliable in unmarried and same-sex relationships than married different-sex relationships, giving support for the use of KMS for individuals in a variety of relationship types. For the current study, good reliability was found for this scale ($\alpha = .95$).

**Communication Patterns Questionnaire-Short Form.** The Communication Patterns Question was originally developed by Christenesen and Sullaway (1984) and consisted of 35 items covering typical couple interactions and communication.
The Communication Patterns Questionnaire-Short Form (CPQ-SF) (Christensen and Heavey, 1990) is an 11-item self-report questionnaire that measures communication within intimate relationships. The CPQ-SF asks respondents to identify typical communication styles when either issues or problems arises and during discussion of issues or problems. Respondents are asked to rate the likelihood that certain issues/problems occur in communication on a 9-point scale from very unlikely to very likely, with total scores ranging from 0 to 99. Example items included: ‘Female tries to start a discussion while male tries to avoid a discussion’ and ‘Both spouses suggest possible solutions and compromises’.

The CPQ-SF has been divided into several different subscales. In order to reduce the number of variables in the analysis of this study, Christensen and Heavey’s (1990) original conceptualisation into a demand/withdraw (6 items) and positive interactions (3 items) subscale was used. Demand/withdraw which assesses a couple’s total amount of negative communication and positive interactions consists of items assessing level of mutual discussion, mutual expression and mutual negotiation. The validity of these subscales has been found by moderate correlations with measures of marital interaction and marital adjustment in a large sample of married and unmarried individuals (Futris, Campell, Nielsen, & Burwell, 2010).

The CPQ-SF has been used previously by researchers in evaluating the efficacy of a couple based intervention in a prostate cancer sample, however the demand/withdraw subscale was used but applied to cancer related communication. (Manne et al., 2011). Reliabilities were found to be between .78 and .81 for coefficient alpha. Reliability has been found to be good for demand/withdraw ($\alpha = .74$) and positive interactions ($\alpha = .78$) by Christensen and Heavey. For the current study, good reliability was found for the subscales of the CPQ-SF, demand/withdraw subscale ($\alpha = .78$) and positive interactions ($\alpha = .87$).
**Dyadic Sexual Communication Scale.** The Dyadic Sexual Communication Scale (DSCS) (Catania, Pollack, McDermott, Qualls, & Cole, 1990) was originally developed as a 13-item scale to measure a respondent’s self-reported perception of their communication related to sexual relationships. Specifically related to discussion around sexual matters with their partners. The original 13-item scale was found to discriminate between those that have and did not have sexual problems (Catania, 1986). Subsequently, Choi, Catania, and Dolcini (1994) created a 4-item version of the DSCS using a large sample of married 18 to 49 year old males and females investigating the correlates with extramarital sex as part of a National AIDS Behavioral Survey. The short-form DSC has 4 items requesting ratings on a 5-point scale: strongly disagree, disagree, neutral, agree, and strongly agree. An example item from this scale is: “Do you find some sexual matters too difficult to discuss with your partner?”. Range of scores is from 4 to 20.

The 13-item version of this scale has been used in a prostate cancer sample by Garos et al. (2007), however the 4-item version was deemed appropriate for this study considering the number of other questionnaires included in the analysis. Reliability of the 4 item version of the DSC was found to be acceptable taken from a male sample as part of the larger study mentioned above (Cronbach’s alpha = .65) (Choi et al., 1994). Normative data from this study found the mean score on the DSC 4-item was 13.22. The current study found that the 4-item DSC had good reliability at (α = .85).

**Treatment Satisfaction Questions.** The post-treatment questionnaire covered satisfaction with modules and the forums, and level of inclusion in each. Three questions were rated on a 10-point scale and covered satisfaction with program (“not at all” to “extremely”), enjoyment of program (“not at all” to “very much”), and usefulness of program (“not at all” to “very useful”). Respondents were given open-
ended questions to express the opinion of the best and worst part of the modules and forum and how each could be improved, including any additional features they might find useful. If men did not work through all the modules they were asked for reasons, using 11 listed reasons and an “other” verbatim option. Men were also asked to provide the number of hours per week they spent online using *My Road Ahead*. Men were asked if they engaged in any other types of mental health support, including support groups and cancer information services.

Questions were included around the level of inclusion or exclusion of partners. If partners were included, men were asked additional questions as to whether information sheets were given to partners, if they viewed the online information and completed the offline exercises together. An open-ended question was asked to evaluate which joint exercises men found most beneficial with their partners.

**Website analytics.** The *My Road Ahead* administrative website allowed information to be download detailing the date each module was accessed. Summary statistics provided information on the precent completed of each module.

**Procedure**

Ethics approval for the study was obtained from Melbourne Health Human Research Ethics Committee, Deakin University Human Research Ethics Committee and Swinburne University Human Research Ethics Committee (Appendix I). Men were invited to participate in the study through several sources (outlined previously). Each advertisement contained a website link to *My Road Ahead*, which when visited provided some information on the program. Men interested in proceeding created an account, which they were subsequently requested to validate. Prior to validation participants were requested to download the consent form and plain language statement and give their consent to participate in the research (see Appendix J).
Men were randomised to one of the three treatment groups immediately after completing the pre-treatment questionnaire by computer sequential randomisation. Men were informed which program they were allocated to after completion of the questionnaires. Three treatment groups were created (Modules, Modules-plus-Form, and Forum only) in order to evaluate whether an online modular program was more efficacious than a basic level of support offered from an online forum.

Of the 67 men who created an account, 2 (2.99%) failed to electronically validate their account. Men who failed to validate their account were sent an email explaining that they had created an account but failed to validate it, providing them with an opportunity to then validate the account or make contact with the administrative team if having any difficulties. Participants were given IT assistance as required. Of the 65 who validated their account, 8 (12.31%) failed to complete pre-treatment questionnaires. The final sample consisted of 57 men who were allocated into the modules-only ($n = 19$), modules-plus-forum ($n = 19$) and forum-only ($n = 19$) groups. After completing questionnaires, men were advised which group they were allocated to.

**Online modules.** The treatment evaluated during this study was a self-directed online program to address the psychosocial needs of men treated for prostate cancer. Those two research groups receiving the online modules (Modules and Modules-plus-Forum) were provided with a video and text giving an overview to the modules. Before commencing the modules, these groups were also provided with suggestions of how to get the most from their program including: committing a minimum of one hour per week to each of the modules; completing offline exercises; building and using a personalised logbook; and partner involvement.

It was recommended that participants complete the modules in their specified order and skills acquired in previous modules were used in subsequent modules.
However participants were able to access the beginning of each module at any point. Each module comprised of a similar format, commencing with an overview of the module, videos entailing prostate cancer survivors’ experiences, videos from health professionals providing information, education on specific topics, development of strategies to address difficult areas for men with prostate cancer, online exercises, offline exercises, and information for partners. More detailed information on each module is outlined in the previous chapter.

**Forum.** The Modules-plus-Forum and Forum group were allocated access to the *My Road Ahead* forum. As outlined previously the Forum group was considered to be similar to a control group in this study. A separate forum was created for each of these groups. Upon completion of the questionnaires, participants allocated to these groups were given information about the use of the forum (see Appendix K). At any time point, men in either group could gain access to the forum. Those who are enrolled into the Modules-plus-Forum were given prompts at the end of each module to login to the online forum if they were interested.

The two forums were divided into two topic areas: ‘introduce yourself’ and ‘general’. Weekly topics were placed on the forum in the hope to encourage discussion. Topics were varied and covered those areas identified as important to men treated for prostate cancer, including sexuality, psychological distress, relationships (intimate and other), urinary dysfunction, and coping with uncertainty. Some topics were general whereas some were specific. Examples topics are included Appendix L.

The forums were checked daily (week days only) by a moderator. The moderator was a provisional psychologist who screened comments by participants and decided if they were appropriate for posting on the forums. Posts that involved
any obscene language or negative comments around specific health professionals or services were omitted.

**Email contact.** Weekly email contact was given to all participants in this study from a provisional psychologist. Emails were relatively generic and were aimed at motivating participants to return to the modules and/or forum. Emails varied depending on whether a participant was using the program at the appropriate rate or not. Emails also included contact details for any participants who were having technical difficulties or difficulty understanding the content and requirements of the program. Example emails are in Appendix M.

**Follow-up data collection.** For all three groups, participants were requested to complete post-test questionnaires at 10 weeks after completing pre-test questionnaires. A series of automatic and personalised emails were sent to all men encouraging them to complete the questionnaire. Follow-up questionnaires were completed at 12 weeks and 6 months after completion of the program. For the purpose of this thesis, only the immediate follow-up data are reported. At these specified time points, men were sent reminder emails to login and complete questionnaires. At 10 weeks, participants no longer had access to the modules or forum. After completing the final follow-up questionnaire, participants who were randomised to the forum-only group received an email notifying them that they had access to the *My Road Ahead* online modules. These participants were not requested to complete pre-test questionnaires.
CHAPTER 9: Results I

The results for *My Road Ahead* are presented in the next two chapters. This chapter presents pre-test descriptive data and attrition rates during the study. The next chapter presents results regarding the efficacy of *My Road Ahead*. Statistical analyses were conducted using SPSS version 21.

**Descriptive Data at Pre-Test**

Table 9.1 contains the pre-test descriptive data for the total sample ($N = 57$). Before reporting these statistics, data were screened for missing values. There were limited missing values. One participant who responded that he was single on two occasions within the survey later answered three questionnaires that were designed for those in a relationship (this case was entered as missing). In addition, two participants who responded that they were married, completed three partner related questionnaires, but skipped the marital affection subscale of the PCQoL scale. For these two cases, mean substitution was used for this variable, based on the mean for the group as recommended by Tabachnick and Fiddel (2001). For ED aid use, there were missing data for one person who selected “yes” to injection therapies but did not select any further options for the type, frequency and satisfaction. The categorical data for this variable were left as it is, however the two metric variables covering frequency and satisfaction level were also replaced with mean substitution based on group means. No other missing values were observed, an expected finding given that the website did not permit unfinished questions.

Mean age of participants was 61.42 ($SD = 6.79$, *Range* = 42 to 76 years). The sample was not ethnically diverse, consisting entirely of men who identified as Anglo-Celtic/Caucasian or European. The sample was predominately from urban
locations. Just over half of participants were employed part-time with several other men engaged in other forms of employment. The sample was generally well educated with almost half having some form of university degree, however almost a third had only completed some level of high school.

The majority of the sample established that they were heterosexual, with four men identifying as bisexual, and one as homosexual. In regards to relationship status, almost all men selected that they were either married/partnered/defacto, with only two men having selected that they were either dating or in a casual relationship, and a final three men were single. Of those in some form of relationship, most had been in that relationship for more than 10 years.

In accordance with the prerequisite for entry into this study, all men were diagnosed and had been treated for localised prostate cancer. Mean time since diagnosis was 24.00 months ($SD = 17.37$, $Range = 6$ to 70 months). Time since first treatment for prostate cancer was 21.70 months ($SD = 16.63$, $Range = 6$ to 60 months). The majority of participants had undergone a radical prostatectomy, with only a small number of participants having had radiation therapy, hormone therapy and active surveillance. Robotic surgery was the most common type of radical prostatectomy. While the majority of men had undergone only one treatment five men had a combination of treatment. Three men had radiotherapy and radical prostatectomy, two men had radiotherapy and hormone therapy, incidiating that all participants had treatment for localised prostate cancer. For those men who selected active surveillance, this was after some form of active treatment (radiotherapy or radical prostatectomy). Table 9.1 also provides information on the incidence of past illnesses, including diabetes, another cancer and heart conditions. Five men reported ever being diagnosed with mental illness (all reported depressive disorder diagnosis
and two with comorbid anxiety) and eight men were currently taking anti-
depressants.

Almost half of the men sampled reported that they had accessed some type of
psychosocial support, and the source of this support varied greatly, with the Cancer
Council Information and Support Service being the most popular source for men.
Many men had also seen healthcare practitioners, with the largest proportion seeing a
urology nurse specialist, a physiotherapist, followed by a sexual rehabilitation
specialist.

The majority of men had used some form of medical intervention for ED. The
most commonly used aid was a PDE5 inhibitor, followed by injection therapy,
vacuum devices and only one man had a penile implant. Since more than one type of
PDE5 inhibitor and injection therapy could be selected, averages for frequency and
satisfactions scores were taken. Men were asked about their frequency of use of
PDE5 inhibitors (three different types) with 57.15% of the time men selecting that
they “tried it once or twice and gave up” and 77.78% reporting low satisfaction.
Views of injection therapies were more positive, with 34.48% of the time “tried it
once or twice and gave up” being selected and 44.83% selecting low satisfaction.
Only eight men reported using vacuum devices, and 66.67% only used it once or
twice and 83.33% reported low satisfaction. Only one man had obtained a penile
implant, reporting low satisfaction.
Table 9.1

*Participant Characteristics at Pre-Test (N = 57)*

<table>
<thead>
<tr>
<th>Continuous variables</th>
<th>Mean</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
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<td>Age in years</td>
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<tr>
<td>PCa treatment</td>
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<td></td>
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<tr>
<td>Months since diagnosis (months)</td>
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<td>70</td>
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<tr>
<td>Months since first treatment (any)</td>
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<td>Sexual function &amp; sexual QoL</td>
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<td>Intercourse satisfaction</td>
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<td>4.41</td>
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Table 9.1 (continued)

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<td>Retired</td>
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<td>Bisexual</td>
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<td>Relationship status</td>
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<td>Married/defacto</td>
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<td>91.23</td>
</tr>
<tr>
<td>Dating/casual</td>
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<td>Single</td>
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<td>5.26</td>
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<td>Relationship duration ((N = 54))</td>
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<td></td>
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<td>1.75</td>
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<td>5-10 years</td>
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<td>10+ years</td>
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Table 9.1 (continued)

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<th>Prostate Cancer Tx</th>
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<td>Prostatectomy</td>
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<td>Radiation therapy</td>
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<td>Hormone therapy</td>
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<td>Active surveillance</td>
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<td>3.51</td>
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</tbody>
</table>

Risk factors reported

| Another cancer                      | 5     | 8.77   |
| Diabetes                            | 4     | 7.02   |
| Heart condition                     | 3     | 5.26   |
| Mental illness                      | 5     | 8.77   |
| Current anti-depressants            | 8     | 14.04  |
| Past anti-depressants               | 11    | 19.30  |

Past support

| Psychologist                        | 6     | 10.53  |
| Psychiatrist                        | 3     | 5.26   |
| Counsellor                          | 3     | 5.26   |
| Support group                       | 8     | 14.04  |
| Cancer Council                      | 10    | 17.54  |
| Telephone                           | 4     | 7.02   |
| Online                              | 6     | 10.53  |
| Any support                         | 24    | 42.11  |

Healthcare practitioners

| Urology nurse specialist            | 30    | 52.63  |
| Physiotherapist                     | 19    | 33.33  |
| Sexual rehabilitation specialist    | 7     | 12.28  |

Erectile aids

| Used PDE5 inhibitors                | 38    | 66.7   |
| Used injection therapy              | 25    | 43.86  |
| Used vacuum devices                 | 6     | 10.53  |
| Used penile implants                | 1     | 1.75   |
| Overall used some Tx                | 44    | 77.19  |

*Note.*  
a As classified by the Australian Bureau of Statistics (ABS, 2012a): urban = population over 99,000; semi-rural = 1000-99,000; rural = less than 1000 people.  
b The Cancer Council Information and Support Service.
Mean values for depression, anxiety and stress were found to be in the normal range, suggesting this sample of men treated for prostate cancer experienced low levels of psychological distress. However, based on the DASS severity ratings, 26.32% of the sample experienced either moderate or severe depression. When considering relationship satisfaction and using a criterion score of 16 or less to identify dissatisfaction with the overall relationship (Crane et al., 2000), summary scores for this variable suggested minor dissatisfaction may have been present among the sample at pre-test ($M = 16.70; SD = 4.92$).

Measures of sexual function across the subscales of the IIEF and the IIEF total score where very similar to Schover et al.’s (2002a) previously reported means from a sample of men treated for prostate cancer. Schover et al. classified having ED as a total IIEF score of under 22. This was reported to be a generous cut-off. In the current sample 52.36% of men had a total IIEF score of under 22.

Measures of sexual QoL (sexual intimacy, sexual confidence, and masculine self-esteem) were very similar to the means found by Clark et al. (2003) when using a sample of men with prostate cancer. Clark et al.’s PCQoL scale does not have specific formalised degrees of severity. However, in their study, Clark et al. found men treated for prostate cancer were found to have statistically lower scores and poorer QoL on each of these subscales in comparison to a sample of men without prostate cancer. Therefore, results from our sample provide further evidence that men treated for prostate cancer may have lower QoL across sexuality and masculine identity domains in comparison to men without prostate cancer.

**Treatment versus Control at Pre-Test.**

Participants were randomly assigned to one of three treatment groups – modules-plus-forum ($n = 19$), modules ($n = 19$), or forum ($n = 19$). To investigate whether randomisation produced equivalence between groups at pre-test, continuous
variables were compared using ANOVAs (Analysis of Variance), and dichotomous variables were compared using chi-square test for independence. The default chi-square value was Pearson’s chi-square. An alpha level of $p < .05$ was used to identify significant group differences for each variable. It was not possible to run comparison for all categorical descriptive variables due to the small numbers in cells for some variables (e.g., relationship status). For the purpose of comparison, some variables were combined in order to conduct chi-square analyses via a dichotomous variable. These included location, employment and education. Expected cell count was less than five for several chi-square analyses and a series of 2x2 cross tabs were conducted to evaluate these variables (see Appendix N). For other variables where re-categorisation was not appropriate and 2x2 cross tabs were not possible due to extremely small cell counts, the number of participants and percentages were still entered into Table 9.2.

**Assumption testing.** Before conducted ANOVAs a series of assumptions needed to be tested and met. The dependent variables that were included in each of the ANOVAs were screened for univariate outliers. Outliers where evaluated using grouped data based on recommendations from Tabachnick and Fiddel (2001) when comparing groups for analyses. Using the criterion of $Z = \pm 3.29$ (Tabachnick & Fiddel, 2001) for univariate outliers, there were no outliers for any variable at pre-test. Normality was also assessed by testing for absolute values of two for skewness (Curran, West, & Finch, 1996). Three variables had skewness scores above the absolute value of two (erectile function, relationship satisfaction, and marital affection). Transformation of these variables made no difference to pre-test comparisons (ANOVAs), as such original scores were retained. In addition, the violation of skewness was minimal. According to Levene’s test, homogeneity of
variance could be assumed for all dependent variables except for depression and sexual confidence. Welch’s statistic was reported for these variables.

As can be seen in Table 9.2, participants randomly assigned to each of the three groups did not differ significantly in terms of demographic and study variables, except for current use of anti-depressants. More participants in the Modules only group reported using anti-depressants than the Forum only group. This suggests that overall equivalence of groups had been achieved through random allocation. For those descriptive variables where analysis of statistical significance between groups was not possible due to small cell numbers, it appears randomisation has worked.
Table 9.2

*Pre-Test Comparison between Participants Randomly Assigned to the Modules, Modules-plus-Forum, and Forum Group*

<table>
<thead>
<tr>
<th>Continuous variables</th>
<th>Modules (n =19)</th>
<th>Modules-plus-Forum (n =19)</th>
<th>Forum (n =19)</th>
<th>F</th>
<th>p</th>
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<tbody>
<tr>
<td>Age in years</td>
<td>61.58 (6.93)</td>
<td>60.95 (6.77)</td>
<td>61.74 (7.02)</td>
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<td>.933</td>
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<tr>
<td>PCa treatment</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Months since diagnosis</td>
<td>21.26 (18.00)</td>
<td>26.00 (13.86)</td>
<td>24.74 (20.25)</td>
<td>0.37</td>
<td>.692</td>
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<tr>
<td>Months since first treatment</td>
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<td>23.26 (14.17)</td>
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<td>Sexual function &amp; sexual QoL</td>
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<tr>
<td>Erectile function</td>
<td>10.16 (10.18)</td>
<td>8.32 (9.80)</td>
<td>6.26 (7.95)</td>
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<td>3.21 (2.92)</td>
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<td>.797</td>
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<td>6.32 (2.36)</td>
<td>6.11 (2.33)</td>
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<td>Intercourse satisfaction</td>
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<td>4.16 (4.65)</td>
<td>3.26 (4.39)</td>
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<tr>
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<td>Sexual intimacy</td>
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<td>Stress</td>
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<td>Relationship function(^b)</td>
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<tr>
<td>Relationship satisfaction</td>
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<td>Marital affection</td>
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Table 9.2 (continued)

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<tr>
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<td>Heterosexual</td>
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<td>18 (94.74)</td>
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<td>3 (15.79)</td>
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### Table 9.2 (continued)

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<td>Current anti-depressants&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>5 (26.32)&lt;sup&gt;*&lt;/sup&gt;</td>
<td>3 (15.79)</td>
<td>0 (0.00)&lt;sup&gt;*&lt;/sup&gt;</td>
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<td>Past anti-depressants&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>4 (21.05)</td>
<td>4 (21.05)</td>
<td>3 (15.79)</td>
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<td>Past support</td>
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<td>4 (21.05)</td>
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<tr>
<td>Psychiatrist&lt;sup&gt;cd&lt;/sup&gt;</td>
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<td>Counsellor&lt;sup&gt;cd&lt;/sup&gt;</td>
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<td>0 (0.00)</td>
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<td>Support group&lt;sup&gt;cd&lt;/sup&gt;</td>
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<td>3 (15.79)</td>
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<td>Cancer Council&lt;sup&gt;cde&lt;/sup&gt;</td>
<td>3 (15.79)</td>
<td>4 (21.05)</td>
<td>3 (15.79)</td>
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<tr>
<td>Telephone&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>2 (10.53)</td>
<td>1 (5.26)</td>
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<td>Online&lt;sup&gt;cd&lt;/sup&gt;</td>
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<td>4 (21.05)</td>
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<td>Any support</td>
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<th>Healthcare practitioners</th>
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<tr>
<td>Urology nurse specialist</td>
<td>12 (63.2)</td>
<td>11 (57.9)</td>
<td>7 (36.8)</td>
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<td>Physiotherapist</td>
<td>8 (42.11)</td>
<td>4 (21.05)</td>
<td>7 (36.84)</td>
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<td>Sexual rehabilitation specialist&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>1 (5.26)</td>
<td>3 (15.79)</td>
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<table>
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<th>Erectile aids</th>
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<tr>
<td>Used PDE5 inhibitors</td>
<td>14 (73.7)</td>
<td>10 (52.6)</td>
<td>14 (73.7)</td>
</tr>
<tr>
<td>Used injection therapy</td>
<td>8 (42.1)</td>
<td>9 (74.4)</td>
<td>8 (42.1)</td>
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<tr>
<td>Used vacuum devices&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>2 (10.5)</td>
<td>2 (10.5)</td>
<td>2 (10.5)</td>
</tr>
<tr>
<td>Used penile implants&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>0 (0.00)</td>
<td>1 (5.3)</td>
<td>0 (0.00)</td>
</tr>
<tr>
<td>Overall used some Tx&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>16 (84.21)</td>
<td>12 (63.16)</td>
<td>16 (84.21)</td>
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</table>

*Welch statistics reported for ANOVA. b<sup>n</sup> = 52 for relationship function variables. cExpected cell count less than five in < 80% of cells, chi-square statistic unable to be computed. d See Appendix N for 2x2 table cross tabs. e The Cancer Council Information and Support Service. *Significant difference between Modules and Forum group at p < 0.05.

### Attrition and Treatment Adherence

This section explores level of attrition and descriptive characteristics related to attrition. The next chapter covers level of program use. In terms of attrition, a man was classified as having dropped out if he either failed to complete post-test data
and/or completed less than 40% of the modules. A flow chart demonstrating attrition rates during the study is provided in Figure 2. There was a moderate level of attrition. Of the 57 men who completed pre-test data and were randomised into one of the three groups, 16 (28.07%) were considered to have dropped out. There were four participants who failed to complete post-test data even though they completed more than 40% of the modules. There were slightly higher drop-out rates in the Modules group \( (n = 7) \) compared to the Forum group \( (n = 4) \) and Modules-plus-Forum group \( (n = 5) \). This meant that the final sample sizes were slightly uneven: Modules \( (n = 12) \), Forum \( (n = 15) \), and Modules-plus-forum \( (n = 14) \).
Validated account but did not complete pre-test questionnaire (n= 65)

Completed pre-test & randomised (n = 57)

Forum (n = 19)
- Completed post-test (n = 15)
- Dropped out (n = 4)

Modules (n = 19)
- Completed post-test & ≥ 40% modules (n = 12)
- Dropped out (n = 7)
  - Did not complete post-test (n = 4)
  - Completed post-test & <40% of modules (n = 3)

Modules-plus-forum (n = 19)
- Completed post-test & ≥ 40% modules (n = 14)
- Dropped out (n = 5)
  - Did not complete post-test (n = 4)
  - Completed post-test & <40% of modules (n = 1)

Figure 9.2. Number of participants and attrition for My Road Ahead.
Assumption testing. Data were screened again for outliers and violations of normality based on grouped data (“completed” and “dropped out”) prior to attrition analyses. Outliers were screened at the criterion of $Z = \pm 3.29$. Two outliers were found for the variables anxiety and stress, both within the “completed” group data. All variables demonstrated acceptable skewness except for anxiety which was above the absolute value of two. For stress, converting this outlier value to three standard deviations above the mean resulted in a consequent $Z$ score less than 3.29. Using this strategy for anxiety, along with converting the outlier to one unit above the second highest value did not improve the normality of the variable including the level of skewness. This variable was therefore transformed using the square root transformation for mildly positively skewed data. Transformation (using SQRT) left no outliers. Independent samples t-tests produced different results for transformed data and are therefore presented below for t-tests as this represents a better example of normality. Means and standard deviations for anxiety are based on the raw data in Table 9.3.

Pre-test data were compared between participants who completed treatment and those who dropped out of treatment. Independent-samples t-tests were used to compare continuous variables, and chi-square tests for independence were used to compare dichotomous variables. For all chi-square analyses, Yates’ Correction for Continuity was the default option applied, and Fisher’s Exact Probability Test was applied when expected cell counts were less than five. An alpha level of $p < .05$ was used to identify significant group differences for each variable. The results of these analyses are displayed in Table 9.3. Levene’s test for equal variance of the two groups was violated for stress and depression.

As indicated in Table 9.3, participants who dropped out compared to those who did not drop out differed significantly at pre-test according to age, where younger
men were more likely to drop out of treatment. Men who dropped out were also more likely to report higher levels of anxiety and to have a history of mental illness. Men who stayed in the RCT were more likely to have previously accessed the Cancer Council Information and Support Service. When all types of support were added together, men who had accessed any type of support were more likely to remain in the study.

Table 9.3
Pre-Test Comparison between Participants who Completed My Road Ahead and Participants who Dropped Out

<table>
<thead>
<tr>
<th></th>
<th>Completed treatment (n = 41)</th>
<th>Dropped out of treatment (n = 16)</th>
<th>t (55)</th>
<th>p</th>
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<td>Continuous variables</td>
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<td>Age in years</td>
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<td>58.38 (8.33)</td>
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<td>.033*</td>
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<td>PCa treatment</td>
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<tr>
<td>Months since diagnosis</td>
<td>24.07 (16.87)</td>
<td>23.81 (19.18)</td>
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<td>Months since first treatment</td>
<td>21.78 (16.31)</td>
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<td>Sexual function &amp; sexual QoL</td>
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<tr>
<td>Erectile function</td>
<td>8.12 (8.96)</td>
<td>8.56 (10.54)</td>
<td>-0.16</td>
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<td>Orgasm function</td>
<td>3.51 (3.05)</td>
<td>3.81 (3.12)</td>
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<tr>
<td>Sexual desire</td>
<td>6.17 (2.11)</td>
<td>6.06 (2.62)</td>
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<td>Intercourse satisfaction</td>
<td>4.22 (4.41)</td>
<td>3.81 (4.53)</td>
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<td>Overall satisfaction</td>
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<td>Total sexual function</td>
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<td>Sexual confidence</td>
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<td>Sexual intimacy</td>
<td>54.09 (33.2)</td>
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<td>Masculine self-esteem</td>
<td>69.28 (23.85)</td>
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<td>Anxiety(^a)</td>
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<td>Depression</td>
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Table 9.3 (continued)

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<td>Marital affection</td>
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<td>General communication</td>
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<td>Positive interactions</td>
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<td>Demand/withdraw</td>
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<td>1 (6.25)</td>
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<td>10+ years</td>
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<td>Radical prostatectomy&lt;sup&gt;c&lt;/sup&gt;</td>
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<td>16 (100.00)</td>
<td>0.01</td>
<td>1.00</td>
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<td>Radiotherapy&lt;sup&gt;c&lt;/sup&gt;</td>
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<td>0 (0.00)</td>
<td>0.89</td>
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<td>4 (9.76)</td>
<td>1 (6.25)</td>
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<tr>
<td>Diabetes&lt;sup&gt;c&lt;/sup&gt;</td>
<td>4 (9.76)</td>
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<td>1 (6.25)</td>
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Table 9.3 (continued)

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<td>Sexual rehabilitation specialist&lt;sup&gt;c&lt;/sup&gt;</td>
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<td>Erectile aids</td>
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<td></td>
<td></td>
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<td></td>
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<tr>
<td>Used PDE5 inhibitors</td>
<td>28</td>
<td>68.29</td>
<td>10</td>
<td>62.50</td>
<td>0.01</td>
<td>.758</td>
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<td>Used injection therapy</td>
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<td>48.78</td>
<td>5</td>
<td>31.25</td>
<td>0.81</td>
<td>.255</td>
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<tr>
<td>Used vacuum devices&lt;sup&gt;c&lt;/sup&gt;</td>
<td>3</td>
<td>7.32</td>
<td>3</td>
<td>18.75</td>
<td>0.61</td>
<td>.335</td>
</tr>
<tr>
<td>Used penile implants&lt;sup&gt;c&lt;/sup&gt;</td>
<td>1</td>
<td>2.44</td>
<td>0</td>
<td>0.00</td>
<td>0.61</td>
<td>1.00</td>
</tr>
<tr>
<td>Overall used some Tx&lt;sup&gt;c&lt;/sup&gt;</td>
<td>31</td>
<td>75.61</td>
<td>13</td>
<td>81.25</td>
<td>0.01</td>
<td>.740</td>
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</table>

Note. <sup>a</sup>t-test based on transformed data. <sup>b</sup>n = 52 for relationship function variables. <sup>c</sup>Expected cell count less than five in < 80% of cells. <sup>d</sup>Chi-square statistic unable to be computed. <sup>e</sup>The Cancer Council Information and Support Service

* p < 0.05. ** p < 0.01

Chapter summary

This chapter presented results regarding pre-test descriptive data of a sample of men treated for prostate cancer who had signed up to take part in *My Road Ahead*. The results were collected from a sample of men who had been treated for localised prostate cancer who were currently single or in some form of relationship and of any sexual orientation.
In relation to the descriptive data, there was a moderate range of age with the men predominately being in a long-term heterosexual relationship. The mean time since treatment for prostate cancer was almost two years and most men had undergone a radical prostatectomy. A substantial number of men had previously accessed some form of psychosocial support. The majority of men had also used some form of ED aid previously. Despite this, reports of frequency and satisfaction with aid use were generally low.

There was a moderate level of attrition in this study, 28.07% were considered to have “dropped out”. Independent samples t-tests and chi-square tests for independence revealed significant differences between those who completed treatment and those who dropped-out. In particular men who dropped out of the study were younger and reported higher levels of anxiety or a history of a mental illness. The next chapter investigates the efficacy of *My Road Ahead*. 
CHAPTER 10: Results II

This chapter presents the results regarding the efficacy of *My Road Ahead*. Pre-test to post-test changes in sexual, psychological and relationship function were compared across the three groups. The second part of this chapter reports on qualitative and quantitative data regarding the feasibility and usability of *My Road Ahead*.

Assumption Testing

Prior to assessing equivalence between groups at pre-test and evaluating the efficacy of *My Road Ahead*, pre-test and post-test data were cleaned again based on the final sample of 41 participants. Data were screened for missing values, outliers and violations of normality. Assumptions were investigated among dependent variables by group (three treatment groups). There was a limited amount of missing data for post-test variables. One man failed to answer the marital affection questionnaire and this was replaced by the group mean for this variable. Outliers were not found for pre-test and post-test data for each of the variables. Violations of skewness (absolute values above two) were found for anxiety at pre-test and post-test, marital affection at pre-test. Marital affection was negatively skewed for the Modules group at pre-test time point. Transformation of this variable led to improved skewness values, however when transforming all variables at each of the time points for repeated measures analysis, this changed the meaning of the results including interactions. It was decided that this variable would be left as an absolute value as it was only just above two (skewness = 2.05).

Anxiety at pre-test was positively skewed for each of the three groups, with violations for the Modules and Forum group (absolute values above two). None of the transformations for positively skewed data returned the anxiety data to normality.
For baseline comparisons of pre-test data across the three groups, both parametric and non-parametric analyses were run to compare the three groups on this variable with no difference in the outcomes (substantive conclusions). Therefore Table 10.1 reports parametric results as these are the original and intended metric of the variables. For non-parametric tests, Kruskal-Wallis Test revealed no significant difference in depression across the three treatment groups, chi-square (2, 435) = 4.03, \( p = .13 \). For anxiety at post-test, the skewness value was just above two for anxiety for the Forum group. The SQRT transformation of this variable improved its level of skewness. However, results of repeated measures analysis for anxiety did not differ when using transformed data (for both pre-test and post-test) compared to untransformed, therefore the original data were used.

At baseline comparison Levene’s test, homogeneity of variance could be assumed for all dependent variables except for depression. Welch’s statistic was reported for this variable. Data were also screened for homogeneity of variance, and homogeneity of variance-covariance matrices. According to Levene’s test, homogeneity of variance could be assumed for all variables, except for masculine self-esteem, sexual intimacy, anxiety and marital affection at post-test. Assessment of Box’s M also revealed no violation of the assumption of homogeneity of variance-covariance matrices except for anxiety. Analyses involving these variables used a more stringent significance value of \( p < .01 \).

**Participant Characteristics Among Treatment and Control Groups after Attrition**

Following attrition, it was considered important to assess whether the treatment groups were equivalent. Pre-test descriptive data for the three groups after attrition are presented in Table 10.1. To assess equivalence between groups at pre-test, continuous variables were compared using ANOVAs and dichotomous variables
were compared using chi-square tests for independence. The default chi-square value was Pearson’s Chi-square. For several variables, chi-square analyses were unable to be computed due to low cell count. A series of 2x2 cross tabs were calculated for these variables and can be found in Appendix O, and for those that the cell counts were still too small Table 10.1 still contains this data in order to be able to visually compare the groups. An alpha of \( p < .05 \) was used to detect significant group differences for each variable. As can be seen in Table 10.1, significant group differences between any of the variables were not found at pre-test, suggesting that equivalence between the three groups could be assumed for all variables.

Table 10.1

*Pre-Test Comparison between the Modules, Modules-plus-Forum, and Forum Group after Attrition*

<table>
<thead>
<tr>
<th>Continuous variables</th>
<th>Modules ((n = 12))</th>
<th>Modules-plus-Forum ((n = 14))</th>
<th>Forum ((n = 15))</th>
<th>(F)</th>
<th>(p)</th>
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</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>63.17 (5.57)</td>
<td>62.50 (5.23)</td>
<td>62.27 (6.68)</td>
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<td>.923</td>
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<tr>
<td>PCa treatment</td>
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<td></td>
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</tr>
<tr>
<td>Months since diagnosis</td>
<td>21.75 (16.29)</td>
<td>26.79 (14.92)</td>
<td>23.40 (19.62)</td>
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<td>.745</td>
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<tr>
<td>(months) (N = 57)</td>
<td></td>
<td></td>
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<tr>
<td>Months since first</td>
<td>19.83 (16.32)</td>
<td>24.36 (14.71)</td>
<td>18.42 (4.76)</td>
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<tr>
<td>treatment (any) (N = 57)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual function &amp; sexual</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>QoL</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Erectile function</td>
<td>9.00 (9.32)</td>
<td>8.64 (9.32)</td>
<td>6.93 (8.83)</td>
<td>0.21</td>
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<tr>
<td>Orgasm function</td>
<td>3.92 (2.97)</td>
<td>3.36 (3.05)</td>
<td>3.33 (3.29)</td>
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<td>Sexual desire</td>
<td>6.08 (2.27)</td>
<td>6.79 (1.93)</td>
<td>5.67 (2.13)</td>
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<td>Intercourse satisfaction</td>
<td>4.42 (4.25)</td>
<td>4.57 (4.40)</td>
<td>3.73 (4.80)</td>
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<tr>
<td>Overall satisfaction</td>
<td>4.92 (3.55)</td>
<td>3.86 (3.25)</td>
<td>4.53 (3.83)</td>
<td>0.30</td>
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<td>IIEF total score</td>
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<td>27.21 (18.68)</td>
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<td>Sexual intimacy</td>
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<td>Masculine self-esteem</td>
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Table 10.1 (continued)

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<th>Depression$^a$</th>
<th>Anxiety</th>
<th>Depression$^a$</th>
<th>Anxiety</th>
<th>Stress</th>
<th>Anxiety</th>
<th>Depression$^a$</th>
<th>Anxiety</th>
<th>Depression$^a$</th>
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<td></td>
<td>5.33 (6.29)</td>
<td>0.83 (2.33)</td>
<td>3.33 (4.62)</td>
<td>10.43 (9.96)</td>
<td>2.86 (3.66)</td>
<td>9.00 (10.55)</td>
<td>8.13 (8.63)</td>
<td>3.87 (6.91)</td>
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<td>17.38 (4.09)</td>
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<th>n (%)</th>
<th>n (%)</th>
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<td>Relationship status$^c$</td>
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<td>1-5 years</td>
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<td>0 (0.00)</td>
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<td>5-10 years</td>
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<tr>
<td>10+ years</td>
<td>10 (83.33)</td>
<td>13 (92.86)</td>
<td>12 (80.00)</td>
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Table 10.1 (continued)

<table>
<thead>
<tr>
<th>Prostate cancer treatment</th>
<th>11 (91.67)</th>
<th>13 (92.86)</th>
<th>15 (100.00)</th>
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<td>Radical prostatectomy&lt;sup&gt;cd&lt;/sup&gt;</td>
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<tr>
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<td>3 (21.43)</td>
<td>0 (0.00)</td>
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<tr>
<td>Hormone therapy&lt;sup&gt;cd&lt;/sup&gt;</td>
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<td>1 (7.14)</td>
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<td>Active surveillance&lt;sup&gt;cd&lt;/sup&gt;</td>
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<td>Another cancer&lt;sup&gt;cd&lt;/sup&gt;</td>
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<td>1 (7.14)</td>
<td>2 (13.33)</td>
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<td>2 (16.67)</td>
<td>1 (7.14)</td>
<td>1 (6.67)</td>
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<td>Heart condition&lt;sup&gt;cd&lt;/sup&gt;</td>
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<td>1 (7.14)</td>
<td>1 (6.67)</td>
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<tr>
<td>Mental illness&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>0 (0.00)</td>
<td>1 (7.14)</td>
<td>0 (0.00)</td>
</tr>
<tr>
<td>Current anti-depressants&lt;sup&gt;cd&lt;/sup&gt;</td>
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<td>2 (14.29)</td>
<td>0 (0.00)</td>
</tr>
<tr>
<td>Past anti-depressants&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>1 (8.33)</td>
<td>3 (21.29)</td>
<td>2 (13.33)</td>
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</table>

<table>
<thead>
<tr>
<th>Past support</th>
<th></th>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Psychologist&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>0 (0.00)</td>
<td>1 (7.14)</td>
<td>3 (20.00)</td>
</tr>
<tr>
<td>Psychiatrist&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>1 (8.33)</td>
<td>2 (14.29)</td>
<td>0 (0.00)</td>
</tr>
<tr>
<td>Counsellor&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
<td>3 (20.00)</td>
</tr>
<tr>
<td>Support group&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>3 (25.00)</td>
<td>3 (21.29)</td>
<td>2 (13.33)</td>
</tr>
<tr>
<td>Cancer Council&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>3 (25.00)</td>
<td>4 (28.57)</td>
<td>3 (20.00)</td>
</tr>
<tr>
<td>Telephone&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>2 (16.67)</td>
<td>1 (7.14)</td>
<td>1 (6.67)</td>
</tr>
<tr>
<td>Online&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>1 (8.33)</td>
<td>3 (21.29)</td>
<td>1 (6.67)</td>
</tr>
<tr>
<td>Any support</td>
<td>6 (50.00)</td>
<td>8 (57.14)</td>
<td>8 (53.33)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Healthcare practitioners</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Urology nurse specialist&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>9 (75.00)</td>
<td>10 (71.43)</td>
<td>5 (33.33)</td>
</tr>
<tr>
<td>Physiotherapist&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>6 (50.00)</td>
<td>4 (28.57)</td>
<td>6 (40.00)</td>
</tr>
<tr>
<td>Sexual rehabilitation specialist&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>0 (0.00)</td>
<td>2 (14.29)</td>
<td>3 (20.00)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Erectile aids</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Used PDE5 inhibitors&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>8 (66.67)</td>
<td>9 (64.29)</td>
<td>11 (73.33)</td>
</tr>
<tr>
<td>Used injection therapy</td>
<td>6 (50.00)</td>
<td>7 (50.00)</td>
<td>7 (46.67)</td>
</tr>
<tr>
<td>Used vacuum devices&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>1 (8.33)</td>
<td>2 (14.29)</td>
<td>0 (0.00)</td>
</tr>
<tr>
<td>Used penile implants&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>0 (0.00)</td>
<td>1 (7.14)</td>
<td>0 (0.00)</td>
</tr>
<tr>
<td>Overall used some Tx&lt;sup&gt;cd&lt;/sup&gt;</td>
<td>9 (75.00)</td>
<td>10 (71.43)</td>
<td>12 (80.00)</td>
</tr>
</tbody>
</table>

<sup>a</sup>Welch statistics reported for ANOVA. <sup>b</sup>n = 52 for relationship function variables. <sup>c</sup>Expected cell count less than five in < 80% of cells, chi-square statistic unable to be computed. <sup>d</sup>See Appendix O for 2x2 table cross tabs. <sup>e</sup>The Cancer Council Information and Support Service.
Efficacy of *My Road Ahead*

The efficacy of *My Road Ahead* was evaluated by a series of mixed ANOVAs testing sexual, psychological and relationship functioning. A mixed model MANOVA was not selected due to the small sample size for three groups. For each of these ANOVAs, the between subjects factor was group (Modules, Module-plus-Forum and Forum) and the repeated measures factor was time (pre-test and post-test). Only participants who had provided pre-test and post-test data and completed greater than 40% of the program were included in the analyses, leaving 12 participants in the Modules group, 14 in the Modules-plus-Forum group and 15 in the Forum only group. The significance level for each analysis was set at $p < 0.05$, except when homogeneity of variance was violated (as highlighted previously).

**Sexual function and sexual QoL.** To investigate the first hypothesis, that men who completed the modules (Modules or Modules-plus-Forum groups) will demonstrate significantly greater improvement in sexual function and sexual QoL from pre-test to post-test than those who received the forum only (Forum group), a series of mixed model ANOVA were conducted. The dependent variables that contribute to sexual function and sexual QoL are found in Table 10.2 with the means and standard deviations at pre-test and post-test.

Using Wilk’s lambda, each of these analyses failed to reveal a significant interaction effect for group by time for erectile function, $F(2, 38) = 0.94, p = .400$, partial $\eta^2 = .05$, observed power = 0.20, orgasmic function, $F(2, 38) = 0.62, p = .545$, partial $\eta^2 = .03$, observed power = 0.15, sexual desire $F(2, 38) = 0.06, p = .943$, partial $\eta^2 = .00$, observed power = 0.06, intercourse satisfaction, $F(2, 38) = 0.06, p = .944$, partial $\eta^2 = .00$, observed power = 0.12, overall satisfaction, $F(2, 38) = 0.52, p = .601$, partial $\eta^2 = .03$, observed power = 0.13, IIEF sexual function total, $F(2, 38) = .64, p = .531$, partial $\eta^2 = .03$, observed power = 0.15, sexual confidence, $F(2, 38) =$
0.39, \( p = .682 \), \( \text{partial } \eta^2 = .02 \), observed power = 0.11, sexual intimacy, \( F(2, 38) = 1.86, \ p = .169 \), \( \text{partial } \eta^2 = .09 \), observed power = 0.36, and masculine self-esteem, \( F(2, 38) = 0.30, \ p = .741 \), \( \text{partial } \eta^2 = .02 \), observed power = 0.60. This result fails to support the first hypothesis, suggesting that any changes in sexual function and sexual QoL factors from pre-test to post-test were similar for the treatment groups (Modules and Modules-plus-Forum) and the control group (Forum).

Although there was no significant interaction effect for each of the sexuality variables, there were some main effects of time that were worth exploring in more detail. There was a significant main effect of time for sexual intimacy, \( F(1, 38) = 9.76, \ p = .003 \), \( \text{partial } \eta^2 = .20 \), observed power = 0.86, and for masculine self-esteem, \( F(2, 38) = 7.81, \ p = 0.008 \), \( \text{partial } \eta^2 = .17 \), observed power = 0.78, suggesting that overall all groups improved across time in their levels of sexual intimacy and masculine self-esteem.

Although there was no interaction effect for sexual intimacy, pairwise comparisons revealed that while at pre-test there was no significant difference between the three groups, at post-test there was a significant difference between the Modules and Forum group \( (p = 0.001) \), and the Modules-plus-Forum and Forum group \( (p = 0.030) \). Although the interaction was not significant, it was in the expected direction.
Table 10.2
Summary Scores for Sexual Function and Sexual QoL at Pre-Test and Post-test for the Modules, Modules-plus-Forum and Forum Group

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Modules (n = 12)</th>
<th>Modules-plus-Forum (n = 14)</th>
<th>Forum (n = 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-test</td>
<td>Post-test</td>
<td>Pre-test</td>
</tr>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Erectile function</td>
<td>9.00 (9.32)</td>
<td>9.25 (8.38)</td>
<td>8.64 (9.32)</td>
</tr>
<tr>
<td>Orgasm function</td>
<td>3.92 (2.97)</td>
<td>3.17 (2.66)</td>
<td>3.36 (3.05)</td>
</tr>
<tr>
<td>Sexual desire</td>
<td>6.08 (2.27)</td>
<td>5.75 (2.22)</td>
<td>6.79 (1.93)</td>
</tr>
<tr>
<td>Intercourse satisfaction</td>
<td>4.42 (4.25)</td>
<td>4.58 (4.74)</td>
<td>4.57 (4.40)</td>
</tr>
<tr>
<td>Overall satisfaction</td>
<td>4.92 (3.55)</td>
<td>4.92 (3.09)</td>
<td>3.86 (3.25)</td>
</tr>
<tr>
<td>IIEF total score</td>
<td>28.33 (18.98)</td>
<td>27.67 (18.74)</td>
<td>27.21 (18.68)</td>
</tr>
<tr>
<td>Sexual confidence</td>
<td>48.44 (25.99)</td>
<td>55.73 (26.17)</td>
<td>33.93 (38.19)</td>
</tr>
<tr>
<td>Sexual intimacy</td>
<td>63.99 (29.98)</td>
<td>85.42 (14.48)</td>
<td>58.93 (35.15)</td>
</tr>
<tr>
<td>Masculine self-esteem</td>
<td>78.91 (17.48)</td>
<td>89.58 (10.09)</td>
<td>70.09 (21.40)</td>
</tr>
</tbody>
</table>
**Psychological function.** A series of ANOVAs for relationship function were conducted to test the second hypothesis that those men who participated in *My Road Ahead* modules (Modules and Modules-plus-Forum groups) would report significantly greater improvements in psychological function from pre-test to post-test than those who receive the forum only (Forum group). The means and standard deviations for each of the psychological function dependent variables can be found in Table 10.3.

This hypothesis was not supported. Using Wilk’s lambda each of the ANOVAs failed to reveal a significant interaction effect for group by time for stress, $F(2, 38) = 0.70, p = .501$, partial $\eta^2 = .04$, observed power = 0.16, anxiety, $F(2, 38) = 0.38, p = .685$, observed power = 0.11, partial $\eta^2 = .02$, and depression, $F(2, 38) = 1.02, p = .371$, partial $\eta^2 = .05$, observed power = 0.21.
Table 10.3

Summary Scores for Psychological Function at Pre-Test and Post-test for the Modules, Modules-plus-Forum and Forum group

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Modules (n = 12)</th>
<th>Modules-plus-Forum (n = 14)</th>
<th>Forum (n = 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-test Mean (SD)</td>
<td>Post-test Mean (SD)</td>
<td>Pre-test Mean (SD)</td>
</tr>
<tr>
<td>Stress</td>
<td>5.33 (6.29)</td>
<td>5.83 (5.75)</td>
<td>10.43 (9.96)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>0.83 (2.33)</td>
<td>0.83 (1.34)</td>
<td>2.86 (3.66)</td>
</tr>
<tr>
<td>Depression</td>
<td>3.33 (4.62)</td>
<td>3.12 (4.13)</td>
<td>9.00 (10.55)</td>
</tr>
</tbody>
</table>
**Relationship function.** To investigate the third hypothesis, that men who participated in modules (Modules or Modules-plus-Forum groups) would report significantly greater improvements in relationship function from pre-test to post-test than those who received the Forum only, a series of mixed ANOVAs were conducted. The means and standard deviations for each of these dependent variables at pre-test and post-test are presented by group in Table 10.4.

Since Levene’s test was violated, a stricter $p$ value was used, and using Wilk’s lambda, the ANOVA for marital affection was approaching a significant interaction effect for group by time, $F(2, 36) = 4.10, p = .025$, partial $\eta^2 = .19$, observed power = 0.69. Although not significant, the effect size for this interaction was large, where the Modules and Modules-plus-Forum groups demonstrated improvements in marital affection over time, whereas the Forum group demonstrated decreased marital affection over time. There was no interaction effect for relationship satisfaction, $F(2, 36) = 0.73, p = .491$, partial $\eta^2 = .04$, observed power = 0.16.

None of interaction effects for communication variables were significant, including positive interactions, $F(2, 36) = 1.63, p = .211$, partial $\eta^2 = .08$, observed power = 0.32, and demand/withdraw, $F(2, 36) = 2.41, p = .104$, partial $\eta^2 = .12$, observed power = 0.46. The interaction for demand/withdraw approached significance ($p = 0.104$) with a moderate effect size. Although not significant, the Modules-plus-Forum and Modules group the level of demand/withdraw communication decreased while this type of communication increased for the Forum group. Finally, there was no significant interaction for sexual communication, $F(2, 36) = 0.04, p = .959$, partial $\eta^2 = .00$, observed power = 0.06.
Table 10.4
Summary Scores for Relationship Function at Pre-Test and Post-test for the Modules, Modules-plus-Forum and Forum Group

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Modules (n = 11)</th>
<th>Modules-plus-Forum (n = 13)</th>
<th>Forum (n = 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Pre-test Mean (SD)</td>
<td>Post-test Mean (SD)</td>
<td>Pre-test Mean (SD)</td>
</tr>
<tr>
<td>Relationship satisfaction</td>
<td>14.27 (5.83)</td>
<td>14.45 (7.49)</td>
<td>17.38 (4.09)</td>
</tr>
<tr>
<td>Marital affection</td>
<td>83.60 (22.38)</td>
<td>95.83 (6.72)</td>
<td>86.54 (22.19)</td>
</tr>
<tr>
<td>General communication</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive interactions</td>
<td>18.00 (5.90)</td>
<td>20.73 (7.23)</td>
<td>18.00 (8.24)</td>
</tr>
<tr>
<td>Demand/withdraw</td>
<td>15.73 (8.84)</td>
<td>13.73 (7.90)</td>
<td>15.23 (10.40)</td>
</tr>
<tr>
<td>Sexual communication</td>
<td>13.18 (4.29)</td>
<td>13.64 (4.03)</td>
<td>11.54 (4.03)</td>
</tr>
</tbody>
</table>
Usability and Feasibility of Modules

The following section provides results from the satisfaction questionnaires for the module aspect of *My Road Ahead*. Apart from where stated otherwise, all men who completed the post-test questionnaires and had access to the modules are included in these analyses ($n_{\text{modules-plus-form}} = 15$ and $n_{\text{modules}} = 15$). This includes three additional men in the Modules group and one additional man from the Modules-plus-Forum group who completed the post-test questionnaire but were excluded in the evaluation of *My Road Ahead* due to failure to complete a certain level of the modules.

**Engagement.** Data detailing the percentage amount of modules completed were available for all participants who had access to the modules ($n = 38$). Table 10.5 covers the percent of men who completed each of the modules across the Modules group and Modules-plus-Forum group for the total sample. Most men completed the modules in the recommended order (Module 1 through to Module 6). On average the Modules-plus-Forum group completed a greater percentage of the program ($M = 72.37$, $SD = 32.21$) than the Modules only group ($M = 61.88$, $SD = 3.79$), however this difference was not significant, $t(36) = -0.94$, $p = .352$). Although not significant, this slightly higher level of retention in the Modules-plus-Forum group, may suggest that having access to the forum may have potentially increased engagement in the modules. Not surprisingly, the final sample of participants that were used to evaluate the efficacy of *My Road Ahead* ($n = 26$) reported a higher level of engagement in terms of the percent completed of the total program, Modules ($M = 86.00$, $SD = 21.67$) and Modules-plus-Forum ($M = 87.43$, $SD = 17.16$).

Self-reported average number of hours spent on the modules was 1.82 hours per week ($SD = 1.31$). Time spent on modules was slightly higher for the Modules-
plus-Forum group \((M = 2.08, SD = 1.50)\) than the Modules only group \((M = 1.52, SD = 1.02)\), however this difference was not significant, \(t(26) = 1.14, p = .264\).
Table 10.5

Number of Participants who Completed each of the Modules Broken down into Percentage Categories \((n = 38)\)

<table>
<thead>
<tr>
<th>Percent complete</th>
<th>Module 1</th>
<th>Module 2</th>
<th>Module 3</th>
<th>Module 4</th>
<th>Module 5</th>
<th>Module 6</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Modules plus Forum</td>
<td>Modules plus Forum</td>
<td>Modules plus Forum</td>
<td>Modules plus Forum</td>
<td>Modules plus Forum</td>
<td>Modules plus Forum</td>
<td>Modules plus Forum</td>
</tr>
<tr>
<td>0%</td>
<td>1 (5.26)</td>
<td>1 (5.26)</td>
<td>3 (15.79)</td>
<td>6 (31.58)</td>
<td>8 (42.11)</td>
<td>10 (52.63)</td>
<td>11 (57.89)</td>
</tr>
<tr>
<td>1-20%</td>
<td>0 (0.00)</td>
<td>1 (5.26)</td>
<td>2 (10.53)</td>
<td>1 (5.26)</td>
<td>0 (0.00)</td>
<td>1 (5.26)</td>
<td>2 (10.53)</td>
</tr>
<tr>
<td>21-40%</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
<td>1 (5.26)</td>
<td>0 (0.00)</td>
<td>2 (10.53)</td>
<td>0 (0.00)</td>
<td>3 (15.79)</td>
</tr>
<tr>
<td>41-60%</td>
<td>0 (0.00)</td>
<td>2 (10.53)</td>
<td>3 (15.79)</td>
<td>6 (31.58)</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
<td>1 (5.26)</td>
</tr>
<tr>
<td>61-80%</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
</tr>
<tr>
<td>81-100%</td>
<td>17 (89.47)</td>
<td>17 (89.14)</td>
<td>14 (73.68)</td>
<td>14 (73.68)</td>
<td>11 (57.89)</td>
<td>21 (100.00)</td>
<td>15 (78.95)</td>
</tr>
</tbody>
</table>
Men were given a list of possible reasons they did not finish the program. The most common reason for not finishing was “too busy” \((n = 10)\), “nothing, got what I needed” \((n = 4)\), “lack of motivation” \((n = 3)\), “program not useful” \((n = 2)\), “internet server provider problems” \((n = 1)\), “computer problems” \((n = 1)\), “too unwell” \((n = 1)\), “program too difficult to understand” \((n = 1)\), “too much text” \((n = 1)\), “ran out of time” \((n = 1)\). Table 10.6 highlights the various methods that participants believed would increase engagement in the modules (selected from a list of options).

Table 10.6

<table>
<thead>
<tr>
<th>Participant Reported Methods to Increase Engagement in My Road Ahead</th>
</tr>
</thead>
<tbody>
<tr>
<td>Methods of engagement</td>
</tr>
<tr>
<td>SMS reminders</td>
</tr>
<tr>
<td>Email therapist</td>
</tr>
<tr>
<td>Phone therapist</td>
</tr>
<tr>
<td>Web cam therapist</td>
</tr>
<tr>
<td>Chat room</td>
</tr>
<tr>
<td>Conference call with other program participants</td>
</tr>
<tr>
<td>Face-to-face therapists</td>
</tr>
<tr>
<td>More use of video</td>
</tr>
<tr>
<td>More online activities</td>
</tr>
</tbody>
</table>

**Feedback on modules satisfaction and usability.** Level of program satisfaction was rated as moderate on a 10-point scale \((M = 6.90, SD = 1.92)\). There was no significant difference, \(t(28) = 0.65, \ p = .519\), for the ratings from those who participated in the Modules only \((M = 7.13, SD = 2.00)\) and the Modules-plus-Forum group \((M = 6.67, SD = 1.92)\). Similar results were found for the level of enjoyment of the program, Modules only \((M = 6.73, SD = 2.02)\) and the Modules-plus-Forum group
\[ M = 6.47, \ SD = 2.03 \], with no significant difference between the two groups, \( t(28) = 0.36, p = .721 \).

Ninety percent of men who used the modules reported that they were easy to use; the 10% who reported that they were not easy were from the Modules-plus-Forum group. On a 10-point scale the level of usefulness of the information and exercises from My Road Ahead mean rating was 6.43 \( (SD = 1.96) \), and the two groups were similar, \( t(28) = -.28, p = .785 \). In total, 93.3% of men reported that they would recommend the program to other men with prostate cancer.

Men were asked to provide feedback on the best and worst aspects of the modules and how they thought it could be improved. A total of 26 men provided this feedback. The most frequently reported positive aspects of the modules were: learning about others’ experiences and learning that one is not alone \( (n = 5) \); learning new skills and making changes \( (n = 6) \); the content (specific or general) \( (n = 6) \); a chance to reflect on cancer journey/increase level of awareness \( (n = 4) \); structural components of program (e.g., videos) \( (n = 4) \); and anonymity \( (n = 1) \). Below are some direct quotes from men regarding the best parts of the modules.

“\textit{Gave me better insight into my issues and thought processes, and how to manage them constructively}”.

“\textit{Encouraging me to think about issues that have an impact on life and relationships}”.

For the negative aspects, the most frequently reported comments were: timing of program too late or not relevant \( (n = 5) \); structural/IT aspects \( (n = 3) \); too long \( (n = 2) \); specific or general content \( (n = 5) \); not having a partner or being able to include partner \( (n = 2) \); and having a negative experience related to program \( (n = 2) \). Example quotes regarding the worst parts of the program are below.
“The first two sections were not relevant to me”.

“For me, it was 5 years too late – I had already worked through many if not most issues myself”.

Finally, participants provided feedback on how the program could be improved. Common themes that arose were: changes to specific or general content ($n = 4$); target program to men sooner after treatment or before treatment ($n = 4$); fix structural or IT issues, including clarity around navigating program ($n = 4$); tailor program ($n = 3$); and more face-to-face therapy ($n = 2$). Example quotes covering suggestions on how to improve the program are below.

“Maybe the program could be modified into some streams, depending on the results of the initial questionnaire, participants may be streamed to different modules based on their particular state of mind and/or their stage in the treatment cycle...”.

“Selecting prostate cancer patients for videos that can communicate clearly (not all could) plus videos of spouses talking about impact on them...”.

**Partner inclusion.** Men were encouraged to include their partners when using *My Road Ahead*. Of the men who indicated that this question was applicable to them, exactly half reported including their partner in the program. There was a higher level of partner involvement in the Modules group (61.54%) compared to the Modules-plus-Forum group (36.36%), however, this was not significantly different ($\chi^2(1, 24) = 0.67, p = .414$). Of the twelve men who stated that they included their partner in the treatment process, 83.33% stated that they printed or emailed their partner the information sheets. All of these men said that they at least sometimes included their partner in viewing the online information, videos, or interactive exercises and completed the offline exercises
together. When asked which particular exercises were most beneficial these were some of the responses.

“They were helpful as they resulted in my wife and I communicating - this was the real benefit for me (and her too I think) - we talked about the issues”.

“Where we discussed erectile problems and ways to cope”.

Men who did not include their partner were asked to give reasons why. Twelve men gave a response to this question. These responses could be classified as follows: their partner not being perceived as interested or receptive to such suggestions \( (n = 5) \); relationship or communication difficulties \( (n = 2) \); and not seeing it being relevant or helpful \( (n = 2) \). For example, one man’s response alluded to the communication difficulties that may have been present in their relationship by stating “Scared of the answers I may have gotten”.

**Usability and Feasibility of Forum**

These data were taken from all participants who completed the post-test questionnaire from the Forum group \( (N = 15) \) and the Modules-plus-Forum group \( (N = 15) \). This means there was one additional participant included in the Modules-plus-Forum group who was excluded from efficacy analyses due to completing only 33% of the modular content.

**Engagement.** The self-reported average amount of minutes spent on the forum per week was less for the Modules-plus-Forum \( (M = 4.00, SD = 6.56) \) than the Forum \( (M = 19.29, SD = 27.91) \). Four cases had missing data from the Modules-plus-Forum group and one from the Forum group, and the difference between these groups was found to be approaching significance \( (t(16.14) = -1.91, p = .066) \). Of the 38 men who had access to the forum, 21 posted at least one comment. The total number of posts for
the Forum group was 36, compared to 27 for the Modules-plus-Forum group. A total of 10 men made comments on the forum and 11 men on the Modules-plus-Forum forum. The average number of posts for those who did post any comments was 3.60 for the Modules-plus-Forum group and 2.45 for the Forum only group. Generally men responded to the weekly comments and topic ideas from the moderator. Occasionally men started their own discussion or responded directly to previous comments from other men. Posts from men related to introducing self, offering advice or support, requesting advice or support, sharing personal stories, and general advocacy around prostate cancer. Some examples of posts are below.

(i) **Introducing self**

   Men were encouraged to introduce themselves on the forum, giving any level of personal information they felt appropriate. An example of a participants introduction is below.

   “I'm 57 and had radical prostatectomy Jan 2008 when my PSA was just 5.4. I experience erectile problems and have to wear incontinence pads 24/7. I believe surgery was the best procedure for myself as I wanted the cancer out of me where it could be examined”.

(ii) **Offering advice/support**

   Offering advice and support was a strong theme and many men were open about their experiences and gave suggestions to other men when dealing with a range of problems. Some examples are outlined below.

   [Regarding Viagra]: “Hi. What worked for us was to take it 2 hours after dinner and 1 hour before sex. We also raised the bed so I could stand at the side - this
made penetration much easier with only a three quarter erection. Hope this
helps”.

“I know how you feel - I think. I find it really hard to describe how I am actually
feeling to other people. In fact I have taken to virtually lying most of the time. I
pretend things are going OK, but the reality is that I feel really tired most of the
time, not interested in work, things upset me easily and I feel like taking things out
on the people who are closest to me. I feel like building a huge wall around me
and escaping from the world. I sound pretty pathetic if I do say so! I hope that
with time I will be able to feel more like my 'old' self”.

“ED is not just the man's problem in a marriage relationship. sexual willingness
and stimulation by wife has a big impact on ED when a man is still able to
experience orgasm”.

(iii) Asking for advice/support

Directly asking for advice or support was not as strong a theme as giving. An
example of this theme is below.

“Does anyone have any experience using vacuum pumps? Someone has suggested
trying this to me...”

(iv) Sharing personal stories

Some men used the forum as a means to share their experiences with others,
without explicitly asking for advice or support. An example of this type of comment is
below.

“I have been very lucky in having a partner with which I can talk to openly about
the operation and its effects. It is becoming increasingly frustrating though but I
am feeling like we may be drifting apart to some extent. I think this is because we used to be able to 'communicate' via physical means before as opposed to more verbal pathways currently”.

(v) General advocacy

Finally, the forum was used as a platform for some men to express their opinion about prostate cancer and treatment related topics. PSA testing was one such area that a few men related to, see example below.

“I have read the comments re PSA. I now have many friends who have had prostate surgery based on biopsy results following an elevated PSA and all showed cancerous changes on post surgery examination of the removed prostate. I think it is essential until something else becomes available to use this diagnostic test and feel it has served me and my friends well. The post surgical problems are minor compared with the alternative”.

Feedback on forum satisfaction and usability. Level of forum satisfaction was lower for the Modules-plus-Forum group (\(M = 3.20, SD = 2.40\)) compared to the Forum group (\(M = 5.87, SD = 2.59\)) and this difference was significant, \(t(28) = -2.93, p = .007\). Similar results were found for the level of reported enjoyment when using the forum with the Modules-plus-Forum group reporting significantly lower enjoyment (\(M = 3.07, SD = 2.52\)) compared to the Forum group (\(M = 5.33, SD = 2.80\)), \(t(28) = -2.31, p = 0.028\).

In terms of ease of use, 80.00% of the Forum group compared to only 40.00% of the Modules-plus-Forum group reported that the forum was easy to use. A chi-square test (with Yate’s Continuity Correction and Fisher’s Exact test) revealed that this difference was approaching significance, \(\chi^2(1, 30) = 3.47, p = 0.060\).
In terms of the rated usefulness of posts by the moderator and men, there was a significant difference between the Forum and Modules-plus-Forum group in terms of the rated usefulness of posts by both other men \( (t(28) = -2.66, p = .014) \) and the moderator \( t(28) = -3.08, p = 0.005 \). Men in the Forum group were more likely to report that the other men’s \( (M = 5.07, SD = 3.15) \) and the moderator’s posts \( (M = 5.60, SD = 3.00) \) were more useful than the Modules-plus-Forum group \( (M_{other\ men} = 2.47, SD = 2.10 \) and \( M_{moderator's} = 2.67, SD = 2.16) \).

Men were given a list of possible reasons that they did not use the forum at all or very much. The most common reason for not finishing was “too busy” \( (n = 9) \); “lack of motivation” \( (n = 4) \); “computer problems” \( (n = 2) \); “program not useful” \( (n = 2) \); “too unwell” \( (n = 1) \), and “program too difficult to use” \( (n = 1) \).

Men were asked to provide feedback on the best and worst aspects of the forum and how they thought it could be improved. Twenty-two men provided feedback and the most frequently reported positive aspects of the forum were: learning about others experiences \( (n = 11) \); offering support and help to others’ \( (n = 5) \); and anonymity \( (n = 1) \). For the negative aspects, the most frequently reported comments were related to there not being enough participants or comments \( (n = 7) \); IT or computer related issues with accessing forum \( (n = 2) \), structural aspects (too much text) \( (n = 1) \), and negative experiences including learning about others worse off and there being too many negative comments \( (n = 2) \).

In terms of suggestions for improvements men suggested having more men and posts, and more encouragement to use \( (N = 5) \), using “chat” \( (N = 1) \), and more instructions on how to use, such as an electronic tour \( (N = 2) \). Two men gave specific strategies to improve forum which are listed below. “Provide comments from a specialist. Perhaps Q & A”.

“Provision of areas such as ‘chat’ and maybe even relevant multimedia targeted at certain issues”.

Chapter Summary

This chapter presented results regarding the efficacy of *My Road Ahead* for improving sexual, psychological and relationship function. *My Road Ahead* was evaluated with a sample of men predominately treated for localised prostate cancer by surgery in the past five years.

The results of this study did not support the hypotheses that those that were allocated to the Modules-plus-Forum group would demonstrate significantly greater improvement than the Modules only group, which in turn both would demonstrate significantly greater improvement than the Forum only group, from pre-test to post-test across sexual, psychological and relationship functioning. There were some trends towards significance in some of the sexual QoL and relationship variables.

Feedback regarding the usability and feasibility was also covered in this chapter. Overall program satisfaction was good with the majority of men reporting that they would recommend the program to someone else. Satisfaction with the forum was generally low to average. Feedback on *My Road Ahead* provided valuable information to direct future research. This will be covered in the next chapter along with an overall discussion of the results regarding the development and evaluation of *My Road Ahead*. 
CHAPTER 11: Discussion

This chapter discusses the findings from the development and evaluation of *My Road Ahead*, and examines these findings in the context of previous research. Implications of the findings regarding the efficacy and feasibility of *My Road Ahead* are explored in terms of future treatment of psychosocial issues and needs for men treated for prostate cancer. Limitations of the research will also be highlighted. Considering *My Road Ahead* is a unique and innovative intervention, there will be a particular focus on both the limitations regarding the evaluation of this program and the development, content and structure of the website, which will assist future research evaluating *My Road Ahead* and the development and evaluation of other internet-based programs.

Development of an Internet-Based CBT Program for Men Treated for Prostate Cancer

The first part of this thesis focussed on the development of *My Road Ahead*, an internet-based CBT program for men treated for prostate cancer. This program was developed to address the identified unmet psychosocial needs of men treated for prostate cancer. Despite the strong evidence for the need for psychosocial interventions for men with prostate cancer and their partners, treatments designed to target the complexity of sexual, psychological and relationship functioning in prostate cancer survivors have only been undertaken in the last 10 years.

The development of an online psychosocial intervention for men treated for prostate cancer demonstrated a major advance in this field in terms of providing support for men using a different platform, making treatment accessible for men who may not seek other forms of treatment, and in terms of the potential to disseminate this program broadly across Australia and internationally. A self-directed program with minimal therapist assistance allows for sustainable dissemination at a minimal long-term cost. It
seems that internet-based psychological support is efficacious in other areas of mental health and with other physical illnesses. However this had not been explored for men treated for prostate cancer.

As a result of the many unmet needs of men treated for prostate cancer and limitations of current interventions, the first part of this thesis aimed to address the gap in the literature and community, by developing a program to assist men with many of the difficulties they face after treatment for prostate cancer. *My Road Ahead* was developed from a variety of sources including a group-based CBT program, clinical expertise, multimedia expertise and a comprehensive literature review. *My Road Ahead* had a strong theoretical basis, and the program was largely CBT based with elements of sex therapy and a small component of mindfulness mediation strategies. The overall aims were to address several areas which have been identified as relevant for men including psychological distress, sexual difficulties, relationship difficulties, in addition to addressing urinary dysfunction, uncertainty about the future and communication with friends and health professionals. Partner involvement was considered an important aspect of this program and was optional, with joint exercises and partner information sheets. *My Road Ahead* was open to homosexual or bisexual men and single men, who have been frequently neglected in the literature and past interventions.

Considering this is the first self-directed internet-based program for men with prostate cancer, the components and structure of the program were developed with consideration of the literature regarding the useability and feasibility of various structural components of internet-based interventions in other areas. Several recommendations from past research were incorporated into *My Road Ahead* including weekly email contact, a highly interactive interface (e.g., videos and online exercises), a mood monitor, and open access to modules.
The final program was a 10 week internet-based CBT program for men treated for prostate cancer. The modular aspect of *My Road Ahead* consisted of six modules including online descriptive content, videos from prostate cancer survivors and health professionals, online exercises, offline exercises, and information and exercises for partners. In addition an asynchronous forum was developed, moderated with weekly topics posted to promote discussion. The modular aspect of *My Road Ahead* was considered the treatment that was later evaluated. The forum was developed as a means to firstly assess whether the modular aspect of *My Road Ahead* was more effective than some form of basic support, and to secondly to explore the usability and feasibility of a forum for a group of men treated for prostate cancer.

This section has provided a brief overview of development of the program the content and structure. Later sections in this chapter highlight the significant contribution this program is likely to make in the future, both in terms of further research and for men living with prostate cancer. The next section outlines the evaluation of *My Road Ahead*.

**Evaluation of an Internet-Based CBT Program for Men Treated for Prostate Cancer**

The efficacy of *My Road Ahead* was evaluated with a sample of men who had been diagnosed and treated for localised prostate cancer. As previously highlighted, the evaluation of *My Road Ahead* in this thesis forms part of a larger study which will evaluate the program with a larger sample size and across an extended time period. Firstly, the efficacy of *My Road Ahead* was evaluated across three areas: sexual function (includes sexual QoL), psychological function, and relationship function. Secondly the usability and feasibility of *My Road Ahead* was evaluated. Attrition was also explored
in detail. This section examines the findings from the evaluation of *My Road Ahead* and discusses these findings in relation to past research.

**Efficacy of *My Road Ahead***. Fifty-seven men were randomised into one of the three intervention arms for the evaluation of *My Road Ahead*. All participants completed pre-test questionnaires which included demographic and baseline details. The mean age of participants was 61.25, however age ranged more than 30 years and the sample predominately identified as Anglo Celtic/Caucasian or European. The majority of men were in a heterosexual relationship. Nearly all men had surgery to treat their localised prostate cancer and, although the mean time since diagnosis was 24 months, the upper end time since diagnosis was almost six years. The wide range of time since both diagnosis and treatment for men in this sample suggests that many men may have had unmet psychosocial needs at a range of times post-diagnosis and treatment for which they were seeking assistance with.

**Sexual function and sexual QoL**. The first hypothesis, that men who completed the modular aspect of *My Road Ahead* (Modules or Modules-plus-Forum) would demonstrate significantly greater improvement in sexual function and sexual QoL from pre-test to post-test than those who receive the Forum, was not supported by the results of this study. The multi-dimensional nature of sexuality was captured through the use of a variety of measures including the IIEF (sexual function) and three subscales from the Prostate Cancer QoL scale (sexual intimacy, sexual confidence and masculine self-esteem).

Not finding a positive impact of the *My Road Ahead* intervention on sexual function is consistent with past research using telephoned based and face-to-face and educative and skilled based interventions (Campbell et al., 2006; Lepore et al., 2003; McCorkle; Mischel et al., 2002; Northhouse et al., 2007; Weber et al., 2004). Findings were contrary to other past research that did find some level of positive impact on
sexual function (Cananda et al., 2005; Giesler et al., 2005; Molton et al., 2008; Penedo et al., 2007; Titta et al., 2006) and in an internet-based intervention (Schover et al., 2012). Many of the programs that have had a positive impact on sexual function, placed sexual function as a major focus (Canada et al., 2005; Giesler et al., 2005; Molton et al., 2008; Schover et al., 2012; Titta et al., 2006) or screened for men with sexual problems (Canada et al., 2005; Schover et al., 2012; Titta et al., 2006). Although My Road Ahead placed sexual function and sexuality as a major focus, some men did not complete the modules covering these topics. Although sexuality was a theme throughout the program, it was predominately confined to Module 4 and Module 5.

In the sexual domain, measures of sexual function specifically were most commonly explored in past interventions, followed by measures of sexual bother. In this study three measures of sexual QoL were taken (sexual intimacy, sexual confidence, and masculine self-esteem) which encompass the impact of sexual function changes and prostate cancer on broader areas of sexual self-concept and sexuality. While no other study has used these variables, lack of significant treatment effects for sexual intimacy, sexual confidence, and masculine self-esteem is consistent with past research exploring the impact on an intervention on sexual bother (Campbell et al., 2007, Giesler et al., 2005). However, other research has found a positive impact on sexual bother (Lepore et al.; 2003; Weber et al., 2004) and role limitations of sexual activity (Giesler et al., 2005).

Although there were no treatment effects for each of the sexual QoL measures covered in the current study (sexual intimacy, sexual confidence, and masculine self-esteem), improvements were found for all groups for sexual intimacy and masculine self-esteem across time. This suggests that both the module and forum components of My Road Ahead led to improvements in sexual QoL across the sexual intimacy and masculine self-esteem areas. Given the main effects of time for masculine self-esteem
and sexual intimacy, it is possible that both the forum and the modules had a positive impact on these QoL areas. A larger sample size is needed to tease out the effects of the forum versus the modules of *My Road Ahead*, and whether some level of basic peer and moderator support through the forum accounts for positive treatment effects. Peer support was incorporated into two past interventions that had positive effects on sexual bother (Lepore et al., 2003; Weber et al., 2004).

In addition, there was a moderate effect size for the interaction for sexual intimacy, with the Modules and Modules-plus-Forum group demonstrating a greater increase in QoL in this domain than the Forum-only group. However this interaction was only approaching significance and requires further exploration with a larger sample size. With a larger sample size further analyses could explore the potential interaction effects for those men with poor sexual intimacy, sexual confidence and masculine self-esteem at baseline, where it would be hypothesised that those with poorer function across these measures would be more likely to demonstrate gain from the intervention.

Although only approaching significance, it is not surprising that *My Road Ahead* tended to have a greater impact on QoL related sexuality variables rather than sexual function itself. Given the nature of the treatment for prostate cancer and the likelihood of ED, *My Road Ahead* was developed with a major focus on improving intimacy, communication, and masculine self-esteem, rather than focusing directly on actual sexual function. This is consistent with past researchers who have highlighted that men can either utilise medical interventions and try to return as close to possible to pre-treatment erectile functioning, or they can redefine their concept of sexuality and masculinity (Fergus et al., 2002). Given the limited success of medical interventions, which was also evident in the current study’s sample of men, it seems likely that a combination or a focus on the latter option may be beneficial.
**Psychological function.** The second hypothesis, that men who completed the module components of *My Road Ahead* (Modules or Modules-plus-Forum) would demonstrate significantly greater improvement in psychological function from pre-test to post-test compared to those who received the Forum, was not supported by the results of this study. Psychological distress remained stable across time for all groups.

The lack of significant impact of psychosocial interventions on psychological distress for men treated for prostate cancer was contrary to some previous research (Canada et al., 2005; Weber et al., 2004; Weber et al., 2007) but is consistent with other past research (Berglund et al., 2007; Collins et al., 2013; Giesler et al., 2005; Lepore et al., 2003; Manne et al., 2011).

Although psychological distress has been reported to be elevated in this population, low baseline rates of psychological distress have been previously reported in these samples during studies targeting psychological distress (Canada et al., 2005; Lepore et al., 2003). This is consistent with our sample where a lack of significant findings may be a result of this sample displaying relatively low levels of distress at baseline. It is possible that those seeking help or willing to participate in an internet-based program tend to have higher levels of psychological health.

Considering pre-test scores of psychological distress were not clinically elevated, the small decrease that was evident for the Modules-plus-Forum group for depression may not have been large enough to detect clinically relevant changes over time. It is possible that having a cohort of men treated for prostate cancer with a higher level of psychological distress may have seen improvements across these specific measures. There is often an assumption in the prostate cancer literature that men suffer from psychological distress. However given the inconsistent rates reported it is clear that a large proportion of men do not. Holland et al. (2011) highlight how some level of “distress” is a normal response in response to cancer, which at the upper end may be
considered pathological characterised by anxiety or depression symptoms and disorders. It could be that *My Road Ahead* is appropriate for men who do not have high psychological distress.

In addition, it is possible that the intervention prevented the development of psychological distress at a later time point. Follow-up evaluation of the participants in the current study would provide such information. Roth et al. (1998) suggested that the detection of psychological distress was important and opportunities for educational and supportive type interventions may act as a preventative measure against distress and development of psychological disorders. More discussion related to psychological distress is found in the attrition section of this discussion.

**Relationship function.** The third hypothesis, that men who completed the modular aspect of *My Road Ahead* (Modules or Modules-plus-Forum) would demonstrate significantly greater improvement in relationship function from pre-test to post-test than those who received the forum only (Forum group), was not supported by the results of this study.

Firstly, there was no interaction effect for relationship satisfaction, suggesting that the program did not impact on this variable. Results found an interaction for marital affection which was approaching significance and worth considering due to the large effect size. The interaction was consistent with the anticipation that the module aspects of the program would improve marital affection as this was a major focus of the program. A larger sample size is needed to confirm this trend.

Both general and sexual communication skills were targeted in *My Road Ahead*, however there were no interaction treatment effects for these variables; demand/withdraw communication, positive interactions, and sexual communication. However there was a non-significant moderate effect size for this interaction for demand/withdraw communication which requires further investigation. For
demand/withdraw communication the intervention led to a decrease of this negative form of communication for the Modules and Modules-plus-Forum group and an increase in this type of communication for the Forum. This is not surprising since this was targeted in the program. For marital affection, demand/withdraw communication, and sexual intimacy there was a trend towards the Modules group demonstrating greater improvement than the Modules-plus-Forum group. One explanation for this was that the Modules group were more likely to include their partners in intervention (36.36% of men from the Modules-plus-Forum group versus 61.54% of men from the Modules group). Although this difference in partner inclusion was not significant, it may be clinically meaningful. Qualitative feedback from men suggests that for both treatment groups many partners were not included due to partner’s lack of interest or communication difficulties. Some partners may benefit from a separate program targeting their own needs before or in conjunction with a couple based program. It should be highlighted that there were no reports that partners became distressed from the partner handouts or during the course of their partner accessing the program.

While the lack of positive findings for relationship functioning and partner outcomes was surprising given the previously highlighted importance of addressing the dyadic relationship, this is generally consistent with past intervention research. Although past research has strongly suggested that a man’s intimate relationship is impacted by prostate cancer, and the inclusion of the partner is important, intervention studies have not found support for this so far. Many studies have not found improvements in dyadic adjustment or marital distress across supportive educative interventions (McCorkle et al., 2007; Giesler et al., 2005), three counselling/psychological therapy interventions (Canada et al., 2005; Collins et al., 2013; Manne et al., 2011), and an internet-based counselling intervention (Schover et al., 2012). Many of these studies placed relationship functioning as a major focus. For
example, Schover et al.’s (2012) internet-based study directly targeted relationship functioning through improved sexual communication and affection but found no improvement on relationship functioning variables.

In terms of past research aiming to improve intimate relationship communication patterns for men treated for prostate cancer, there are only a few studies that have taken an actual measure of communication. The only positive effect found for communication was from Northouse’s (2007) couple based supportive/educative intervention which found an improvement in men’s communication with their spouse about their illness. Although Manne et al.’s (2011) couple based intervention placed relationship functioning as a major focus and used several communication enhancement strategies, the authors did not find any treatment main effects for a variety of relationship communication outcomes, including level of disclosure, responsiveness, and use of mutually constructive communication.

The current study found no treatment effect for sexual communication. Although several studies have targeted this in their intervention (Canada et al., 2005; Giesler et al., 2005; Molton et al., 2008; Schover et al., 2012; Titta et al., 2006), this study used a measure of sexual communication. Within the My Road Ahead modules there were exercises that explicitly aimed to improve men’s level of sexual communication. The scale used to measure this, the Dyadic Sexual Communication Scale has been used in its full form by previous researchers using a prostate cancer sample to explore couples’ sexual dysfunction and relational problems (Garos et al., 2007). In the current study the 4-item abbreviated form was utilised. It is possible that this measure was not appropriate for this cohort of men and further testing of this measure may be required. Alternatively, it may be that the intervention did not improve communication in this area. With a larger sample size, the current study could explore whether those with
poorer relationship satisfaction and communication were more likely to improve on those measures.

**Attrition.** Overall attrition from *My Road Ahead* was 28%, which was similar to past internet-based research treating mental health, psychosocial impact of physical health conditions, and sexual problems (Cuijpers et al., 2008; McCabe & Price, 2008; Spek et al., 2007), and similar to Schover et al.’s (2012) rate specific to a prostate cancer sample. A comparison of men who completed treatment and those who discontinued treatment was made using the criterion of completing at least 40% of the module aspect of *My Road Ahead*. Analyses revealed that those who dropped out of treatment had significantly higher levels of anxiety, were of a younger age, and were less likely to have sought previous psychosocial support before participating in the study. This suggests that those men who are most in need may not have found this intervention an appropriate means of support.

Those individuals who had previously sought support may be more suitable to an internet-based intervention which is largely self-directed. These men may have a greater understanding of the processes involved in engaging in some form of support or treatment and possess a higher level of motivation that is necessary to engage in internet-based treatment programs. The finding that men who were younger were more likely to drop out was unexpected, especially given the platform of the program. However, literature suggests that older men are comfortable using the internet to seek information, advice and support (Davison et al., 2004). It may be that the content of the program was not as appealing to younger men. Future programs may need to adjust program content and design for different age groups. Indeed some past researchers have excluded men under a certain age for these reasons (Molton et al., 2008; Penedo et al., 2006; Penedo et al., 2007; Weber et al., 2004; Weber et al., 2007).
The finding that men with higher levels of anxiety were more likely to drop-out was an unexpected finding in this study, however it should be noted that levels were still in the normal range for those that dropped out. It is possible that a certain cohort of men with prostate cancer need to be directed to specialist services for anxiety and distress (e.g., telephone, internet or face-to-face options). This notion fits into proposed models of “stepped care” which have become prominent in the cancer setting. These models suggest different types of psychosocial care for increasing levels of distress and that matching the type of intervention to the level and type of distress or problem is the most efficient model of care (Hutchinson, Steginga, & Dunn, 2006). Indeed others have emphasised the need to screen for psychological distress when considering further supportive care for men with prostate cancer (Korfage et al., 2006). This is discussed in greater detail in the implications section later in this discussion.

Interestingly, the five men who identified themselves as homosexual or bisexual remained in this study. Although this difference did not reach statistical significance, it is an important finding. Programs and research on prostate cancer thus far are heavily skewed towards heterosexual men, with only one study acknowledging homosexual men by asking about sexual orientation (Manne et al., 2011). Latini et al. (2009) has previously emphasised that homosexual men may have differing needs in the face of ED and relationship disruption. Research has only begun to explore and identify the unique needs of homosexual and bisexual men which are likely to then be translated into programs specific to their needs. The retainment of these men in our study highlights that even though the language and content of My Road Ahead was biased towards heterosexual men; homosexual and bisexual men found benefit from the program and also found the internet platform as an acceptable means of delivery.

Given the nature of the study design, reasons for attrition were not directly identified from men who did not complete post-test questionnaires. However, some
reasons for not completing the entire program are covered in the next section, alongside
discussion around general feasibility and acceptability feedback from participants.

**Feasibility and Usability of* My Road Ahead*

A secondary aim of the present study was to evaluate the feasibility and
acceptability of a self-directed internet-based intervention for men treated for localised
prostate cancer. There will be greater focus in this section on the module aspects of the
program which was considered the intervention. As mentioned previously, attrition rates
were relatively low and acceptable, especially for a self-directed internet-based
program. Around half of the participants completed the entire program (six modules).
For many men being too busy was a reason for not completing the program, with only
two men reporting that they did not find the program useful. However, after attrition,
the average percent complete for the entire program was above 85% for both groups.

Although not significant, the Modules-plus-Forum group tended to spend more
time on the modules and complete a greater percent of the program than the Modules
group. It is possible that having access to the forum increased engagement in the
modules, however a larger sample size is needed to see if this relationship reaches
significance. Email contact appeared to enhance the engagement in the modules aspect
of the program with men often returning to the program within 0-7 days after a weekly
reminder email was sent. This is consistent with past research (Spek et al., 2007; Tate et
al., 2003) which suggests that accountability and motivation is increased through
personalised contact including emails.

Overall satisfaction with the program was considered to be good, even though
many men did not finish the program and some reported several areas for improvement,
almost all men reported that they would recommend *My Road Ahead* to someone else.
Several men provided qualitative feedback regarding what they had taken from
participation in the modules, with themes of gaining new skills, learning from others and getting a chance to reflect on their cancer journey being prominent. However, feedback would suggest there are many areas that could be improved. Several men felt that the timing of the program was too long after diagnosis and treatment of prostate cancer. Some men had issues with the specific or general nature of the content. However, there was also conflicting feedback from participants where some specific changes that one man suggested was an area that another man reported he specifically appreciated or enjoyed (e.g., the videos). Two men reported that they wanted some form of face-to-face therapy, highlighting that internet-based programs may not meet the needs of some individuals.

Although men were informed via the website and through weekly emails that they were able to access whichever module was of interest or relevant to them, most men tended to complete the modules in the recommended order. Some feedback suggested that men had missed or misinterpreted these instructions and that more obvious tailoring the program to specific needs may be beneficial. Many of the feedback points covered in this section highlight the need for further tailor interventions, which is discussed in greater detail later in this chapter.

Overall satisfaction with the forum was considered low to adequate. Interestingly there was greater engagement (in terms of posting comments) from the Forum group compared to the Modules-plus-Forum group, although this difference was only approaching significance. Men in the Forum group rated the forum with significantly greater satisfaction and more enjoyable than the Modules-plus-Forum group. A potential reason for this could be that the Modules-plus-Forum group may have felt overwhelmed with expectations that they would complete the modules and post comments on the forum. Although only approaching significance, the Modules-plus-Forum group also rated the forum as more difficult to use than the Forum group, which
could either reflect a difference in the capabilities of the two groups or the fact that the Modules-plus-Forum group felt inundated with instructions.

Around half the men who gave qualitative feedback about the positive aspects of the forum said that they valued learning about others’ experiences, and several men also reported appreciating the opportunity to provide support and help others. Feedback regarding the negative aspects of the forum and the most frequently reported reason for not engaging in the forum more were related to their not being enough participants or comments on the forum. Suggestions for improvements regarding many of these aspects are covered later in this chapter. Finally there was some feedback regarding the forum and the modules aspect of *My Road Ahead* that were related to computer and or website related difficulties.

**Research Limitations and Recommendations for Future Research**

Although this thesis attempted to overcome several methodological problems related to past research, there were still some limitations evident in the current thesis that require consideration. This section will combine limitations of the current research with future recommendations. Future recommendations are explored in terms of study design, and improvements for *My Road Ahead* and for future internet-based interventions for men with prostate cancer.

**Sample.** The first limitation was related to the sample size used to evaluate the efficacy of *My Road Ahead*. As a result, the reliability of the results may have been compromised as it was likely that there was insufficient power for some analyses to detect significant differences. A small sample size also meant that further sub-group analyses were not possible. Several possibilities for further analyses were evident including evaluating whether improvements across dependent variables were related to partner inclusion, baseline characteristics, and baseline levels on dependent variables.
Past researchers have found that while there were no main effects of treatment, there were improvements on certain variables for those reporting higher distress or lower relationship functioning at baseline (e.g., Manne et al., 2011). Given the low levels of distress and high levels of relationship functioning that was evident at baseline in the current sample, a larger sample size would allow exploration of moderator effects. Other moderator effects worth exploring could be masculine self-esteem, considering past research has found greater benefit from interventions with men with lower general self-esteem (Helgeson et al., 2006) and interpersonal sensitivity (where there is an increased likelihood for masculinity to feel threatened) (Molton et al., 2008).

A further limitation of characteristics of the sample was related to demographic characteristics, were the current study had a reasonably homogenous sample, consisting mostly of educated, Caucasian and European men, who were not a representative sample of the population who have prostate cancer in Australia. Further, due to recruitment options and processes, the sample had almost entirely undergone a radical prostatectomy. Finally, although this study aimed to recruit men from rural locations, 80.49% were from urban locations. This percentage is higher than recent figures relaying 2011 figures from the Australian Bureau of statistics that found around two thirds of the Australian population live in these areas (ABS, 2012b).

In terms of recruitment, apart from aiming to obtain a larger sample size, it may be beneficial to recruit a certain number of participants and commence the RCT at a specified time point, rather than allowing men to enter treatment immediately following registration. This would be particularly beneficial for the forum, increasing the amount of activity on the forum, which was reflected as an issue in the qualitative feedback. Feedback from the modules suggested that having a reduced timeframe since diagnosis and treatment as an entry requirement into *My Road Ahead* might be appropriate. Men could also be targeted that have a certain level of distress or sexual and relationship
difficulties. More strict recruitment processes may reduce the variance of dependent measures and therefore increase the likelihood significant treatment effects are found. However, since allowing any man who feels that he needs assistance is more ethical, it may be more appropriate to increase level of tailoring for the intervention (discussed “program modification” section).

Research design. In terms of the research design of the current study there are several options for changes and improvements in terms of evaluating the efficacy of My Road Ahead in the future. The design of the current study, with three intervention groups, was considered a more sophisticated method in comparison to using a wait-list control group, however interaction effects were more difficult to find since it was hypothesised that all three groups would improve across dependent measures to some degree. Future evaluation of My Road Ahead could return to a more common research design, comparing the intervention with standard treatment (control group) or a three group design (Modules, Forum and control group). If the efficacy of My Road Ahead is established through one of these designs, an evaluation using a similar research design to the current study could be consequently implemented.

Limitations in this study were evident in the use of particular measures. Although the IIEF is widely used in prostate cancer and other ED research it is not without problems. The wording for this scale can be confusing for some individuals and does not highlight whether a man has been masturbating or engaging in other sexual activities. An important finding from this study was the potential usefulness of the PCQoL (Clark et al., 2003). This scale was utilised for its ability to discriminate between actual sexual function and sexuality in a broader context including sexual confidence, sexual intimacy, and masculine self-esteem. Out of all the scales used in the current study the subscales of the PCQoL were able to identify some changes and
trends. Future research should consider using this scale in addition to scales that measure sexual function (e.g., IIEF).

Another potential means to analyses data would be to use intent to treat (ITT) analysis. In the current study, those participants who did not complete 40% or more of the program were excluded from analyses. ITT deals with noncompliance and withdrawal from a study by a statistical approach that includes every participant (Gupta, 2011).

The post-test assessment used in the evaluation of the efficacy of My Road Ahead in this study was only taken at an immediate follow-up time point post-treatment. It is possible that trends towards significant findings in the current study may not have been maintained at later time points. On the other hand it is also possible that when introducing follow-up assessment points (e.g., 3 months and 6 months) significant gains may have been made for the different groups. This may have given the men time to put into practice many of the skills they learnt. For example, men may have recently had a conversation with their partner and decided on an erectile aid to use and just begun implementing a plan.

Future research may also seek to compare a therapist assisted version or face-to-face or telephone based treatment with similar content to My Road Ahead. Greater use of objective usability testing through the use of website analytics would be beneficial to incorporate in future research where the amount of time spent on each page and module can be accurately identified. The current study used emails to increase motivation and commitment, which seemed to increase engagement. There are other means by which such support can be provided including the use of text messages, follow-up telephone support, or even an occasional face-to-face meeting (Ritterband et al., 2009). In a review of studies using the internet to promote health behaviour change, Webb et al. (2010) found that the use of SMS had large effects compared to the use of telephone
and emails. Given the increasing use of the internet on Smartphones, the use of SMS and Smartphone Applications (commonly known as “Apps”), integrating these tools is likely to be of benefit in conjunction with internet-based treatments in the future. Apps could be in the form of reminders, tips, and thought monitoring, and Smartphones in general could be used to view the program or connect on the forum. Luxton, McCann, Bush, Mishkind, and Reger (2011) reported that Smartphones and their Apps are already being used in behavioural health care for symptom assessment, psycho-education, and tracking of treatment progress.

**Program modification.** Several recommendations can be made related to the content of both the modules and forum of *My Road Ahead*, some of which have already been covered. The use of internet-based treatment is currently rapidly increasing across many areas, and has only just begun to be applied to the area of cancer, including prostate cancer. The following recommendations come from the feedback in the current trial from participants, from the researchers’ experiences in running this study, and other internet-based treatment in areas other than prostate cancer.

With regards to the content of the program, Module 1 may have focused too heavily on clinical depression. This module may benefit from a more even balance and differentiation between normal emotional responses including grief and sadness and depression and abnormal grief reactions.

In terms of the structural components of *My Road Ahead*, there are other important structural changes that could be made to modules. An open gated structure for the modules was chosen for *My Road Ahead* to increase engagement. Future research could modify this to what Leykin et al. (2011) referred to as “adaptable lesson flow”. A recommended personalised program could be automatically developed by a man’s responses to a baseline questionnaire and by indicating which areas they are distressed or interested about. This is similar to the use of screening questions in face-to-face
interventions in prostate cancer (e.g., Collins et al., 2013; Giesler et al., 2005). This may increase both engagement and the benefits gained from the program. Tailoring has been recommended by other authors for men treated for prostate cancer (Cockle-Hearne et al., 2010; Latini, Hart, Honoré Goltz, Lepore, & Schover, 2011). Support for tailoring also comes from intervention studies reporting moderator effects. Tailoring may retain those men with higher distress for example (drop-out related to anxiety) or those men who found the content was too long or not relevant to them, or that they were too busy. These suggestions are also consistent with feedback from some of the men in the current RCT.

Tailoring through developing a personalised program would mean that men, for example with sexual problems as their only concern, would be directed to the modules relevant to them earlier. If men are not being directed to the entire program, more content could be added to particular modules in the hope to address specific needs more thoroughly. For example, more detail could be added about the use of medical treatment aids in conjunction with psychosocial strategies in Module 5. In addition, the use of videos could increase to include actors covering difficult situations and later modelling effective communication strategies (Schover, 2012, November).

Even though the forum was not the major focus of My Road Ahead, there are several recommendations for future research and use of online forums in this population. This is important since there is very little empirical research assessing online support for cancer patients, especially prostate cancer. Past face-to-face research has matched long-term prostate cancer survivors as peer support partners to more recently diagnosed men (Weber et al., 2004; Weber et al., 2007). Similarly, the My Road Ahead forum could implement past survivors as moderators on the forum. Another innovative idea is for men to be able to set up their own home page, similar to what is found on social networking sites. This was raised at the 2012 IPOS conference.
unpublished research depicted a website with a blog personal page set-up where men could communicate as a group or to individuals. Another idea worth considering and identified by some men in this study, is the use of online chat groups, either audio or text based.

More broadly speaking, the development and evaluation of *My Road Ahead* has provided the foundation for not only improvements to this program itself, but to future adjunct programs. These may include a program specific to the needs of homosexual and bisexual men, single men, those living in rural locations, and a separate program for the partners of men with prostate cancer or a more tailored couple based intervention program. In addition, programs may be developed for men at different stages of disease and at different times post-treatment. *My Road Ahead* sets the stage for an exciting time in the area of internet-based treatment for men with prostate cancer. Implications are discussed in more detail below.

**Implications for Treating the Psychosocial Needs of Men Treated for Prostate Cancer**

Although at this stage we cannot conclude that *My Road Ahead* was effective in improving sexual, psychological and relationship functioning, there were some trends towards improvements in some broader sexual QoL measures and marital affection measure, which as stated in the previous section need to be explored using larger samples and with other potential methodological changes. Regardless, the internet is a rapidly growing platform for delivery of psychosocial interventions for cancer patients, and this study provided several important findings likely to influence both future research and delivery of care.
As highlighted previously, internet-based interventions have many advantages. Internet-based interventions have been growing in many fields of psychology including general psychological distress, more severe mental health disorders, management of health conditions, and in influencing health behaviour change. As highlighted in the Chapter 6, internet-based interventions vary greatly in terms of the level of therapist assistance. *My Road Ahead* was designed with the specific intent to provide psychosocial support requiring minimal therapist support, which affords a major advantage in terms of disseminating this program in the future. Ritterband et al. (2009) suggested that developing an internet-based intervention that is able to significantly impact on behaviour change, elimination of symptoms, and maintain these changes is a major achievement for wide-scale dissemination goals. The current study suggests that a self-directed online psychosocial intervention for men with prostate cancer is acceptable and feasible. However there are several areas of improvement that have been highlighted in previous sections and further evaluation research with a larger sample size will add certainty to the program’s feasibility.

With a growing number of men with prostate cancer the health community needs to find a means to deliver interventions effectively. There have been many calls for the integration of the assessment, provision of information and the delivery of more complex interventions as part of routine cancer care (Holland et al., 2011; Hutchinson et al., 2006). As mentioned previously, models of stepped-care have been proposed as a means to disseminate care efficiently and effectively. Here the level of distress is matched to the psychosocial intervention and more complex and usually costly treatment is available for those who do not benefit from more basic levels of care (Bower & Gilbody, 2005; Hutchinson et al., 2006; Kreber et al., 2012). Decisions are usually made through assessment and patient preferences (Kreber et al., 2012). Stepped care is considered similar to tailored interventions (Latini et al., 2011). In
tailored psychosocial interventions the intervention is tailored to the needs of the specific individual and stepped care is often driven by cost concerns where the most appropriate intervention is given to an individual (Latini et al., 2011).

Scogin, Hanson and Welsh (2003) suggested that self-directed programs can often serve as one of the first steps in such a model. Internet-based interventions in particular may be placed well into this first step, where additionally supportive options are available if the internet-based program is not sufficient or effective (Cuijpers et al., 2008). In Krebber et al.’s (2012) protocol paper evaluating stepped-care for neck and lung cancer patients, their internet program fitted into the more basic level of guided self-help via the internet or a booklet. Given that My Road Ahead was a CBT skills based program it may be suited to address higher levels of care in addition to Krebber et al.’s identified level. In reviewing Hutchinson et al.’s (2006) tiered model of stepped care, a comprehensive CBT internet-based program could potentially cover mild to moderate levels of distress in areas such as communication skills and stress management. Specialist care for moderate to severe distress may be more appropriate for mood and anxiety disorders. Therefore, My Road Ahead and similar future internet-based programs may be suited to mild to moderate presentations of distress and associated levels of needs. At the same time internet-based interventions may be a simply a preference for many men, in terms of anonymity and convenience.

Finally, as highlighted previously My Road Ahead signifies the development of the first self-directed comprehensive psychosocial intervention for men treated for prostate cancer, and as such provides the foundation for future programs and refinements of My Road Ahead itself.
Summary and Conclusion

The primary aim of the present study was to investigate the efficacy of an internet-based psychosocial intervention for men treated for prostate cancer, focusing on sexual, psychological and relationship functioning. A secondary aim was to investigate the feasibility and acceptability of such a program for men treated for prostate cancer. A self-directed CBT program was developed and tested through a complex process resulting in a comprehensive, interactive and flexible program which took advantage of the benefits of online technology and used this as a platform to roll out a manualised intervention to address many of the needs of men with prostate cancer.

*My Road Ahead* was administered to 57 men treated for localised prostate cancer in the last 60 months. Results from the evaluation of the study found no significant treatment effects for sexual functioning, psychological functioning, and relationship functioning measures. There were some trends for interaction effects for sexual intimacy and marital affection that should be evaluated by using a larger sample size. A larger sample size is necessary to clarify whether *My Road Ahead* is effective and to allow for further analyses into the factors that may predict outcomes. A larger sample size will also allow further exploration of the potential benefits or lack of benefits from the forum itself and the forum in conjunction with the modules. Results also revealed that an internet-based program is both feasible and acceptable to men treated for prostate cancer. However this finding should be interpreted cautiously given the small sample size and several recommendations for future research and changes to *My Road Ahead* have been made. In particular, the development of a website that allows the internet-based intervention to be more clearly and strongly tailored to the needs of participants seems appropriate when taking into consideration that while men treated with prostate cancer have several identifiable unmet needs, there is great variability in terms of actual patterns of needs at different times and for specific individuals.
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Appendix A: Partner Information Sheet
Module 4: Partner Information
Prostate cancer and erectile dysfunction

Your partner is now at Module 4 of the program. This module looks at why sexual function often changes after prostate cancer treatment and what can be done about it. Some partners find the changes to their man’s sexual functioning confusing and frustrating and this sheet may help you understand what is going on. There are also some communication exercises for you to participate in. The next module addresses relationship and intimacy issues in more detail.

Prostate cancer & erectile dysfunction (ED)
You are probably already aware that ED is a very common side effect of treatment for prostate cancer. This is because the nerves necessary for erections are often damaged during radiation and surgery. This does not mean that they are permanently damaged but that there will be a period of time where function is impaired, usually many months and sometimes this damage does not recover.

What can be done about men’s changes to sexual function?
(1) Challenge thoughts associated with masculinity, intimacy, and sexuality (this module looks at this)
(2) Use medical aids (covered in module 5)
(3) Improve communication between a couple (covered in module 5)

Sex, intimacy, and relationships
Although intimacy and communication will be addressed in more detail in the next module, it is important to highlight that sexual issues affect both members of a couple and the best way to tackle ED is together.

The flow diagram below represents an overview of how ED can impact on your sex life and relationship.

It is important not to wait until your partner’s erections return to how they were before treatment. Not being intimate or communicating as well as not having sex for a period of time means other problems may arise even when erections return.

Research has found that some men and their partners find that having to deal with ED actually results in improvements to their sex lives and relationships in the long run! This might be because it forces the couple to think about things differently and to explore new ways of achieving sexual pleasure together.
**ED affects you too**

It is important for both the man and has partner to acknowledge the loss associated with ED. Research suggests that some women choose not to talk to their partner about ED and loss of sexual activity for fear of upsetting him or because they think it shouldn’t be important or discussed in the context of having cancer. Since ED is an issue that affects both members of a couple it is important to communicate and come up with solutions together. Make sure you join your partner with the exercise he is asked to do to get the most benefit from this program.

**Exercise:**

Think about how your partner’s ED has impacted on your life. Write down the changes you have noticed in your partner with regards to sexual functioning – both physically and emotionally, and how this has affected you. This shouldn’t be a blame based exercise and try not to feel guilty about how you are feeling. This is simply an exercise to acknowledge how things have been affecting you. Your partner has also been asked to complete this exercise. When you have both finished use what you have written to share your experiences.

---

**Important things for you to know**

- It is not you! Sometimes partners think that the changes to their partner’s sexual functioning are because they are less attracted to them or they are somehow causing the problem. This is rarely the case.
- Be positive and non-judgemental. Don’t assign blame.
- Your partner’s sexual problems can impact on your sexual functioning. Since dealing with sexual problems in relationships can be difficult, now can be an excellent time to think about and discuss any sexual issues you may have. Sexual problems are extremely common in women but are probably less spoken about than they are in men. Common issues for women include: loss of desire and arousal, and pain during sex. It is also a good time to think about your needs and what you might like to change in your sexual relationship.
**Sexual beliefs & myths**

When there are changes in our sexual functioning and sexual relationships it can be helpful to look at some sexual beliefs we may hold that are not entirely accurate. We all develop certain attitudes and beliefs about sex and sexuality which come from our family, peers, teachers, religious beliefs, sexual partners, and the media. Below is a list of statements related to sex, ED and prostate cancer.

<table>
<thead>
<tr>
<th>Myth</th>
<th>Feedback</th>
<th>Tick if this is a belief you hold</th>
</tr>
</thead>
<tbody>
<tr>
<td>A man wants sex at anytime with anybody</td>
<td>People often believe this when they hold the view that men are always ready, willing and able to have sex. This is not the case and holding such a view can be damaging to a man’s self esteem.</td>
<td>□</td>
</tr>
<tr>
<td>ED is mostly in a man’s mind</td>
<td>ED can have both psychological and physiological causes. Problems with blood flow or nerve damage can have a big impact on erections. Psychological factors such as stress and anxiety may contribute to ED.</td>
<td>□</td>
</tr>
<tr>
<td>ED is just the man’s problem</td>
<td>If a man has a partner then they are likely to be impacted by ED, especially if the change in sexual function leads to withdrawal or loss of intimacy or mood changes. If all sexual contact is avoided then this is a problem shared by both members of a couple.</td>
<td>□</td>
</tr>
<tr>
<td>Men should know everything about sex</td>
<td>Some believe that men should just know how to have sex or please their partners and not need to seek help or knowledge from elsewhere (ie counsellors or books). It may not be until something changes, such as the case with ED, where there are major changes to our sex lives that we realise sex is not a simple and logical process. No-one can claim that they know everything about sex – adapting to changes means learning new ways of having a sexually satisfying relationship.</td>
<td>□</td>
</tr>
<tr>
<td>Penetrative sex is the only way to have sex</td>
<td>It is possible to have intimacy and a satisfying sex life without penetrative sex. Holding the view that penetrative sex is the only way to have sex means that if a man has ED he will avoid all forms of sexual contact for fear that all physical contact must lead to sex. This will result in the man (and his partner) feeling unattractive, unwanted, depressed or anxious.</td>
<td>□</td>
</tr>
<tr>
<td>Only men should initiate sex and take the lead</td>
<td>Men often do initiate sex but that doesn’t mean that they prefer to! Women have very similar sexual desires and needs to men and there is no reason why a woman shouldn’t initiate sex.</td>
<td>□</td>
</tr>
<tr>
<td>A man can only</td>
<td>Neither an erection nor ejaculation is necessary for a</td>
<td>□</td>
</tr>
</tbody>
</table>
have an orgasm with an erection | man to have an orgasm.

| Prostate cancer treatment negatively impacts on a man’s sex drive (libido) | Researchers have found that the only prostate cancer treatment to impact on libido is the use of hormone therapy. No other treatments for prostate cancer have been linked to loss of libido from a physical point of view; that is, there doesn’t seem to be a physical or medical reason why libido changes after surgery or radiotherapy. However the stress and anxiety related to the diagnosis and treatment of prostate cancer may be enough to impact on libido and many men report a significant drop in libido after prostate cancer treatment. |

What may be happening for your man?

Partners of men with prostate cancer are often unaware of the significant impact that ED can have on a man’s sense of masculine identity and his confidence and self esteem. Having no or limited erections can often make your partner feel he is somehow “less of a man”.

Research has found that men who are more likely to conform to the stereotype of masculinity may struggle more adjusting to the changes ED may bring.

Masculine stereotypes include:
- Physical strength
- Self-reliance
- Being in control
- Being rational and not being emotional
- Be the breadwinner
- Be tough and ready for violence
- Sexual performance (potency)
- Being strong

Exercise:

Think about the stereotypes listed above. Are there any that you think your partner relies on when he thinks of what a man should be like, or what he should be like as a man?

Do you think it might be worth talking to him about expanding his idea of what it means to be a man?

Things to try and do this week:

(i) Sit down with your partner and share what each of you has written for the first exercise.

(ii) Also, do something this week that you and your partner enjoy. It may be something that you used to do that you haven’t done for a while or it may be something you have always wanted to do.
Appendix B: Welcome/start-up pages/instructions
**Welcome**

Are you aware that the after treatment for prostate cancer can have to challenges and long lasting support? My Road Ahead offers an interactive, information and supportive resource to help you move ahead in your life.

**Begin My Road Ahead**

My Road ahead has been developed as a research project to support men after treatment for prostate cancer.

It has been developed to specifically focus on the issues faced by men after treatment for localized prostate cancer. It is for men aged 65 years and over who are in the early stages of life.

To take part in the research, we invite you to register as a user. You will need to be 50 or above to access the materials of the following topics:

- At least one per week for 12 weeks
- Once every 4, 6 months after the program.

**Melbourn Health Foundation**

Your details are important in our procedure, as we are bound to keep your details secure.

Privacy: Consent to have all about it here

NEXT

Cancel
How it works

By participating in My Road Ahead, you're helping yourself and others to navigate the challenges often faced after treatment for prostate cancer.

1. Complete your confidential profile
   Create your own personal account so you can navigate your road ahead and log in and out as often as you need to. You will need to answer some questions about yourself and prostate cancer experiences so that your progress can be mapped.

2. Participate
   You will be randomly assigned to receive access to one of three options: the online modules, the online forum or both. To participate you will need to log in for 1-2 hours per week over the 10 weeks, use the information regularly and record your experiences.

3. Complete ongoing questionnaires
   You will receive a reminder to complete the follow-up questionnaires each time they are due. These questionnaires will help us understand how you are going and are vital for the success of our research.

4. Your feedback will be used for research
   While your personal details will not be shared, all the information you provide us will be used to evaluate whether My Road Ahead is useful for men after prostate cancer treatment. Your feedback will help us to be able to offer this program to others in the future.

You will have a limit of 10 weeks access.
The program will be available to you for only 10 weeks. Please make sure you make the most of the program while you have access.

NEXT  
Cancel

Your Pledge

Your commitment to this project is important. We expect the following:

- [ ] I will use My Road Ahead regularly.
- [ ] I will use this for 1-2 hours per week for 10 weeks.
- [ ] I will complete questionnaires when requested.
- [ ] I am committed

Please tick

NEXT  
Cancel
Consent Form

Click here to download the research participant information and consent form. It is important that you read this prior to consenting to take part in this research.

I have read and I understand the Participant Information version 4 dated 30/01/2012.

I freely agree to participate in this project according to the conditions in the Participant Information.

I have been given the option of printing 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.

I understand that if I select “I agree to the study conditions” button located below I am giving my consent to participate in this research project without the need for my signature.

☐ I agree to the study conditions
☐ I give consent to use the data I provide for use in future research
☐ I accept and agree to the terms of use for this website.

NEXT

Cancel

Get Started

Please enter your details below.

Email Address: 

Screen Name: 

Your screen name will be seen by others. If you wish to remain anonymous please do not use your real name.

Password:

Confirm Password:

How did you find out about this program?

- select -

NEXT

Cancel

Privacy Concerns? Read all about it here

If you need assistance please email the researchers at: myroadaheadhelp@gmail.com
Done!
Now check your email.

Please open this email and click the link to validate your account.

Once validated you will be able to login to the website using your screenname and password.

If you are having any issues and need help please check our Frequently Asked Questions.

Success!
Your account is validated.

Congratulations your email account has been validated and you are now able to login and begin using the website.
Welcome

Introducing Dr Addie Wootten, a Clinical Psychologist, who will lead you through the My Road Ahead support program

Begin your Confidential Profile

Thank you for deciding to participate in My Road Ahead. Before you get started we need to know how you are at the moment and any difficulties you have been experiencing. We will keep track of your progress over time and use the information you provide to see if My Road Ahead has made any difference to your health and wellbeing.

Please note:

- All of the questions are very important to us. Some may not seem that relevant to you but we would really appreciate your feedback.
- Some of the questions also ask about personal information.
- All the information you provide will be stored securely and you will remain anonymous.
- All information will be used and analysed in a way that ensures you will never be identified individually.
- Once you have created your profile you will have access to My Road Ahead. Without your assistance this research would not be possible.

GET STARTED
* screenshot depends on which group allocated
Appendix C: Overview of *My Road Ahead* once questionnaires are completed
Complete Questionnaires

Questionnaires help us evaluate whether My Road Ahead is useful and is vital in developing this program so that others can benefit in the future. You will be reminded to complete each questionnaire via email.

You will be asked to complete the questionnaires at the following times:
- Before you start the program
- Half way through the program (a very short one)
- After completing the program (at 10 weeks)
- 12 weeks after completing the program
- 6 months after completing the program

It is very important that you complete each questionnaire when you receive an email reminder.

Navigate prostate cancer topics

My Road Ahead contains 6 modules. We recommend you complete the modules in order and spend 1-2 weeks on each module. The modules are:

1. Introduction to the program and the emotional impact of prostate cancer
2. Tasks for helpful thinking and effective communication
3. Coping with physical changes
4. Sexuality and masculinity
5. Sexuality and intimacy
6. Putting it all together and planning for the future

Need help?
Email us at myroadaheadhelp@gmail.com and one of our friendly support staff will be in touch shortly.
Watch video content

We have included a range of videos in each of the modules from men who have had prostate cancer and different health professionals. We hope this will be an enjoyable and interesting way to learn more.

Complete online exercises

There are some online exercises throughout the program to give you a chance to develop your skills in each of the modules. You will be asked to enter responses to questions on online worksheets. These responses will remain confidential and will be stored in your personalized logbook.

Need help?
Email us at myroadaheadhelp@gmail.com and one of our friendly support staff will be in touch shortly.
Complete downloadable exercises

At the end of each module there are exercises to give you a chance to practise what you have learnt in the module. These can be downloaded and printed allowing you to think about these topics away from the computer.

Need help?
Email us at myroadaheadhelp@gmail.com and one of our friendly support staff will be in touch shortly.

Involve your partner

If you have a partner we encourage you to discuss the information you learn from the program with them.

Research suggests that a partner and your relationship can be strongly impacted by a prostate cancer diagnosis and subsequent treatment. In fact, prostate cancer has been referred to as the “couple's disease”.

There will be handouts for you to print for your partner at the end of each module and some of the information will be particularly relevant for your partner and there are specific exercises for them to do by themselves or with you.

Need help?
Email us at myroadaheadhelp@gmail.com and one of our friendly support staff will be in touch shortly.
If you don't have a partner

For some of the exercises that involve a partner you may be able to use a close friend or family member. Otherwise there will be other options for homework and exercises you can do by yourself.

You will not be disadvantaged by not having a partner; this program is designed to be useful for all men.

Bookmark topics of interest

As you move through the modules there might be topics that you would like to bookmark which you can then easily access at a later time. These bookmarks will be stored under the "my bookmark" tab under the "logbook" section.
Logbook

You have access to your own logbook where any answers you give to online exercises will be stored. You can make other entries at any other point in time so that you can use this like your own personal journal to log your experiences.

Need help?
Email us at myroadaheadhelp@gmail.com and one of our friendly support staff will be in touch shortly.

Log your mood

At the beginning and end of each module you have the opportunity to log your mood across a few different dimensions. You can view your mood recordings at any time under “my mood” tab in the “logbook” section. This will allow you to see whether your mood has changed during the time you have access to My Road Ahead.

Need help?
Email us at myroadaheadhelp@gmail.com and one of our friendly support staff will be in touch shortly.
Share your experiences

This Forum has been set up so that you can communicate with other men on the prostate cancer journey. One way to use the forum is to share your experiences. Other men are likely to find this interesting and many men might be going through similar experiences.

Need help?
Email us at myroadtowardrecovery@gmail.com and one of our friendly support staff will be in touch shortly.

---

Help others by providing support

You might find some comments on the forum from men where you think you could provide support or some suggestions. Men who have posted these comments are likely to be very appreciative of this support, mostly just to know that they are not alone.

Need help?
Email us at myroadtowardrecovery@gmail.com and one of our friendly support staff will be in touch shortly.
Ask questions

Another great way to contribute to the forum is to ask questions. No matter how simple the question seems, it is likely that someone else will be interested in the answer and it will generate some discussion.

Need help?
Email us at myroadaheadhelp@gmail.com and one of our friendly support staff will be in touch shortly.

You only have 10 weeks access to My Road Ahead

We suggest you plan how much time you need to spend each week logged into the program so that you can make the most of it.

Need help?
Email us at myroadaheadhelp@gmail.com and one of our friendly support staff will be in touch shortly.
Appendix D: Module component of *My Road Ahead*
Homescreen

Logbook
Mood monitor
Example screen shots from Module 1

Prostate Cancer & You
What’s Ahead...

→ Learn about how prostate cancer and its treatment is affecting different areas of your life
→ Look at how prostate cancer may make you feel
→ Understand common emotional reactions to prostate cancer and its treatment

Anxiety
- Fearfulness
- Excessive worry
- Nervousness
- Feeling isolated
- Hyperalertness
- Shakiness
- Irritability

Prostate Cancer Specific
- Worry about cancer recurrence
- Fear that you body might let you down again
- Fear of incontinence
- Fear of a relationship breakdown

Depression
- Lack of energy
- Early waking
- Fluctuations in mood
- Feeling of worthlessness
- Irritability / short tempers
- Inability to enjoy things
- Difficulty concentrating
- Anticipating the worst
- Feeling anxious
- Loss of memory

Prostate Cancer Specific
- Loss of interest in activities you used to enjoy
- Loss of sense of masculinity or identity
- Loss of interest
Anxiety and Stress

Prostate cancer and its treatment bring much change to a person’s life. It is normal to feel worried and anxious during treatment and recovery. There may be some specific fear and worries such as:

- Will the cancer come back?
- What will my test results be?
- What will I do if I can’t go back to work in the same capacity?
- Will my wife/partner look at me the same way?

These are perfectly normal concerns and worries to have in reaction to prostate cancer and its treatment. They can also be helpful in motivating us to make changes in our lives and better prepare for the future.

The body’s response to anxiety: fight, flight or freeze

When we are anxious and we think we are in danger, our brain sends signals to our nervous system to send immediate messages throughout the body, to either:

- **Fight**  
  Take the situation head on

- **Flight**  
  Escape from the situation

- **Freeze**  
  As in a kangaroo caught in headlights

This ‘fight, flight, freeze’ response involves physical reactions, illustrated in the following diagram.

<table>
<thead>
<tr>
<th><strong>Fight</strong></th>
<th><strong>Flight</strong></th>
<th><strong>Freeze</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase heart rate</td>
<td>Irritability (grumpy or short tempered)</td>
<td>Dry mouth</td>
</tr>
<tr>
<td>Increase breathing rate</td>
<td>A feeling of fear or apprehension</td>
<td>Muscle tension</td>
</tr>
<tr>
<td>‘Butterflies’ in the stomach or nausea</td>
<td>Trembling, shaking or a feeling of restlessness</td>
<td></td>
</tr>
</tbody>
</table>
Feelings, thoughts and behaviours related to anxiety

In addition to the body’s physical response to anxiety you may have other feelings, thoughts and behaviours that keep your anxiety response going like a vicious cycle. This is illustrated in this diagram.

Depression

Everyone feels sad at different times

Normal feelings of sadness

We all feel sad or down at some point in our lives. Sadness or feeling down are normal reactions to things such as disappointment when things go wrong, or when we lose something or someone we value or love.

When faced with these situations, feelings of constant sadness generally last for a few hours or up to a few days. We usually find ourselves feeling better after talking with someone, or doing something enjoyable, or even after some time has passed.

Depression is more than feeling sad

Depression is more than just feeling sad. It involves a loss of interest in activities you usually enjoy and you may experience changes to your weight, energy or sleep patterns. You may also feel worthless or guilty and find it hard to find the point to your life. Depression can cause substantial distress and difficulty carrying out daily activities.
Example screen shots from Module 2

Prostate Cancer & You
What's Ahead...

In this module, you will:
→ Learn how communication plays a role in coping with prostate cancer
→ Become aware of the three main communication styles
→ Begin to develop assertiveness skills to aid communication about sensitive and personal topics
→ Learn about the connection between what we think, what we feel and how we act
→ Understand how mood influences our thinking and our actions

Prostate cancer and communication

Developing good communication skills is helpful for everyone. For men with prostate cancer, there are times where communication is particularly important.

Other family members & close friends

Family and friends may also be greatly affected and your relationship with them may change. There may be changes in both the physical and emotional support you need from friends and family. Effective communication can help you express your needs.

Medical staff

You may have difficulty understanding the information and options provided by medical professionals or expressing what services you would prefer or like.
Communication styles

There are three main communication styles:

- **Passive Style**: Opinions, feelings and wants are withheld altogether or expressed indirectly or only in part. The underlying message is "I’m weak and inferior and you are powerful and right". People who use the passive style often avoid decision-making but may be left feeling frustrated, down or low in confidence.

- **Assertive Style**: Opinions, feelings and wants are clearly stated whilst respecting the rights of others. The underlying message is "You and I may have our differences, but we are equally entitled to express ourselves to one another". People who use the assertive style are able to actively participate in decision making whilst maintaining self-esteem and respect for others.

- **Aggressive Style**: Opinions, feelings and wants are honestly stated but at the expense of someone else’s feelings. The underlying message is "I’m superior and right, you are inferior and wrong". People who use the aggressive style may end up with what they want but they may make enemies or put people off talking with them.

Technique for communicating assertively

The technique involves a three-step process of looking at the following:

1. **Your thoughts**: About the particular situation. You express them by making a non-judgemental, non-blaming description of the problem as you see it. Try to stick as closely to the facts as possible, without making judgements about the motives or feelings of others.

2. **Your feelings**: These are described using "I" statements about your emotional reaction to the problem. For example "I feel hurt, angry, upset, disappointed when ...". Try to avoid implying that you hold the other person responsible for your feelings. The main message is that you are trying to solve a problem, not blame the other person for it happening.

3. **Your wants**: These are specific requests for what you would like to happen. It is important that these are expressed in specific rather than general terms so that the other person understands exactly what you are asking for.
An example of the power of our thoughts.

Here is an example of how our thoughts influence our feelings. Imagine you are at your doctor’s office waiting for your next PSA test result.

<table>
<thead>
<tr>
<th>THOUGHTS</th>
<th>FEELINGS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sitting in the doctor’s office receiving PSA test result.</td>
<td>Fearful, angry, scared, worried, tense.</td>
</tr>
<tr>
<td>My PSA has probably gone up, maybe it’s even spread.</td>
<td>Tentative, a little nervous, safe.</td>
</tr>
<tr>
<td>I’m not sure it has gone up or it’s just fine, either way I trust my doctor will be able to look after me.</td>
<td>Calm, happy, in control.</td>
</tr>
<tr>
<td>I think my PSA will be fine, nothing to worry about.</td>
<td></td>
</tr>
</tbody>
</table>

This example suggests that our feelings are not due to what actually happens (waiting in the doctor’s office for your test results) but the thoughts we have about that situation.

Unhelpful thoughts

1 of 7

Type of thought

Black and white thinking: viewing situations in extremes, e.g. as ‘great’ or ‘awful’.

Example

“If I can’t get an erection hard enough for intercourse there is no point starting anything”.

Why is this way thinking unhelpful?

This type of thinking doesn’t allow for an “in between” view.
It is unrealistic to always think in extremes, as usually there are many shades of grey; it isn’t pure black or white.
Example screen shots from Module 3

Physical Changes
What’s Ahead...

In this module you will:

→ Learn about physical changes that can occur with prostate cancer
→ Learn tools for coping with incontinence
→ Learn stress management and relaxation techniques

Physical Changes after Prostate cancer treatment

Head and brain:
Any stressful or traumatic event can have a big impact on thinking, memory and attention. As stress levels rise the brain has to work harder and harder to cope and so we may experience problems such as:

→ Poor memory
→ Forgetfulness
→ Difficulty concentrating
→ Difficulty solving problems
→ Feeling overwhelmed
→ Headaches
→ Blurred vision or sore eyes
Mark's anxiety-avoidance cycle

Mark is invited to play golf with his friends

Worry about what might happen at the event.
Mark starts to think "I can't play golf yet, I'll feel, I can't stand this"

Precipitating event:
(Being invited to a social gathering)

Anxiety related symptoms:
Mark feels sick, a bit shaky and starts to sweat.

Reinforcement of the need to worry about incontinence in public.

Avoidance behaviour:
Each time Mark thinks of playing golf he starts to feel uneasy and keeps declining the offer to play golf with his friends.

Click here to Download the Anxiety Avoidance Cycle

Breathing relaxation

Breathing as a relaxation technique can be very simple and effective in reducing stress and anxiety.

Many people find that they breathe by taking shallow breaths from their chest. In deep breathing or diaphragmatic breathing, you train yourself to take deep full breaths from the abdomen rather than short shallow breaths from the chest.

Progressive muscle relaxation (PMR)

PMR involves tensing and relaxing different muscle groups in the body. Muscle tension is a common symptom of stress and anxiety.

Often we are not aware that we are tense at resting until we do something like PMR.
Breathing relaxation

Breathing as a relaxation technique can be very simple and effective in reducing stress and anxiety.

Many people find that they breathe by taking shallow breaths from their chest. In deep breathing or diaphragmatic breathing, you train yourself to take deep full breaths from the abdomen rather than short shallow breaths from the chest.

Progressive muscle relaxation (PMR)

PMR involves tensing and relaxing different muscle groups in the body. Muscle tension is a common symptom of stress and anxiety.

Often we are not aware that we are tense at resting until we do something like PMR.
Example screen shots from Module 4

Sexuality & Masculinity
What's Ahead...

In this module you will:

→ Understand why sexual function is often changed after prostate cancer treatment

→ Learn about the overall impact of changes to sexual function

→ Learn about how traditional male role norms about sexuality define masculinity

→ Expand your definition of masculinity

→ Start to identify and challenge any negative thoughts about sexuality and manhood that you might be experiencing

Why is it important to do something about ED?

ED is known to impact on:

→ Men's perceptions of themselves and their bodies. Feeling ashamed about changes to your body and your ability to perform sexually can in turn decrease sexual desire and arousal

→ Relationship intimacy. A man may begin to avoid all sexual contact if he is no longer able to get an erection. A man may also feel guilty if he is no longer able to satisfy his partner

→ Everyday interactions with women

→ Sexual imagining and fantasy life

→ Men's perception of their masculinity, which could lead to feelings of low self-esteem, helplessness and low self-confidence
How ED can strain relationships

The flow diagram below represents an overview of how ED can impact on your sex life and relationship.

Some stereotypes about masculinity

- Physical strength
- Self-reliance
- Being in control
- Being rational
- Not being emotional

- Being the breadwinner
- Being tough and ready for violence
- Sexual performance (potency)
- Being strong
Common myths related to sex, ED and prostate cancer.

Question 1 of 8

"A man wants sex at anytime with anybody"

Do you hold this belief?

YES  NO

Logbook Exercise

"Step 1. Think about a situation recently where you felt anxious, upset or concerned about your sexual ability. Write down the details - when, where, who, and what happened etc."

Think about how your experience of ED has impacted your life. Write down the changes you have noticed since your prostate cancer treatment. Think of the different aspects of your life. Have you noticed any changes that could be related to how you feel about your change in sexual functioning?

e.g. Tried to have sex with my wife in the evening but couldn't get an erection.
e.g. (single men). Out having a drink with 4 male friends at the pub and they were talking about various women they had dated recently.
**Challenge your unhelpful thoughts**

Use the form below to complete these steps using one of your unhelpful beliefs. You can use this step-by-step process with as many problems as you like.

<table>
<thead>
<tr>
<th>Automatic thoughts</th>
<th>I cannot get an erection</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I'm not a real man</td>
</tr>
<tr>
<td>Feelings</td>
<td>Sad / Guilty</td>
</tr>
<tr>
<td>Evidence for</td>
<td>I can't get an erection – my body isn't working properly.</td>
</tr>
<tr>
<td>Evidence against</td>
<td>Many things add up to make me a man – not just erections</td>
</tr>
<tr>
<td>Alternative thoughts</td>
<td>I'm a caring husband, father and grandfather and I am a man.</td>
</tr>
<tr>
<td>New feelings</td>
<td>Happier</td>
</tr>
</tbody>
</table>

**Offline exercises**

Print off the offline exercises download above and try to work through at least three examples in the Thought Record Form.

**Without a partner**

Think back to the earlier exercise where you wrote down the ways in which the change to sexual function has impacted on your life. Pick one area and think about how this has impacted on your behaviour.

For example if this change has impacted on your confidence in meeting new people and you have been avoiding social situations try and think of a way to challenge these thoughts and then plan something that might get you started on this again. You could call an old friend you haven’t seen for awhile and arrange to meet for a drink or go out with a friend and their friends who you don’t know. Start off small but use this as an experiment to see if you can observe your thoughts and beliefs in this situation.

**With a partner**

Print off the offline exercises download above and try to work through at least three examples in the Thought Record Form.

1. If your partner has completed their exercise make sure you organise a time to sit down together and share what you have written. There is no need to try and solve these things just yet. This is the first step in both of you finding a way to start talking about these changes. We will explore ways of improving how you feel about these things later in this module and in Module 5.

2. Use the Thought Record Form to monitor any thoughts and feelings associated with specific situations related to sex and intimacy. You can also talk to your partner about challenging your thoughts about ED, sex, and masculinity.

3. Do something this week that you and your partner enjoy. It may be something that you used to do that you haven’t done for a while or it may be something you have always wanted to do.
Example screen shots from Module 5

Sexuality & Masculinity
What’s Ahead...

In this module you will:

→ Learn more about the impact of erection problems on intimacy
→ Learn how to enjoy intimacy and sexual interactions even when an erection is not possible
→ Redefine what good sex means to you
→ Learn and practice specific communication about sex and intimacy

Positive or negative evaluation without a partner

This flowchart illustrates the way a positive or negative evaluation can have a big impact on your level of talking and flirting with women:

Positive evaluation
- I really like this person and find them very attractive. I think I will talk to them more.

Negative evaluation
- There is no point in talking to them because I can't get erections and won't be able to have a "normal" sexual relationship.

Arousal
- Feel more attracted to others and curious about where it might lead.

No arousal
- Feel anxious, worried and tense.
The role of your evaluation of your sexual behaviour with a partner

The final part of this process is the thoughts you have about the sexual behaviour you engage in. The way you 'rate' or judge what you are doing will impact on how enjoyable it is for you.

Thoughts that often get in the way of intimacy

With a partner

Below is a diagram displaying common thoughts that have a bad impact on sex and intimacy. The outcomes of these thoughts are also addressed.

Thoughts

- I can't satisfy my partner.
- I don't want to disappoint my partner.
- My partner says she doesn't mind that we can't have penetrative intercourse, but I know she's just saying that to make me feel better.
- What's the point of starting something I can't finish.
- If I can't get an erection my partner will think I'm not a real man anymore.
- If we start something she will expect it to lead to more.

Feelings

- Inadequate
- Low self-esteem and confidence
- Anger
- Sadness
- Isolation
- Frustration
- Grief

Behaviour

- Withdraw from partner
- No intimacy
- Isolate self
- Less communication

Impact on partner

- Fear of no longer being attractive
- Sadness over loss of relationship
- Anger because of changed relationship
- Miss the closeness and connection
Redefining what "good sex" means to you

Beliefs about what it means to be a good lover, husband or partner will determine the thoughts that you have now in the context of erection difficulties after prostate cancer treatment.

Think back to the last module where a number of beliefs were listed that could lead to negative thoughts about sex when erection problems occur.

Beliefs are generalised type statements that we live by:

E.g. All men should be the providers for their family
E.g. In order for sex to be enjoyable for both people it must involve intercourse
E.g. You're not a real man if you can't have sex

The last module listed beliefs that could lead to negative thoughts about sex when erection problems occur. You can revisit module four to refresh yourself.

Communicating assertively about sexual intimacy

Below is an example of how Mark used the assertiveness techniques to broach the subject of intimacy with his wife and to discuss how he wanted to improve things between them.

**Situation**

I feel as though I have withdrawn from our relationship. I don't feel like we spend time together any more and I have stopped holding hands with her, or taking her out for dinner.

**Feelings**

I feel inadequate as a man and a husband. I feel sad that this has happened and also a bit guilty.

**Thoughts**

I think I can't satisfy her anymore. Sex used to be great and we both enjoyed it, but now I can't do that and I'm letting her down. So now when we're in bed I think what's the point, why start something I can't finish.

**Partner**

Does she blame me for what's happening? Is there any way that I can satisfy her even without having a full erection?

**Plan**

Would she be willing to try working on this together? Maybe we could try the positive erotic focus strategy to just work on re-building our sexual feelings and see where that takes us.
Example screen shots from Module 6

Planning for the future
What's Ahead...

In this module you will:

- Explore the impact of cancer on beliefs about death and mortality
- Explore your thoughts and beliefs about your future and any fears you might be experiencing about prostate cancer
- Learn tools for coping with fears about cancer recurrence and uncertainty in the future
- Review what you have learnt in this program
- Reflect on what you have achieved from this program.

Living with uncertainty and your mortality

As we have discussed throughout this program, cancer brings up many thoughts and feelings. One aspect that can often be affected is our feeling of being able to rely on our body. Cancer can bring up feelings of vulnerability and thoughts about mortality; life and death. Cancer can bring a realisation that we are not immortal.

Grief, loss, and thoughts about death are normal and may take some time to process.

You may find yourself thinking about the following:

- Reflecting on your life (both positive and negative experiences)
- Questioning whether you have done everything you want to
- Worried about what may happen to your family and friends without you
Fear of recurrence

Frequent PSA tests following prostate cancer treatment is normal but often raises anxiety and worry. This worry around the time of PSA tests is normal and often eases over time. Here is a diagram of how this worry seems to rise and fall but eventually level off. As you can see anxiety levels tend to reduce in between each PSA test and then rise when the test draws near.

Mindfulness exercises for daily life

Mindfulness involves focusing on the present moment rather than worrying about the past or future. Mindfulness teaches people to live in "being gear" rather than "thinking gear". Being gear is about accepting all thoughts – whether they are negative or not – are just thoughts.

Notice five things

This is a simple exercise to centre yourself, and connect with your environment. Practice it throughout the day, especially any time you find yourself getting caught up in your thoughts and feelings.

1. Pause for moment
2. Look around, and notice five things you can see.
3. Listen carefully, and notice five things you can hear.
4. Check in your body and notice five things you can physically feel (i.e. such as the clothes on your skin, the wind in the air).
Logbook Exercise

Building up your tools for a happy and healthy future

Take some time now to think about all the ways you can look after yourself. Use the space below to fill out some strategies you think might work for you in the future.

**Behaviour**: What behaviour is a warning sign for me and what behaviours help me?

e.g. If I start to withdraw and not talk to my family that is a warning sign that I am not feeling too good. Getting regular exercise like a walk each morning helps me to feel good.

---

Logbook Exercise:

**Tips for maintaining gains in the program.**

Take some time to reflect on what you have gained over the duration of this program. In order to maintain these gains think about the goals you would like to achieve into the future. Setting goals allows you to focus on areas of your life you have improved and want to continue improving.

What are your goals or what would you like to work towards into the future:

- **Short-term** (next month):
- **Medium-term** (next 6-12 months):
- **Long-term** (more than 12 months):
Appendix E: Letter to potential participants
Dear [first name],

The Urology Department at the Royal Melbourne Hospital, in collaboration with the Australian Prostate Cancer Research Centre Epworth, Swinburne University of Technology and Deakin University, is conducting research into providing an internet based psychological support program for men who have been diagnosed and treated for prostate cancer, My Road Ahead.

We are writing to you to invite you to participate in phase three of the study which is a randomised controlled trial of the effectiveness of My Road Ahead, the online program that has been developed. Participation will involve taking part in one of three internet-based groups; either taking part in the 10 week intervention, the 10 week intervention plus using an online forum, or just using the forum. If you agree to take part you will be randomly assigned to one of these three groups.

My Road Ahead aims to support men through the challenges often faced after treatment for prostate cancer.

A flyer is attached for your information. Please go to www.myroadahead.org for further details and click on “What is My Road Ahead” link to hear about how this program works.

Participation in this study is completely voluntary. We would like to emphasise that you do not have to participate in this research project to receive any medical care that you may require.

Yours sincerely,

Anthony Costello, F.R.A.C.S., M.D.
Professor and Director of Urology
The Royal Melbourne Hospital
Appendix F: Example letters to health professionals & advertising material
www.myroadahead.org

My Road Ahead is an online support program designed to be used by men after treatment for prostate cancer. This program aims to support men through the challenges often faced after treatment for prostate cancer. Men are not routinely offered psychosocial support despite strong evidence that being diagnosed with prostate cancer poses significant quality of life concerns for men and their partners and consequently a significant potential of developing a range of mental health disorders, including Major Depression and Anxiety disorders. Sexual dysfunction poses a particular threat to a man’s psychological functioning as well as relationship functioning. Lack of psychosocial support is in part due to lack of available resources and this project aims to provide a structured, self-directed psychological support intervention that is accessible and appealing over the internet.

To watch the introductory video click here: https://www.myroadahead.org/what-is-my-road-ahead

Research
The My Road Ahead Program is being offered as part of a randomised controlled trial. This research involves an evaluation the efficacy of My Road Ahead. Men who agree to participate in the program will be randomised into one of three groups: (1) My Road Ahead only; (2) My Road Ahead plus online moderated bulletin board; or (3) online moderated bulletin board only. Eligible men include those that have received treatment between 6 months and 5 years ago.

As this is a research program men will be required to consent to take part in the study and complete a range of questionnaires over a period of 6 months to assess their quality of life, mood state, relationship functioning, communication styles and their medical history. All participant information
will be kept strictly confidential. Participants in all groups will be asked to complete these questionnaires at 5 time points, when they consent to participate (baseline week 1), at the midpoint of the 10 week program (week 5), at the conclusion of the 10 week program (week 10), 12 weeks later (week 22) and 6 months after completing the 10 week program. They will also be asked to log into the online intervention at least once per week for between 1-2 hours per week over the course of the 6 modules.

**Accessing the Health Provider Login**

Please have a look at the program in more detail using the following details. Below is a health provider login for you to use. Please **DO NOT** pass this on to anyone else. If your patients would like to use the program they will need to create their own login.

**Web link:** http://www.myroadahead.org

**Username:** healthprovider  
**Password:** health

**Details of the online program**

*My Road Ahead* is a 6-module online self-directed psychological support covering a range of topics including:

- Module 1: Introduction to the program and the emotional impact of prostate cancer
- Module 2: Tools for helpful thinking and effective communication
- Module 3: Coping with physical changes
- Module 4: Sexuality and masculinity
- Module 5: Sexuality and intimacy
- Module 6: Putting it all together and planning for the future.

**Some important features of the program include:**

*Moderated bulletin board:* This forum offers the opportunity to share experiences, ask questions and share information. This is a space to share thoughts, ideas, tips or information with other men who might be going through similar experiences. Unlike other forums on the internet this forum will be moderated by the experienced researchers. Only appropriate information will be included on this forum. A link to the bulletin board is provided here: http://www.myroadahead.org/forum/.

*Partner inclusion:* My Road Ahead has been designed for men who do and do not have a partner. If a man does have a partner he is encouraged to discuss the information he learns from the program with them. Additionally, there are specific handouts for partners and specific exercises designed for partner inclusion. There are alternative exercises for men without partners.

*Online & offline exercises:* My Road Ahead consists of several online exercises for men to participate in as they proceed through the program. This provides men with an opportunity to practice and consolidate what they have learnt in each module. Some of the skills acquired are also used in later modules. For example, the following link involves a communication based exercise: http://www.myroadahead.org/module/two/page/20.

*Logbook:* As the men go through the program they have the option to bookmark any topics of particular interest. Answers to offline exercises will also be transferred to the logbook. At the end of the program the men will be able to use the logbook to look back and reflect on where they have come from as well as any goals they would like to work towards in the future. Here is a link to the logbook: http://www.myroadahead.org/logbook.

*Video:* There are online videos in each module with information from various health professionals or prostate cancer survivor’s reporting on their personal experiences. An example video about men’s
experience with sexual difficulties can be viewed via this link: http://www.myroadahead.org/module/four/page/3.

How do men participate?
To participate, men simply log in to the following website: www.myroadahead.org

How has this program been funded?
beyondblue and the Prostate Cancer Foundation of Australia have funded this program.

Who are the researchers?
Chief Investigator:
- Dr Addie Wootten, Department of Urology, Royal Melbourne Hospital and the Australian Prostate Cancer Research Centre at Epworth

Co-Investigators:
- Ms Katherine Chisholm, Department of Psychology; Deakin University
- Professor Marita McCabe, Department of Psychology; Deakin University
- Dr Jo Abbott, National eTherapy Centre; Swinburne University of Technology
- A/Prof Britt Klein, National eTherapy Centre; Swinburne University of Technology
- A/Prof David Austin, National eTherapy Centre; Swinburne University of Technology
- Professor Anthony Costello, Department of Urology, Royal Melbourne Hospital and the Australian Prostate Cancer Research Centre at Epworth
- A/Prof Declan Murphy, Department Robotic Surgery, Peter MacCallum Cancer Centre and the Australian Prostate Cancer Research Centre at Epworth

Further Information
Dr Addie Wootten
Email: myroadaheadhelp@gmail.com
Telephone: (03) 9936 8032
Post card sized flyer
Appendix G: Advertising on Beyond Blue
Programs and projects

Improving awareness of depression and anxiety amongst men is a key priority for beyondblue. Many of beyondblue's programs and services include a significant focus on the particular needs of men. These include:

**Online support program for men after treatment for prostate cancer NEW!**

Men who have received treatment for prostate cancer in the last 5 years are invited to take part in a study investigating the benefits of a newly developed online support program called My Road Ahead. If you would like to learn more about this please go to [www.myroadahead.org](http://www.myroadahead.org)
Appendix H: Questionnaire
Demographics and Background Questions

How did you hear about or find this program?
- Doctor or other health professional
- Friend or family member
- Advertisement
- Support group
- Surfing on the internet
- Media (TV, radio, magazine, newspaper)
- Other: Please specify

ABOUT YOU

Date of birth:

Residential postcode:

Employment status:
- Full time
- Part time
- Casual
- Retired
- Student
- Home duties
- Disability Support
- Unemployed
- Other: Please specify

Gross annual household income:
- Less than $20,000
- Between $20,000 and $50,000
- Between $50,000 and $75,000
- Between $75,000 and $125,000
- Over $125,000
- Decline to answer

Education history:
What is the highest level of education you have achieved?
- None
- Primary school
- High school up to Year 9
- High school year 10 to year 12
- TAFE / Trade certificate / skills based training or apprenticeship
- Other certificate
- Diploma
- Undergraduate university degree
- Postgraduate university degree
- Other: Please specify

English Language
- Is English your first language
Please indicated your ethnic background:
- Anglo-celtic/Caucasian
  - List of countries
- Asian
  - List of countries
- African
  - List of countries
- European
  - List of countries

Please choose which country you were born in:
[Full list of countries provided].

RELATIONSHIPS

Sexual orientation:
- Heterosexual
- Homosexual
- Bisexual
- Transgender or intersex

Marital status:
- Married
- Partner/DeFacto
- Dating or casual relationship
- Single

Duration of relationship:
- 1 month or less
- between 1 and 6 months
- between 6 months and 12 month
- between 1 year and 5 years
- between 5 years and 10 years
- more than 10 years

DIAGNOSIS

What was the date of your prostate cancer diagnosis:

What treatment have you had for your prostate cancer:
- Radical prostatectomy
  - Date of surgery
    - Open
    - Laparoscopic
    - Robotic
- Radiotherapy
  - Date
- Brachytherapy
  - Date
- Hormone therapy
  - Date
- High Intensity Focused Ultrasound (HIFU)
YOUR HEALTH

Have you ever been diagnosed with another form of cancer?
- No
- Yes – (verbatim response follows)

Do you have any of the following health concerns (yes/no):
- Diabetes
- Heart condition
- Do you take nitrate medication
- Have you ever been diagnosed with a mental illness
  - Yes
    - Details (space to write)
- Are you currently taking anti-depressant medication for low mood
- Have you taken anti-depressant medication for low mood in the past
  - Yes
    - Date

SUPPORT

Since your diagnosis of prostate cancer, how frequently have you sought support from the following:
- Psychologist
  - How frequently have you accessed this type of support? (open?)
- Psychiatrist
  - How frequently have you accessed this type of support? (open question)
- Counselor or relationship counselor
  - How frequently have you accessed this type of support? (open question)
- Support group
  - How frequently have you accessed this type of support? (open question)
- The Cancer Council information and support service
  - How frequently have you accessed this type of support? (open question)
- Other telephone support
  - Please specify:
    - How frequently have you accessed this type of support? (open question)
- Online support
  - How frequently have you accessed this type of support? (open question)
- Other: Please specify (open question)
  - How frequently have you accessed this type of support? (open question)

Since your diagnosis of prostate cancer have you consulted with any of the following healthcare practitioners?
- Urology nurse specialist
  - How frequently have you accessed this type of support? (open question)
- Physiotherapist
• How frequently have you accessed this type of support? (open question)
  o Sexual rehabilitation specialist/ endocrinologist/ sexual health
  • How frequently have you accessed this type of support? (open question)

**TREATMENTS**

**Prior use of erectile function interventions:**
Since your diagnosis of prostate cancer have you received any of the following treatments for erectile dysfunction or sexual rehabilitation

- Oral medications (yes/no)
  - Viagra
    • How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    • How satisfied have you been with this? (Low/Moderate/High)
  - Levitra
    • How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    • How satisfied have you been with this? (Low/Moderate/High)
  - Cialis
    • How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    • How satisfied have you been with this? (Low/Moderate/High)

- Injection therapies (yes/no)
  - Caverject
    • How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    • How satisfied have you been with this? (Low/Moderate/High)
  - Tri- or bi-mix
    • How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    • How satisfied have you been with this? (Low/Moderate/High)

- Vacuum devices (yes/no)
  • How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
  • How satisfied have you been with this? (Low/Moderate/High)

- Penile implant devices (yes/no)
  • What date was this surgically implanted:
  • How satisfied have you been with this? (Low/Moderate/High)
MY ROAD AHEAD QUESTIONNAIRE

Thank you for taking part in My Road Ahead. We would like to know how you are going at the moment. We would greatly appreciate it if you could take the time to complete the questionnaires. These questionnaires will tell us how you are feeling, physically and emotionally and are very important for our research evaluating whether My Road Ahead has any benefits for men who took part in the program.

YOUR QUALITY OF LIFE
(Prostate Cancer QoL Scale)

These questions ask about how you may feel about urinary problems and how they may affect your life. If you have no problems at all in these areas, simply circle the number under "not at all."

How true has each of the following statements been for you during the past 4 weeks?

URINARY PROBLEMS
How true has each of the following statements been for you during the past 4 weeks?

<table>
<thead>
<tr>
<th></th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Leaking urine makes me feel dirty.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>1.2 I am sometimes embarrassed or humiliated because of my urinary problems.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>1.3 I'm often afraid of having an accident and making a mess.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>1.4 My urinary problems make me feel helpless.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>1.5 I feel nervous when I don't know where the bathrooms are.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
### SEX

How true has each of the following statements been for you **during the past 4 weeks**?

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.6</td>
<td>My urinary problems complicate everything I do.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>1.7</td>
<td>I avoid situations in which I might not be able to get to a bathroom in time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>1.8</td>
<td>My urinary problems have affected my enjoyment of life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1</td>
<td>Trying to have sex is too complicated.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.2</td>
<td>My sex life feels unnatural to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.3</td>
<td>I feel helpless to act on my sexual urges.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.4</td>
<td>When it comes to getting close physically, I have to be careful not to start something I can't finish.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.5</td>
<td>I am worried that I might embarrass myself if I try to have sex.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.6</td>
<td>Thinking about my sex life leaves me with an uneasy feeling.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.7</td>
<td>When I hear talk about sex I feel like the odd man out.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.1</td>
<td>I'm confident in my sexual ability.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.2</td>
<td>I am able to enjoy physical intimacy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
3.3 I feel good about my sexuality.  

3.4 I feel good about the way I deal with my own sexual needs and desires.

RELATIONSHIPS

The following statements are about your relationship with your spouse or partner.

Do you have a spouse or a partner who is like a spouse to you?

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

→ If NO, go to Section FIVE.

YOUR PARTNER

How true has each of the following statements been for you during the past 4 weeks?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>A little bit</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My spouse or partner seems cool and distant from me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

| 4.2       |             |          |            |           |
| My partner avoids embracing, kissing or caressing me. | 1 | 2 | 3 | 4 | 5 |

| 4.3       |             |          |            |           |
| I feel that my spouse or partner may want to turn to others for affection. | 1 | 2 | 3 | 4 | 5 |
MANHOOD

How true has each of the following statements been for you during the past 4 weeks?

<table>
<thead>
<tr>
<th></th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>I feel as if I am no longer a whole man.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.2</td>
<td>I feel like I've lost part of my manhood.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.3</td>
<td>I’m not the man I used to be.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.4</td>
<td>I feel that others think that I’m not the man I used to be.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.5</td>
<td>I feel weak and small.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.6</td>
<td>I worry about being compared unfavorably to other men.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.7</td>
<td>I feel I have been too emotional.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.8</td>
<td>It’s hard to think things through coolly and logically.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

TREATMENT

How true is each of the following statements for you?

<table>
<thead>
<tr>
<th></th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.1</td>
<td>I am confident that my cancer is under control.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.2</td>
<td>I worry that my cancer might come back.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.3</td>
<td>I worry about my cancer spreading.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Statement</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>---</td>
<td>---------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>6.4</td>
<td>I wonder whether the treatment I got for prostate cancer really worked.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.5</td>
<td>It worries me that I can’t tell what is going on with my prostate cancer.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.1</td>
<td>I had all the information I needed when a treatment was chosen for my prostate cancer.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.2</td>
<td>My doctors told me the whole story about the effects of the treatments.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.3</td>
<td>I knew the right questions to ask my doctor.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.4</td>
<td>I had enough time to make a decision about my treatment.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7.5</td>
<td>I am satisfied with the choices I made in treating my prostate cancer.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.1</td>
<td>I wonder if I would have been better off with a different treatment.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.2</td>
<td>I sometimes wonder whether it was really worthwhile being treated at all.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.3</td>
<td>I sometimes feel the treatment I had was the wrong one for me.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.4</td>
<td>If I had to do it over, I would choose some other treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.5</td>
<td>I sometimes wish I could change my mind about the kind of treatment I chose for my prostate cancer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.1</td>
<td>I feel that my cancer has given me a better outlook on life.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9.2</td>
<td>I feel that coping with cancer has made me a stronger person.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## OUTLOOK

During the past 4 weeks, how much have you felt...

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>10.1 My health could take a turn for the worse at any time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10.2 I sometimes worry about dying before my time.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10.3 I worry about what my doctor will find next.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10.4 I worry that changes in my medical condition will not be detected early.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10.5 I am uneasy about the present state of my health.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10.6 I live in fear that my PSA will rise.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

## PSA

How true has each of the following statements been for you during the past 4 weeks?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at All</th>
<th>A Little Bit</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>11.1 I keep close track of my PSA.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11.2 Knowing my PSA level is comforting to me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
YOUR MOOD

(Depression, Anxiety, Stress Scale)

Please read each statement and select a number which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

Your Mood - Source: www.psy.unsw.edu.au

The rating scale is as follows:

- 0. Did not apply to me at all
- 1. Applied to me to some degree, or some of the time
- 2. Applied to me to a considerable degree, or a good part of time
- 3. Applied to me very much, or most of the time

<table>
<thead>
<tr>
<th>Statement</th>
<th>Did not apply to me at all</th>
<th>Applied to me to some degree, or some of the time</th>
<th>Applied to me to a considerable degree, or a good part of time</th>
<th>Applied to me very much, or most of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I found it hard to wind down.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. I was aware of dryness of my mouth.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. I couldn't seem to experience any positive feeling at all.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. I experienced breathing difficulty (eg, excessively rapid breathing,</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>breathlessness in the absence of physical exertion)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I found it difficult to work up the initiative to do things.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. I tended to over-react to situations.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. I experienced trembling (eg, in the hands).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>8. I felt that I was using a lot of nervous energy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. I was worried about situations in which I might panic and make a fool of myself.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. I felt that I had nothing to look forward to.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. I found myself getting agitated.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. I found it difficult to relax</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. I felt down-hearted and blue</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. I was intolerant of anything that kept me from getting on with what I was doing.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. I felt I was close to panic.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. I was unable to become enthusiastic about anything.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. I felt I wasn’t worth much as a person.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. I felt that I was rather touchy.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat).</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. I felt scared without any good reason.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. I felt that life was meaningless.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
**SEXUAL FUNCTIONING**
(International Index of Erectile Function)

Please read each statement and indicate how much the statement applied to you over the past week by ticking a circle. There are no right or wrong answers. Do not spend too much time on any statement. Over the past 4 weeks...

1. **How often were you able to get an erection during sexual activity?**
   - 0 = No sexual activity
   - 1 = Almost never/never
   - 2 = A few times (much less than half the time)
   - 3 = Sometimes (about half the time)
   - 4 = Most times (much more than half the time)
   - 5 = Almost always/always

2. **When you had erections with sexual stimulation, how often were your erections hard enough for penetration?**
   - 0 = No sexual activity
   - 1 = Almost never/never
   - 2 = A few times (much less than half the time)
   - 3 = Sometimes (about half the time)
   - 4 = Most times (much more than half the time)
   - 5 = Almost always/always

3. **When you attempted sexual intercourse, how often were you able to penetrate (enter) your partner?**
   - 0 = Did not attempt intercourse
   - 1 = Almost never/never
   - 2 = A few times (much less than half the time)
   - 3 = Sometimes (about half the time)
   - 4 = Most times (much more than half the time)
   - 5 = Almost always/always

4. **During sexual intercourse, how often were you able to maintain your erection after you had penetrated (entered) your partner?**
   - 0 = Did not attempt intercourse
   - 1 = Almost never/never
   - 2 = A few times (much less than half the time)
   - 3 = Sometimes (about half the time)
   - 4 = Most times (much more than half the time)
   - 5 = Almost always/always

5. **During sexual intercourse, how difficult was it to maintain your erection to completion of intercourse?**
   - 0 = Did not attempt intercourse
   - 1 = Extremely difficult
   - 2 = Very difficult
   - 3 = Difficult
   - 4 = Slightly difficult
   - 5 = Not difficult

6. **How many times have you attempted sexual intercourse?**
   - 0 = No attempts
   - 1 = One to two attempts
   - 2 = Three to four attempts
   - 3 = Five to six attempts
   - 4 = Seven to ten attempts
   - 5 = Eleven + attempts

7. **When you attempted sexual intercourse, how often was it satisfactory for you?**
   - 0 = Did not attempt intercourse
   - 1 = Almost never/never
   - 2 = A few times (much less than half the time)
<table>
<thead>
<tr>
<th>Question</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. How much have you enjoyed sexual intercourse?</td>
<td>3 = Sometimes (about half the time)</td>
</tr>
<tr>
<td></td>
<td>4 = Most times (much more than half the time)</td>
</tr>
<tr>
<td></td>
<td>5 = Almost always/always</td>
</tr>
<tr>
<td>9. When you had sexual stimulation or intercourse, how often did you</td>
<td>0 = No intercourse</td>
</tr>
<tr>
<td>ejaculate?</td>
<td>1 = No enjoyment</td>
</tr>
<tr>
<td></td>
<td>2 = Not very enjoyable</td>
</tr>
<tr>
<td></td>
<td>3 = Fairly enjoyable</td>
</tr>
<tr>
<td></td>
<td>4 = Highly enjoyable</td>
</tr>
<tr>
<td></td>
<td>5 = Very highly enjoyable</td>
</tr>
<tr>
<td>10. When you had sexual stimulation or intercourse, how often did you</td>
<td>0 = No sexual stimulation/intercourse</td>
</tr>
<tr>
<td>have the feeling of orgasm or climax?</td>
<td>1 = Almost never/never</td>
</tr>
<tr>
<td></td>
<td>2 = A few times (much less than half the time)</td>
</tr>
<tr>
<td></td>
<td>3 = Sometimes (about half the time)</td>
</tr>
<tr>
<td></td>
<td>4 = Most times (much more than half the time)</td>
</tr>
<tr>
<td></td>
<td>5 = Almost always/always</td>
</tr>
<tr>
<td>11. How often have you felt sexual desire?</td>
<td>1 = Almost never/never</td>
</tr>
<tr>
<td></td>
<td>2 = A few times (much less than half the time)</td>
</tr>
<tr>
<td></td>
<td>3 = Sometimes (about half the time)</td>
</tr>
<tr>
<td></td>
<td>4 = Most times (much more than half the time)</td>
</tr>
<tr>
<td></td>
<td>5 = Almost always/always</td>
</tr>
<tr>
<td>12. How would you rate you level of sexual desire?</td>
<td>1 = Very low/none at all</td>
</tr>
<tr>
<td></td>
<td>2 = Low</td>
</tr>
<tr>
<td></td>
<td>3 = Moderate</td>
</tr>
<tr>
<td></td>
<td>4 = High</td>
</tr>
<tr>
<td></td>
<td>5 = Very high</td>
</tr>
<tr>
<td>13. How satisfied have you been with your overall sex life?</td>
<td>1 = Very dissatisfied</td>
</tr>
<tr>
<td></td>
<td>2 = Moderately dissatisfied</td>
</tr>
<tr>
<td></td>
<td>3 = About equally satisfied and dissatisfied</td>
</tr>
<tr>
<td></td>
<td>4 = Moderately satisfied</td>
</tr>
<tr>
<td></td>
<td>5 = Very satisfied</td>
</tr>
<tr>
<td>14. How satisfied have you been with your sexual relationship with your</td>
<td>1 = Very dissatisfied</td>
</tr>
<tr>
<td>partner?</td>
<td>2 = Moderately dissatisfied</td>
</tr>
<tr>
<td></td>
<td>3 = About equally satisfied and dissatisfied</td>
</tr>
<tr>
<td></td>
<td>4 = Moderately satisfied</td>
</tr>
<tr>
<td></td>
<td>5 = Very satisfied</td>
</tr>
<tr>
<td>15. How do you rate you confidence that you could get and keep an</td>
<td>1 = Very low</td>
</tr>
<tr>
<td>erection?</td>
<td>2 = Low</td>
</tr>
<tr>
<td></td>
<td>3 = Moderate</td>
</tr>
<tr>
<td></td>
<td>4 = High</td>
</tr>
<tr>
<td></td>
<td>5 = Very high</td>
</tr>
</tbody>
</table>
# ARISING ISSUES & ISSUE DISCUSSION

(Communications Patterns Questionnaire)

<table>
<thead>
<tr>
<th></th>
<th>Very unlikely</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th>Very likely</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>When issues or problems arise, how likely is it that...</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Both spouses avoid discussing the problem</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8 9</td>
</tr>
<tr>
<td>2. Both spouses try to discuss the problem</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8 9</td>
</tr>
<tr>
<td>3. Female tries to start a discussion while males tries to avoid a discussion</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8 9</td>
</tr>
<tr>
<td>4. Male tries to start a discussion while female tries to avoid</td>
<td>1 2 3 4 5 6 7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8 9</td>
</tr>
</tbody>
</table>

| **During a discussion of issues or problems, how likely is it that...** |       |   |   |   |   |   |   |            |
| 5. Both spouses express feelings to each other                     | 1 2 3 4 5 6 7 |   |   |   |   |   |   | 8 9        |
| 6. Both spouses blame, accuse, or criticise each other            | 1 2 3 4 5 6 7 |   |   |   |   |   |   | 8 9        |
| 7. Both spouses suggest possible solutions an comprises            | 1 2 3 4 5 6 7 |   |   |   |   |   |   | 8 9        |
| 8. Female pressures, nags, or demands while male withdraws, becomes silent, or refuses to discuss the matter further | 1 2 3 4 5 6 7 |   |   |   |   |   |   | 8 9        |
| 9. Male pressures, nags, or demands while female withdraws, becomes silent, or refuses to discuss the matter further | 1 2 3 4 5 6 7 |   |   |   |   |   |   | 8 9        |
| 10. Female criticises while male defends himself                  | 1 2 3 4 5 6 7 |   |   |   |   |   |   | 8 9        |
| 11. Male criticises while female defends herself                  | 1 2 3 4 5 6 7 |   |   |   |   |   |   | 8 9        |
YOUR RELATIONSHIP SATISFACTION
(Kanas Marital Satisfaction Survey)

1. How satisfied are you with your relationship?
   - Extremely dissatisfied
   - Very dissatisfied
   - Somewhat dissatisfied
   - Mixed
   - Somewhat Satisfied
   - Very Satisfied
   - Extremely Satisfied

2. How satisfied are you with your partner as a spouse?
   - Extremely dissatisfied
   - Very dissatisfied
   - Somewhat dissatisfied
   - Mixed
   - Somewhat Satisfied
   - Very Satisfied
   - Extremely Satisfied

3. How satisfied are you with your relationship with your partner?
   - Extremely dissatisfied
   - Very dissatisfied
   - Somewhat dissatisfied
   - Mixed
   - Somewhat Satisfied
   - Very Satisfied
   - Extremely Satisfied
INTIMACY AND COMMUNICATION
(Dyadic Sexual Communication Scale)

Your communication about sex and sexual intimacy.

Here is a list of statements different people have made about discussing sex with their primary partner. Please select how much you agree or disagree with it.

<table>
<thead>
<tr>
<th></th>
<th>Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Do you find some sexual matters too difficult to discuss with your partner?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>Does your partner have difficulty in talking to you about what he/she likes during sex and sexual intimacy?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>Is talking about sex and sexual intimacy with your partner fun for the both of you.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>Do you find that it is easy for you to tell your partner what you do or do not like to do during sex?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

YOUR CONFIDENCE

I feel confident in most areas of my life.

- Almost never/never
- A few times (much less than half the time)
- Sometimes (about half the time)
- Most times (much more than half the time)
- Almost always/always
Post-treatment Questionnaire

Thank you for taking part in My Road Ahead. We would like to know how you are going at the moment. We would greatly appreciate it if you could take the time to complete the questionnaires. These questionnaires will tell us how you are feeling, physically and emotionally and are very important for our research evaluating whether My Road Ahead has any benefits for men who took part in the program.

SUPPORT

Since you started the program have you received any other type of psychological or mental health support:

- Psychologist
  - How frequently have you accessed this type of support? (open?)
- Psychiatrist
  - How frequently have you accessed this type of support? (open question)
- Counsellor or relationship counsellor
  - How frequently have you accessed this type of support? (open question)
- Support group
  - How frequently have you accessed this type of support? (open question)
- The Cancer Council information and support service
  - How frequently have you accessed this type of support? (open question)
- Other telephone support
  - Please specify:
    - How frequently have you accessed this type of support? (open question)
- Online support
  - How frequently have you accessed this type of support? (open question)
- Other: Please specify (open question)
  - How frequently have you accessed this type of support? (open question)

Since commencing this program have you consulted with any of the following healthcare practitioners?

- Urology nurse specialist
  - How frequently have you accessed this type of support? (open question)
- Physiotherapist
  - How frequently have you accessed this type of support? (open question)
- Sexual rehabilitation specialist/ endocrinologist/ sexual health
  - How frequently have you accessed this type of support? (open question)
TREATMENTS

Prior use of erectile function interventions:

Since commencing this program have you received any of the following treatments for erectile dysfunction or sexual rehabilitation:

- **Oral medications (yes/no)**
  - **Viagra**
    - How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    - How satisfied have you been with this? (Low/Moderate/High)
  - **Levitra**
    - How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    - How satisfied have you been with this? (Low/Moderate/High)
  - **Cialis**
    - How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    - How satisfied have you been with this? (Low/Moderate/High)

- **Injection therapies (yes/no)**
  - **Caverject**
    - How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    - How satisfied have you been with this? (Low/Moderate/High)
  - **Tri- or bi-mix**
    - How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
    - How satisfied have you been with this? (Low/Moderate/High)

- **Vacuum devices (yes/no)**
  - How frequently have you used this type of treatment? (Tried it a few times and gave up/ On and off/ Regularly)
  - How satisfied have you been with this? (Low/Moderate/High)

- **Penile implant devices (yes/no)**
  - What date was this surgically implanted:
  - How satisfied have you been with this? (Low/Moderate/High)
Program Satisfaction Questionnaire
(For those participants who completed the modules aspect of My Road Ahead)

Please select the reason(s) why you chose to use this online program:
- Preference for anonymity
- Nothing else available
  - Preference for self-help methods of support
  - Financial constraints
  - Convenience factor (travel, time)
- Mobility restrictions due to disability or chronic health condition
- Concerns about possible stigma
- Curious
- Other (Please specify)

Please rate how satisfied you are with the My Road Ahead program? (1 = not at all → 10 = extremely satisfied)

How much did you enjoy using the program (1 = not at all → 10 = very much)

Did you ask your partner to be involved?
- Not applicable
- No
  - Please specify why
- Yes
  - Did you print out or email the partner information sheets for your partner
    - Yes
    - No
  - Did you include your partner in viewing the online information, videos or interactive exercises?
    - No
    - Sometimes
    - Frequently
  - Did you complete the offline exercises together
    - No
    - Sometimes
    - Frequently
  - What exercises with your partner did you find the most beneficial
    - Please specify:

Was My Road Ahead easy to use? (Yes/No)

How useful did you find the information and exercises provided in My Road Ahead name]? (1 = not at all → 10 = very useful)

Would you recommend [insert name] to a friend, colleague or family member with prostate cancer? (yes/no)

If you did not work through the entire My Road Ahead program – what stopped you?
Please tick as many as apply to you:
- Nothing – I got what I needed
- Too busy
- Too unwell
- Lack of motivation
• Program was boring
• Program was too difficult to use
• Program material was too hard to understand
• The program was not useful
• Too much text to read
• Internet Server Provider problems
• Computer problems
• Other (please specify)

Please select any of the following features that would have engaged you more with the online program.
• SMS reminders,
• Email therapist,
• Phone therapist,
• Web cam therapist,
• Chat room,
• Conference call with other program participants
• Face-to-face therapist
• More use of video
• More use of audio
• More online activities
• Other (please specify)

What was the best part of the program?
• Please specify:

What was the worst part of the program?
• Please specify:

How could the program be improved?
• Please specify:

How many hours per week did you spend on average reading / viewing the content in the online program?
• Please specify:
Forum Satisfaction Questionnaire
(For those participants who completed the forum aspect of My Road Ahead)

Please rate how satisfied you are with the forum? (1 = not at all \(\rightarrow\) 10 = extremely satisfied)

How much did you enjoy using the forum (1 = not at all \(\rightarrow\) 10 = very much)

Was the forum easy to use? (Yes/No)

How useful did you find the information posted on the forum by other men with prostate cancer (1 = not at all \(\rightarrow\) 10 = very useful)

How useful did you find the information posted on the forum by the moderator? (1 = not at all \(\rightarrow\) 10 = very useful)

If you didn’t use the forum much what stopped you from using it more?
Please tick as many as apply to you:
- Nothing – I got what I needed
- Too busy
- Too unwell
- Lack of motivation
- Program was boring
- Program was too difficult to use
- Program material was too hard to understand
- The program was not useful
- Too much text to read
- Internet Server Provider problems
- Computer problems
- Other (please specify)

What was the best part of the forum?
- Please specify:

What was the worst part of the forum?
- Please specify:

How could the forum be improved?
- Please specify:

How many minutes per week did you spend on average reading / viewing the content in the forum?
- Please specify:
Appendix I: Ethics approval
22nd July 2011

Dr Addie Wootten
Department of Urology
Level 3 Centre
Royal Melbourne Hospital
Parkville Vic 3050

Dear Dr Wootten,

MH Project Number: 2010.282

Project Title: My Road Ahead: An Online Psychological Support Program for Men with Prostate Cancer

HREC Approval Date: 22 July 2011

I am pleased to advise that the above project has received ethical approval.

Participating Sites:
- Royal Melbourne Hospital

Approved Documents:
- Protocol December 2010
- Base line Pre-Intervention Questionnaires – Time 1: Demographic and Background questionnaire
- Post-Intervention Questionnaires – 6 weeks – Time 2: Program Satisfaction Questionnaire
- Questionnaire 1: Your Quality of Life
- Questionnaire 2: Your Mood
- Questionnaire 3: Your Sexual Functioning and Satisfaction
- Questionnaire 4: Your Communication Patterns
- Questionnaire 5: Your Relationship Satisfaction
- Questionnaire 6: Your Communication about Sex and Sexual Intimacy
- Questionnaire 7: Your Confidence
- Access to support Questionnaire
- Use of erectile function interventions Questionnaire
- Advertisement
- Flyer
- Focus Group Flyer
- Participant Information and Consent From Version 3 dated 13/7/2011 Focus Group
- Participant Information and Consent From Version 3 dated 13/7/2011 Pilot Group
- Participant Information and Consent From Version 3 dated 13/7/2011 Randomised Controlled Trial

Site Specific Assessment:

Please note: You cannot commence this study until you have completed all the requirements of the Site Specific Assessment and have received the “Approval to Conduct a Research Project at Melbourne Health” certificate.

The Melbourne Health HREC operates and is constituted in accordance with the National Statement on Ethical Conduct in Human Research 2007.

HREC Approval Of New Project (non SERP) - Template version 01.07.2011
Memorandum

To: Prof Marta McCabe  
School of Psychology  
B

cc: Miss Katherine Chisholm

From: Deakin University Human Research Ethics Committee (DUHREC)

Date: 01 August, 2011

Subject: My Road Ahead: An online psychological support program for men with prostate cancer

Please quote this project number in all future communications

Approval granted by Melbourne Health HREC for this project will be noted at the DUHREC meeting to be held on 29 August 2011.

It will be noted that approval has been granted for Prof Marta McCabe, School of Psychology, to undertake this project as stipulated in Melbourne Health HREC approval documentation.

The approval noted by the Deakin University Human Research Ethics Committee is given only for the project and for the period as stated in the memo. It is your responsibility to contact the Human Research Ethics Unit immediately should any of the following occur:

- Serious or unexpected adverse effects on the participants
- Any proposed changes in the protocol, including extensions of time
- Any events which might affect the continuing ethical acceptability of the project.
- The project is discontinued before the expected date of completion.
- Modifications are requested by other HRECs.

In addition you will be required to report on the progress of your project at least once every year and at the conclusion of the project. Failure to report as required will result in suspension of your approval to proceed with the project.

DUHREC may need to audit this project as part of the requirements for monitoring set out in the National Statement on Ethical Conduct in Human Research (2007).

Human Research Ethics Unit  
research-ethics@deakin.edu.au  
Telephone: 03 9251 7123
Appendix J: Information and consents
Participant Information and Consent Form
Royal Melbourne Hospital; Melbourne Health

Full Project Title: My Road Ahead: An online psychological support intervention for men after treatment for localised prostate cancer.

Principal Researcher: Dr Addie Wootten

Associate Researchers:

Deakin University: Prof Marita McCabe, Miss Katherine Chisholm

Swinburne University: Dr Jo Abbott, A/Prof David Austin, A/Prof Britt Klein,

Royal Melbourne Hospital: Prof Anthony Costello, A/Prof Declan Murphy,

1. Introduction

You are invited to take part in this research project. This is because you have been treated for prostate cancer. The research project is aiming to develop and evaluate a psychological support program for men who have been treated for localised prostate cancer. This program will be accessible over the internet.

This Participant Information and Consent Form tells you about the research project. It explains the procedures involved. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don’t understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or healthcare worker.

Participation in this research is voluntary. If you don’t wish to take part, you don’t have to. You will receive the best possible care whether you take part or not.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- understand what you have read;
- consent to take part in the research project;
- consent to participate in the research processes that are described;
- consent to the use of your personal and health information as described

You will be given a copy of this Participant Information and Consent Form to keep.

2. What is the purpose of this research project?

My Road Ahead is an online internet based program that has been initiated by the principal investigator, Dr Addie Wootten, in collaboration with a team of researchers and clinicians from the Royal Melbourne Hospital, Swinburne University of Technology and Deakin University. The research has been funded by beyondblue and the Prostate Cancer Foundation of Australia (PCFA). This program is being developed because of the known impact that prostate cancer can have on many aspects of life including psychologically, emotionally and socially or within relationships and aims to offer a self-directed program to help people cope with these challenges.
There are three phases of this research. You have been invited to take part in phase three – a randomised controlled trial of the effectiveness of the online program, My Road Ahead.

Phase one was conducted to develop the program and explore all aspects of the content of the program. During phase two feedback was obtained from men who had experienced prostate cancer. This phase informed the pilot test conducted in phase two about the usability and acceptability of the online program.

The purpose of this phase of the project is to conduct a randomised controlled trial examining the effectiveness of the online program, My Road Ahead, compared to My Road Ahead plus a moderated bulletin board and a bulletin board alone. Approximately 150 participants will be recruited to this study.

You have been invited to take part in this study because you have been treated for localised prostate cancer in the last five (5) years.

The My Road Ahead Program:

The My Road Ahead program has been developed by a group of researchers and clinicians who have examined what challenges men face after treatment for prostate cancer. After treatment for prostate cancer men have reported experiencing challenges such as stress, anxiety, sadness, depression, and changes in identity, masculinity, relationships, intimacy and sexuality. Of course, each man will experience their own individual responses to prostate cancer but many men report some of these challenges. The My Road Ahead program aims to offer a way for men to develop their own ways of coping with these challenges and improving how they feel, in terms of their emotions and their relationships and connections with others.

The My Road Ahead program is a six (6) module online program that offers a range of topics to work through at an individual pace. It is anticipated that each module will take about one (1) to two (2) weeks to complete (1-2 hours per week), totalling ten (10) weeks across the program.

Module 1: Introduction & Relaxation and Stress Management
Module 2: Emotions and psychological distress
Module 3: Coping with physical changes
Module 4: Sexuality and Masculinity
Module 5: Sexuality and Intimacy
Module 6: Living with uncertainty and planning for the future

The moderated bulletin board:

A moderated bulletin board will be hosted on the website. This bulletin board will be moderated by a psychologist, or provisional psychologist under supervision, and will offer a ‘virtual space’ for participants to ask questions of each other as well as the researchers and psychologist. The content of the information displayed on the bulletin board will be guided by the types of questions and comments received from the participants and will only be moderated in the form of answering questions and making sure that all content is not offensive. It will be updated each day (Monday to Friday) and accessible across the course of the study. You can use an anonymous name when using this bulletin board.
3. **What does participation in this research project involve?**

This is a randomised controlled trial (RCT) comparing the responses of participants randomly assigned to take part in one of three groups:

**Group 1:** Participating in the My Road Ahead program

**Group 2:** Participating in the My Road Ahead program plus the moderated bulletin board

**Group 3:** Participating in the moderated bulletin board only (with optional access to the My Road Ahead program offered at the end of the study)

Before allocation to one of the groups all participants will be asked to provide a current email address, a password and complete five short online surveys assessing:

- Mood, including stress, anxiety and depression
- Quality of life including emotional, physical, functional and social aspects of quality of life
- Detailed intimate questions about your sexual functioning
- Relationship satisfaction
- Communication styles within your relationship
- Program satisfaction (groups 1 & 2)

We anticipate that the questionnaires will take approximately 45 minutes to complete.

Participants in all groups will be asked to complete these questionnaires at three (4) time points.

1. Baseline, after giving your consent to participate in the study (week 1)
2. At week 10
3. At week 22
4. At 6 months post program

You will also be asked to complete a brief questionnaire about your mood at the midpoint (week 5).

The first 30 participants to take part in this study will also be asked to undertake a brief (20-30 minute) telephone interview. If you are one of the first 30 participants you will be invited to provide your telephone number and first name when you complete the week 12 questionnaire. If you wish to take part in this interview and provide your contact details a researcher will then call you to conduct the telephone interview where you will be asked about your experience with the program, any difficulties you encountered and any suggestions for improving the program for the future.

Use of the online program will involve engaging in the online program over the internet and working through each of the six (6) modules over the 10 weeks of access (for 1-2 hours each week). Each module will cover a different topic and provide information to you by video, audio, written text and animated diagrams. You will be given interactive tasks to complete online while working through the program and offline in your everyday life (e.g. communication tasks). There will be 10 weeks between the start of the first questionnaire and the second questionnaire so that if it takes you a bit longer than one module per week you will have time to complete all six by the time the second questionnaire is to be completed.

At the start of each week you will receive a reminder email about where you are up to in the program and a reminder to return to the program again if you have not yet completed it.

Use of the moderated bulletin board will involve your logging into the program website and accessing the bulletin board, where you can ask questions of the psychologist or other men taking part in the study. You can use this bulletin board as much or as little as you like.

You will not be paid for your participation in this research.
4. **What are the possible benefits?**

We cannot guarantee or promise that you will receive any benefits from this project. However, the potential benefit of engaging in the study include learning new ways of relaxing, communicating or managing incontinence or sexual difficulties as well as the benefits often found by people when they explore their own emotional state in relation to a distressing experience such as cancer. The program may enable you to process some emotions about your prostate cancer experience that you have not processed before.

5. **What are the possible risks?**

We do not anticipate any risks of your participation. However, talking about emotions and the psychological impact of prostate cancer could potentially highlight your own emotions. You will be given support at all times by the research team. Referral to alternative free psychological or medical support can be offered if required. If after considering the questions you have any concerns or feel distressed about the issues raised then please contact the researchers who can arrange counselling for you. Dr Addie Wootten, Clinical Psychologist can be contacted on (03) 9342 7458 or addie.wootten@mh.org.au If at any point you decide you no longer wish to participate in the study you are free to withdraw. 

6. **What if new information arises during this research 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.

7. **Are there alternatives to participation?**

You do not have to participate in this research project in order to receive any medical care you may require. You do not have to participate in this research project in order to receive any medical care you may require. If you require support there are a number of options you could consider. The Cancer Council Victoria offers a cancer information and support service that can be contacted by calling 13 11 20. If you would like to speak with a trained counsellor over the telephone Lifeline offers a 24 hour service by calling 13 11 14. If you would like to access individual psychological therapy it is best to talk to your GP about obtaining a referral to a psychologist in your local area. Alternatively arrangements can be made for you to access psychological or psychiatric services through the public hospital service in Victoria.

8. **Do I have to take part in this research project?**

Participation in any research project is voluntary. If you do not wish to take part you don’t have 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 or 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 Royal Melbourne Hospital.

9. What if I withdraw from this research project?

If you decide to withdraw from this project, please notify a member of the research team by completing a short online exit survey before you withdraw. This notice will allow that person or the research supervisor to inform you if there are any health risks or special requirements linked to withdrawing.

10. How will I be informed of the results of this research project?

A summary of the feedback and outcome of the research will be available for you, written in plain language, after the completion of the project. Information contained in the summary will not identify individual participants. Please contact the researchers to obtain this information and the results of the study will also be made available on the program website at the conclusion of the study.

11. What else do I need to know?

- What will happen to information about me?

Any identifying information obtained in connection with this project will remain confidential. The type of information collected and stored will include the online consent form and questionnaires obtained from you. Information will be kept in electronic files stored on the secure server which can only be accessed by the researchers involved in the project. In any publication or report, information will be provided in such a way that you cannot be identified. Data will be published in group format, and if published in individual format (e.g. a quote) it will not identify you. Information will be stored for a period of seven years and then disposed of by shredding and electronic deletion. In this time, we may use the data for other research and development purposes but the data would refer to group data and would not be identifiable. If the data is used again it will be kept for a further (7) years before being destroyed.

- How can I access my information?

In accordance with relevant Australian and/or Victorian Privacy and other relevant laws you have the right to access the information collected and stored by the Researchers about you. You also have the right to request any information with which you disagree be corrected. Please contact the researchers if you would like to access your information.

- What happens if I am injured as a result of participating in this research project?

If you suffer an injury as a result of participating in this research project, hospital care and treatment will be provided by the public health service at no extra cost to you if you elect to be treated as a public patient.

- Is this research project approved?

The ethical aspects of this research project have been approved by the Human Research Ethics Committee of Royal Melbourne Hospital.
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.

12. **Who can I contact?**

Who you may need to contact will depend on the nature of your query, therefore, please note the following:

**For further information:**

If you require further information or if you have any problems concerning this project, you can contact the principal researcher.

Name: Dr Addie Wootten  
Role: Clinical Psychologist  
Telephone: (03) 9342 7458  
Email: addie.wootten@mh.org.au

**For complaints:**

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact either the ethics committee of Royal Melbourne Hospital (Reference number: 2010.282) Swinburne University (reference number: To be provided once obtained) or Deakin University (reference number: To be provided once obtained).

Royal Melbourne Hospital:  
Name: Ms Angela Gray;  
Position: Manager, Human Research Ethics Committee;  
Telephone: (03) 9342 8530.

Swinburne University:  
Research Ethics Officer  
Office of Research and Graduate Studies (H68)  
Swinburne University of Technology  
PO Box 218  
Hawthorn, VIC, 3122  
Telephone: (03) 9214 5218  
Email: resethics@swin.edu.au

Deakin University:  
The Manager, Office of Research Integrity,  
Deakin University, 221 Burwood Highway, Burwood Victoria 3125,  
Telephone: 9251 7129,  
Facsimile: 9244 6581;  
Email: research-ethics@deakin.edu.au
13. Consent

Online Consent Form

Randomised Controlled Trial
Version 4, dated 30/01/2012

Full Project Title: My Road Ahead: An online psychological support intervention for men after treatment for localised prostate cancer.

I have read and I understand the Participant Information version 4 dated 30/01/2012

I freely agree to participate in this project according to the conditions in the Participant Information.

I have been given the option of printing 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.

I understand that if I select “I agree to the study conditions” button located below I am giving my consent to participate in this research project without the need for my signature.
Appendix K: Example pages from the forum
Welcome to the My Road Ahead Forum

This Forum has been set up so that you can communicate with other men on the prostate cancer journey. This is a space to share thoughts, ideas, tips or information with other men who might be going through similar experiences as you are. You will see that the Forum is set up with topics. Click into any area that you are interested in and feel free to contribute as much, or as little, as you like.

The Forum is moderated. This means that a member of our team will look at each message before it is posted onto the site. This ensures that no irrelevant or offensive material is published on the site. You should note that this also means that there will be a delay in posting your comments. We will endeavor to post comments within 48 hours but the site will only be moderated Monday to Friday so you might experience longer delays at some times.

You should also note that this is not a space to request urgent support or advice. If you are experiencing high levels of distress or require urgent assistance please click on the ‘seek help’ tab at the top of this page. This will provide you with information about crisis or emergency support.

We recommend that you log into this Forum at least a few times per week and spend as much time as you like reading through the comments posted.

CONNECT ON THE FORUM

This is a support forum for men who have experienced prostate cancer. This forum does not provide crisis support. If you are experiencing high levels of distress, require immediate support or are feeling suicidal contact Lifeline (available 24/7) on 13 11 14 or if someone is at immediate risk of suicide, call 000.
Appendix L: Example moderator comments on the forum
**Example 1**

“Feeling a bit down and low”
Many men who have prostate cancer and receive treatment often report changes in their feelings and emotions. The reactions can vary greatly depending on the individual and their circumstances. Does anyone feel like sharing what the prostate cancer has been like for them emotionally?

**Example 2**

“Erectile dysfunction”
Erectile dysfunction is extremely common for those men who have been treated for prostate cancer. There are many different medical aids that are offered to men to assist with erectile dysfunction, including Viagra, vacuum pumps, and penile implants. Has anyone used these or anything else, and would like to discuss any positive or negative outcomes?

**Example 3**

“Intimacy and relationships”
I speak regularly to men after they have had treatment for prostate cancer and a common problem discussed is the impact that sexual difficulties can have on their intimate relationship. Some men talk about not knowing how to be intimate anymore and a wall developing between partners. Some single men also speak about not knowing how to even consider starting a new relationship because of their worries about sexual difficulties. Has anyone experienced changes on their relationship or on their confidence in starting a new relationship because of sexual difficulties?
Appendix M: Example weekly emails to participants
Hello Bruce,

We hope that this email finds you well.

**Well done for finishing Module 2!** We hope that you got something out of this module.

Don’t forget you only have 10 weeks in total and you have had access to *My Road Ahead* for 4 weeks now. Whenever you are ready we suggest you move on to Module 2. However you are welcome to look at any of the modules that you think might be of interest or relevant to you.

Also, don’t forget to check out recent posts on the **forum**.

Cheers,

The My Road Ahead Research Team

If you would like to talk to someone about My Road Ahead or if you are having any technical difficulties please email us – myroadaheadhelp@gmail.com OR call (03) 9936 8032.
Appendix N: Assumption testing - Chi-square tests
### Chi-square Statistics for 2 x 2 Crosstab Comparisons Referred to in Table 9.3

<table>
<thead>
<tr>
<th>Variable</th>
<th>Modules &amp; Modules-plus-Forum</th>
<th>Modules &amp; Forum</th>
<th>Modules-plus-Forum &amp; Forum</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>0.16 (.693)</td>
<td>0.00 (1.00)</td>
<td>0.16 (.693)</td>
</tr>
<tr>
<td>Prostate cancer treatment</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radical prostatectomy</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Radiotherapy</td>
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<td>0.53 (.486)</td>
<td>1.45 (.230)</td>
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<tr>
<td>Hormone therapy</td>
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<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Active surveillance</td>
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<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Risk factors reported</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Another cancer</td>
<td>0.00 (1.00)</td>
<td>0.28 (.604)</td>
<td>0.28 (.604)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Heart condition</td>
<td>0.53 (.486)</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Mental illness</td>
<td>0.00 (1.00)</td>
<td>1.45 (.230)</td>
<td>0.53 (.486)</td>
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<tr>
<td>Current anti-depressants</td>
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<tr>
<td>Past anti-depressants</td>
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<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Past support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
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<td>2.52 (.105)</td>
<td>0.20 (.660)</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
<td>0.53 (.486)</td>
</tr>
<tr>
<td>Counsellor</td>
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<td>1.45 (.230)</td>
<td>1.45 (.230)</td>
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<tr>
<td>Support group</td>
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<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Cancer Council†</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Telephone</td>
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<td>Online</td>
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<td>Healthcare practitioners</td>
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<td>Sexual rehabilitation specialist</td>
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</tr>
<tr>
<td>Erectile aids</td>
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<td></td>
</tr>
<tr>
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<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Used penile implants</td>
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<td>-</td>
<td>0.00 (1.00)</td>
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<tr>
<td>Overall used some Tx</td>
<td>1.22 (.269)</td>
<td>0.00 (1.00)</td>
<td>1.22 (.269)</td>
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</table>

*Note. p values are in parentheses. All chi-square analysis in table used Yate’s Correction for Continuity and Fisher’s Exact Test.

†The Cancer Council Information and Support Service.

* p < 0.05
Appendix O: Assumption Testing: Chi-square
### Chi-square Statistics for 2 x 2 Crosstab Comparisons Referred to in Table 10.1

<table>
<thead>
<tr>
<th>Variable</th>
<th>Modules &amp; Modules-plus-Forum</th>
<th>Modules &amp; Forum</th>
<th>Modules-plus-Forum &amp; Forum</th>
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<tr>
<td><strong>Prostate cancer treatment</strong></td>
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<td></td>
</tr>
<tr>
<td>Radical prostatectomy</td>
<td>0.00 (1.00)</td>
<td>0.01 (.444)</td>
<td>0.00 (.483)</td>
</tr>
<tr>
<td>Radiotherapy</td>
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<tr>
<td><strong>Risk factors reported</strong></td>
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</tr>
<tr>
<td>Another cancer</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
</tr>
<tr>
<td>Diabetes</td>
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<td>0.04 (.569)</td>
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<tr>
<td>Heart condition</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
<td>0.00 (1.00)</td>
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<tr>
<td>Mental illness</td>
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<td>0.00 (.483)</td>
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<td>Current anti-depressants</td>
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<tr>
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Table continued - Chi-square Statistics for 2 x 2 Crosstab Comparisons Referred to in Table 10.1

<table>
<thead>
<tr>
<th></th>
<th>Oral medications</th>
<th>Used vacuum devices</th>
<th>Used penile implants</th>
<th>Overall used some Tx</th>
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<td>Oral medications</td>
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<td>Used vacuum devices</td>
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<td>0.61 (.224)</td>
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<tr>
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<td>0.00 (.483)</td>
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</tbody>
</table>

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