SEXUAL ADJUSTMENT AND SELF-PERCEPTION IN MEN FOLLOWING PROSTATE CANCER

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Declaration

The work presented in this thesis is the original work of the author, except as acknowledged in the text. I hereby declare that I have not submitted this material, either in whole or in part, for any other degree at this time or any other time.

Signature ..................................................  Date ...............................................

[Signature]

[Date: 20th March, 2011]
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# TABLE OF CONTENTS

Declaration 2  
Acknowledgements 3  
Table of Contents 4  
List of Tables, List of Figures and Appendices 7  

Abstract 9  

## Chapter 1- Introduction/Literature Review 11  
  Prevalence of Prostate Cancer 11  
  Diagnosis of Prostate Cancer 12  
  PSA testing- International and Australian Findings 13  
  Goals of treatment 14  
  Treatment Options for Localised Prostate Cancer 15  
  Treatment Related Side Effects 17  
  The Impact of Urinary Dysfunction 18  
  The Impact of Bowel Dysfunction 18  
  The Impact of Sexual Dysfunction 19  
  Desire and Orgasm 22  
  Use of Erectile Aids/treatments 24  
  Treatment Decision-Making 29  
  Quality of Life Outcomes 31  
  Quality of Life: Sexual Wellbeing 32  
  Quality of Life: Psychological Wellbeing 33  
  Self-Perception and Self-Esteem 35  
  Coping With Post-Treatment Change 36  
  Effect of Diagnosis and Treatment on Relationships 39  
  Information Needs 40  
  Summary 43  
  Study Aims 44  

## Chapter 2 – Method 46  
  Ethical Considerations 46  
  Participants 46  
  Study Design 47
Recruitment process 47
Procedure 47
Measures 48
Semi-structured interviews 55
Data Analysis 56
Quantitative Data 56
Qualitative Data 57

Chapter 3 – Results 59
Demographic and Clinical Characteristics of the sample 59
Quantitative Results 63
Quality of Life 63
Sexual Function and Relationship 69
Psychosocial Well-being and Function 71
Anxiety and Depression 75
Unmet Needs 76
Qualitative Results 78
Theme 1: Change in Self-Identity 79
Physical Changes 79
Changes in Self-Perception 86
Psychosocial Adjustment 89
Existential Issues 91
Changes in Relationships 92
Theme 2: Communications and Support 94
Doctor-Patient Communication 94
Partner-Patient Communications 97
Communication with/support from Other Health Professionals 99
Support from Other Men With Prostate Cancer and Prostate Cancer Support Groups 99
Information Needs And Recommendation For Future 100
Theme 3: Adjustment Process 107
Lifestyle changes 107
Coping Strategies 108
Striving for Acceptance and Integration 110

113
Chapter 4 – Discussion

Changes in Self Identity

The impact of physical changes on sexual identity 114
Changes in self-esteem/self-perception and its impact on self-identity 121
Psychological adjustment and its impact on self-identity 123
Existential issues and their impact on self-identity 125
Changes in an intimate relationship and its impact on self identity 126

Communication and Support

Doctor-Patient communication 128
Partner-Patient Communication 130
Communication with/support from Other Health Professionals 131
Communication With Other Men With Prostate Cancer And Support Groups 132
Information Provision and Recommendations for Future 133

Adjustment Process

Lifestyle Changes 137
Coping Strategies 137
Striving For Acceptance and Integration 139

Chapter 5 – Limitations and Strengths of the Study

Implications for Practice and Future Research 143
Conclusion 145
TABLES

1. FACT-P Cronbach’s alpha 49
2. EPIC Cronbach’s alpha 50
3. MSS Cronbach’s alpha 51
4. SEAR Cronbach’s alpha 53
5. HADS Cronbach’s alpha 54
6. SCNS-SF34 Cronbach’s alpha 55
7. Demographic characteristics of the sample 61
8. Stratification of participants and participation mode by treatment type and time since treatment (Clinical characteristics of sample) 62
9. FACT-P Means and Standard Deviations 63
10. FACT P and FAIT U Items and participants’ responses 65
11. The EPIC – Means and Standard Deviations 66
12. The EPIC: Categorised responses to individual items 68
13. MSHQ- responses only 70
14. MSS – Items listed according to Factor 71
15. MSS Means and Standard Deviations 72
16. SEAR Means and SD’s 73
17. SEAR descriptive statistics of items, 74
18. HADS Means and Standard Deviations 75
19. HADS descriptive statistics 75
20. Supportive Care Needs Survey (SCNS-SF34) Means and Standard Deviation 76
21. Supportive Care Needs Survey (SCNS-SF34): Items of need 77
FIGURES

Figure 1. Diagram of penile injection therapy
Figure 2. Vacuum erection device.
Figure 3. Penile prosthesis
Figure 4. Model of psychosexual adjustment following prostate cancer treatment depicting main themes and subthemes that emerged from the qualitative analysis

REFERENCES

APPENDICES

Appendix 1 – Ethics Approval, University of Sydney
Appendix 2 – Ethics Approval, Concord Hospital
Appendix 3 – Advertisement, Prostate Support Group Newsletter
Appendix 4 – Participant Information Sheet
Appendix 5 – Men’s Sexual Function and Sexual Self-Perception Following Prostate Cancer - Questionnaire
Appendix 6 – Men’s Sexual Function and Self Perception following Prostate Cancer – Interview questions
Appendix 7 – Men’s Sexual Self Schema
Appendix 8 – Glossary of Terms
ABSTRACT

Prostate cancer is the most common cancer in men in Australia, with high survival rates. As a result, many men are living with the consequences of the disease and its treatment, which can affect urinary, sexual, and bowel function as well as a man's self-image and intimate relationships. Whilst most of the literature describes the frequency of treatment side effects, little is known about how these side-effects impact on the men's intimate relationships and their self-perception. Natural hesitancy to confront sexual issues and a lack of appropriate resources commonly inhibit the appropriate management of post-treatment difficulties which many prostate cancer survivors endure. The aim of this study was to explore experiences of men with prostate cancer; focusing on the impact of the disease and its management on sexuality, body image, self-esteem, personal relationships, overall quality of life and unmet needs.

The study used qualitative and quantitative methodology, with 24 men, recruited via the Concord Hospital Prostate Cancer Support group newsletter. Twenty-four men completed standardized measures assessing sexual functioning, sexual self-schema, quality of life, urinary, bowel and hormonal symptoms, psychological wellbeing, and unmet needs. Of those 24 men, 21 participated in face-to-face semi-structured interviews, which were transcribed and subjected to content analysis.

The participants scored lower on quality of life issues relating to urinary, sexual and hormonal symptoms, and on perception of their sexual relationship and self-esteem, compared to a prostate normative sample. The majority of men (71%) were not able to have erections, over one third (38%) reported they were not satisfied with their sexual life (38%) with a further 33% reporting being “only a little bit or somewhat” satisfied. Half (50%) the men reported they were satisfied with their relationship in general. Men indicated significant changes in their self-image, with 77% reporting that they no longer felt like a "whole man". Almost half of the participants reported unmet needs related to sexual feelings/relationships (48%), and just over a quarter reported unmet needs related to information about changes in sexual relationships (43%). One third of men (33%) expressed a need for psychological help related to feeling down or depressed.

The qualitative analysis of the participants’ interviews revealed the following three themes which contributed to the understanding of the men’s post-treatment psychosexual adjustment: i) Changes in self-identity, ii) Communication and support, and iii) Adjustment process. Within the overall “Change in Self-Identity” theme there were five sub-themes, related to Physical, Self-Perception, Emotional, Existential and Relationship changes. The “Communication and support” theme comprised of six sub-themes: communication and support between men and their Doctor, Partner,
Other Health Professionals, Other Men with Prostate Cancer and Support Groups, as well as Information Needs and Recommendations for the Future. Finally, the “Adjustment Process” theme included the sub-themes of Lifestyle Change, Coping Strategies, and Striving for Acceptance & Integration.

As a consequence of their treatment for prostate cancer, men in the current study reported side effects of erectile dysfunction, urinary incontinence, urine leakage during arousal or at orgasm, reduced penile size, lack of or reduced ejaculate, change in intensity of orgasm, reduced desire and pain. Physical side effects impacted on men’s identity, their sexual relationship, lifestyle, day-to-day life, overall relationships and their overall quality of life. The study revealed the importance of adequate patient-health professional communication in facilitating post-treatment adjustment.

Findings from this study have a number of important implications. Health professionals working in this setting need to ensure patients and partners are provided with appropriate amounts of information in ways that will best ensure their understanding of the issues, especially during the decision-making process. The information about side-effects of prostate cancer treatment needs to be communicated within a broader psycho-sexual context rather than the current focus on urinary or erectile dysfunction. Patients would benefit from access to multidisciplinary sources of care, including prostate nurse-led psycho-educational sessions, psychological care as well as access to support groups.

It is anticipated that the obtained findings will inform the development of a psycho-educational intervention/tool to be used as a resource for men/couples during the post-treatment recovery and rehabilitation. It is hoped that provision of such an intervention early in the disease trajectory will lead to improved quality of care and quality of life of men affected by prostate cancer and their partners/families.
CHAPTER 1

INTRODUCTION/LITERATURE REVIEW

Research into sexual outcomes following prostate cancer can be classified as a discipline within psycho-oncology. Psycho-oncology is a multi-disciplinary research and clinical sub-speciality focusing on the psychological, behavioural, social, and ethical components of cancer. These components are being addressed within two main dimensions: a) the psychological impact of cancer and its implications on patients, their partners/caretakers, family and friends, and health professionals, and b) the psychological, behavioural, and social aspects influencing the disease and recovery process. [1] These components warrant research attention due to the increasing prevalence of the diagnosis of prostate cancer in Australia and subsequent diversity of treatment modalities currently available, each with inherent side-effects.

Prevalence of Prostate Cancer

According to recent (2008) worldwide data provided by the World Health Organisation’s International Agency for Research on Cancer, GLOBOCAN, prostate cancer is the second most diagnosed cancer in men (13.6% of all cancers). Almost 75% of diagnoses are registered in developed countries and there is a 25-fold variation in incidence rates worldwide with the highest rates being in Australia/New Zealand, Western and Northern Europe and North America. This significant variation in incidence is a consequence of extensive use of prostate specific antigen (PSA) testing in those areas. According to GLOBOCAN, prostate cancer is the sixth highest cause of cancer death in men and was estimated to cause 6.1% of total cancer deaths worldwide in 2008. There is a 10-fold variation in mortality rates worldwide with death rates tending to be high in black populations, low in Asia and intermediate in Europe and Oceania, including Australia. [2] Further information related to PSA testing and increased incidence of prostate cancer is included on page 13.

In Australia, cancer of the prostate is the most common cancer diagnosed in men (29.5%) and the second most common cause of cancer deaths after lung cancer, accounting for 13% of all male cancer-related deaths [3]. It is less common in men younger than 50 years, with the risk of developing the disease increasing with age [4]. The most ‘at risk’ age group for a prostatic cancer diagnosis is 55-69 years. Men younger than 55 years, whilst less likely to suffer from prostate cancer, have a higher mortality rate should the disease occur at that time [5]. One in 9 men is affected with prostate cancer before the age of 75 years, and 1 in 5 before the age of 85 years. The
incidence rate of prostate cancer has increased by 8.7 per 100,000 between 2006 and 2007 in New South Wales.

According to the Australian Institute of Health and Welfare data, the likelihood of being diagnosed with prostate cancer has increased in all age groups from 45 years-55 years to 70 years-79 years since Prostate Specific Antigen (PSA) testing was introduced in the late 1980’s. The mortality rate has decreased in the most ‘at risk’ age group of 55 years-69 years (35.1/100,000 population in 1986 compared with 28.7/100,000 in 2006). [3]

Prostate cancer tends to progress slowly [6], however, men with Gleason Scores of 8 - 10 at diagnosis are more likely to experience an accelerated disease progression than those with lower Gleason scores. [7, 8] Nevertheless survival rates are still relatively high with 5-year survivorship rates approximately 88% in New South Wales. [1] It is found the prostate cancer survival rate is greater in higher socio-economic areas and highest in major cities. There is a 21% higher mortality rate for men in rural and regional Australia compared to that in capital cities. [9]

Given the survival rate discrepancy between men living in cities compared to those in regional and rural Australia, together with the high prevalence, high survival rates, and significant effects of treatment, it is clear that many men are living with the physical and psychological consequences of a diagnosis of localised prostate cancer, its treatment and possible side effects. This prompts an escalating need for an increased understanding of the experiences of prostate cancer for men and their families from diagnosis to long term effects.

The focus of this review will target men with localised and locally advanced prostate cancer, leaving issues associated with metastatic prostate cancer to be addressed at a future date.

**Diagnosis of Prostate Cancer**

The prostate gland is an essential part of the male reproductive system, its secretions forming part of the ejaculate that carries spermatozoa from the testes via the vas deferens through the penis. The normal prostate gland in an adult male is about the size of a walnut, sits deep in the male perineum at the base of the bladder and is palpable via the rectum. The urethra, the tube carrying urine from the bladder, also passes through the prostate on its way through to the penis [10] A significant nerve complex involved in erectile and orgasmic function is adjacent to the prostatic capsule. [11]

In the absence of specific symptoms the PSA blood test can indicate the possibility of prostate cancer although men may present with symptoms such as an urgency to urinate, pain and difficulty
associated with urination, urinary frequency particularly at night, a weak urinary stream and occasionally blood in the urine. Following a raised prostate specific antigen (PSA) blood test result and digital rectal examination (DRE), possibly indicating changes in the prostate, a more definitive diagnosis can be made by rectal ultrasound-directed multiple needle biopsies. Pathological examination of the obtained tissue determines the presence of cancer cells with the Gleason score indicating the aggressiveness of the cancer.

Of those men diagnosed with prostatic cancer about 90% will be diagnosed with a clinically localised disease.. [7] Bone and CT scans can be conducted to establish whether there has been metastatic activity beyond the prostate. Advanced prostate cancer may metastasise to bones causing pain at that site and may be associated with other signs of systemic disease such as weight loss and fatigue. Although a primary and integral part of a differential diagnosis, and a diagnostic tool for recurrence and progression of the cancer, positive prostate specific antigen blood tests alone are not conclusive evidence of prostatic cancer and false-positive and false-negative results may occur.

**PSA Testing - International and Australian Findings**

The PSA blood test can detect abnormal levels of the prostate specific antigen, however elevated PSA levels do not always indicate the presence of cancer and in some cases of prostate cancer they may not be above age-related normal levels [12]. According to Welch et al (2009), the use of PSA screening has resulted in over 1 million extra men, particularly younger men, being diagnosed and treated for prostatic cancer in the USA alone. These authors suggest that as well as PSA screening having a possible effect on cancer-specific mortality rates, over-diagnosis due to screening may also account for much of the increase in recorded incidence of prostate cancer [13].

In recent randomised trials of PSA screening in Europe and the USA, the European trial found PSA screening reduced the prostate cancer related mortality rate by 20% [14], whereas the American study found no significant effect on cancer related deaths [15]. A number of cancers found by PSA testing will be low grade, small volume disease with excellent prostate cancer-specific 10 year survival rates without immediate intervention [5]. Both the European and American studies found “a dramatic excess incidence” of prostate cancer in the screened group compared to the control group, suggesting that there may be a substantial over diagnosis and subsequent treatment of the disease. [13]

Although there is no PSA screening policy in Australia, the Urological Society of Australia and New Zealand (USANZ) PSA Testing Policy (2009) “currently does not recommend the use of mass
population-based PSA screening as public health policy, as published studies to date have not taken into account the cost effectiveness of screening, nor the full extent of over-detection and over-treatment”. [5]

The USANZ, however, does suggest that PSA testing and rectal examination be offered to men considered to be at increased risk (i.e. age range of 55-69 years), subsequent to their being provided with information concerning the risks, benefits and appropriateness of PSA testing. The USANZ also suggests that men deemed at risk aged 40-55 years can undergo a baseline PSA and DRE, with further monitoring as appropriate thereafter, considering the fact that men under 55 years, whilst less likely to be diagnosed with prostate cancer, are more likely to die from the disease after diagnosis than are older men [5] due to the aggressiveness of cancers occurring at the younger age.

It has been suggested screening for prostate cancer may be the first contact with the health system for some men and may provide an opportunity for assessment of other conditions such as hypertension, type 2 diabetes, raised cholesterol levels and sundry other conditions as seen relevant by the physician. Thus interventions for health issues unrelated to prostate cancer may be identified and treated, thereby contributing to a decrease in mortality rates. This may explain, to some extent, why men with prostate cancer have a survival rate the same as, or better than, men without prostate cancer. [16] It is not considered that all diagnosed prostate cancers warrant immediate intervention or treatment. In the absence of significant disease, a watchful waiting strategy may be adopted until disease progression indicates intervention is required. [4]

**Goals of treatment**

The goals of treatment for early detected localised prostate cancer are curative in intent aiming to reduce the risk of mortality and morbidity as a consequence of disease progression and, importantly, to minimise the physical side effects of treatments and their impact on quality of life. [7, 17] Where active treatment is indicated the choice of the treatment modality is based not only on the stage of the disease, but also the individual’s life expectancy (10 years or more), his age and any concurrent health issues, as well as his own wishes to instigate or withhold treatment.

In the absence of a cure for advanced prostate cancer, treatment in the form of chemical or surgical hormone deprivation may be used to temporarily suppress disease progression. [4] Chemotherapy may be instituted in the latter stages of the disease to treat symptoms not relieved by simpler therapies. Radiation or surgery may be used to relieve metastatic bone pain. The goals of treatment at this stage of the disease are those of supportive care such as management of pain,
fatigue, urinary, bowel symptoms and quality of life issues. Ideally, all care should include psychosocial support for the patient and the caregiver and not only be instigated at the commencement of palliative care strategies. [18] Comprehensive, timely, appropriate, supportive treatment at all stages of the disease trajectory is the objective for patients and health care professionals alike.

**Treatment Options For Localised Prostate Cancer**

Men diagnosed with localised prostate cancer may be presented with a number of possible treatment options, the most common of which are: i) observation without treatment with a view to intervention in the event of disease progression (i.e. active surveillance or watchful waiting), ii) surgical removal of the prostate (radical prostatectomy), or iii) radiotherapy. Androgen deprivation therapy (ADT), often referred to as hormone treatment, may also be offered as adjuvant therapy alongside another mode of treatment for prostate cancer. [7] Within treatment options there are different methods of delivering that treatment such as open, laparoscopic or robot-assisted laparoscopic surgery, and external radiation or brachytherapy.

**Active surveillance**, with the option for delayed intervention if necessary may be chosen by men with low-risk disease who are concerned about side effects of treatment. It is also a consideration for older men for whom aggressive therapy is unwarranted in terms of life expectancy and disease stage. [4, 19]

**Radical prostatectomy** involves the surgical removal of the prostate gland and seminal vesicles and may be performed as an open operation, laparoscopically with or without robotic assistance. [7] The process of removing the prostate has the potential to cause urinary incontinence and affect erectile ability due to damage to nerves and blood vessels associated with erectile function and will result in the absence of ejaculate at orgasm along with possible changes in the sensation of orgasm due to the loss of contractile sensation in the now absent prostate and seminal vesicles.[20]

Open prostatectomy is the most frequently used surgical treatment for prostate cancer, with laparoscopic and robot assisted techniques becoming more commonly available, although their long-term outcomes are not yet well described. [21] A diagnosis of localized disease without evidence of clinical or radiographic metastatic disease is the prerequisite for open, laparoscopic or robotic assisted radical prostatectomy. While long-term data is not yet available, results from high volume centres and experienced surgeons are reported as comparable across the three techniques.
However published data from high volume centres may not be replicable by lower volume surgeons at less well-equipped institutions. Nonetheless, robotic technology has been well marketed, especially to high-end consumers, and has been widely adopted in elite clinics particularly in the US.

Radiation treatment may be delivered externally, external beam radiation therapy (EBRT) or internally (brachytherapy), the latter being administered at either a high or low dosage depending on disease stage and volume. Since 2003, the use of brachytherapy (high and low dosage rates) has become more common and external beam radiotherapy techniques now include greater use of conformal therapy and image guidance. As well as damage to surface skin areas, potential damage to structures adjacent to the prostate resulting in bowel and urinary problems can occur. Radiation damage to the non-cancerous areas of the prostate and seminal vesicles, blood vessels and nerves associated with erectile function, can result in a greater or lesser degree of loss of erectile functioning, changes in orgasmic sensations and reduced volume of ejaculate.

Androgen deprivation (hormone) therapy (ADT) is used to reduce testosterone to castrate level. Testosterone is the hormone produced mainly in the testes which is responsible for the continuing growth of prostate cancer. Hormone deprivation is achieved by one of two methods of castration: surgical orchidectomy - permanent removal of the testes, or the currently more common chemical option, leutinizing hormone releasing analogues. Both methods of castration can result in side effects which may have a significant impact on quality of life. The less permanent chemical castration may also be offered as adjuvant therapy along with other modes of treatment for prostate cancer.

All active prostate cancer treatments have the potential for short- and/or long-term side-effects which may affect a man’s quality of life, and his personal and intimate relationships. These facets of recovery are less well researched therefore further research is required to gain a greater understanding of men’s experience of treatments and their side effects on their sexual identity, relationships and quality of life. Such information would serve to inform novel strategies for interventions to ameliorate difficulties arising from various treatment modalities and their side effects.
Treatment-Related Side Effects

Possible prostate cancer treatment side effects can be both physical and psychological. Surgical and radiation treatment side effects can include urinary incontinence, changes in sexual function such as erectile dysfunction, reduced volume of, or no, ejaculate, orgasmic changes including reduced sensation and urine loss during orgasm (climacturia); reduced penile length, faecal incontinence, bleeding from the bowel, lack of or reduced libido, fatigue and reduced body image and self-esteem. [4, 21, 26] Androgen deprivation therapy reduces testosterone to castrate levels resulting in many side effects including fatigue, weight gain, loss of muscle mass, loss of body hair, hot flushes, sexual dysfunction, diminished genitalia size, depression, mood swings, and reduced cognitive function with associated decline in quality of life. Long term androgen deprivation increases the risk of osteoporosis, heart disease, obesity and diabetes. [29]

Urinary dysfunction is more common amongst men treated by radical prostatectomy and bowel problems are more commonly reported by men treated with radiotherapy, whilst sexual dysfunction at 3 years post treatment is common across all treatments modalities. [21]

Incidence rates for side effects can vary, with fewer side effects being produced by the more experienced specialist surgical and radiation oncologists treating large numbers of patients with prostate cancer in high-quality facilities. [30] However, not all prostate cancer patients have access to such expert care [21] and limited data is available to describe the outcomes of the broader population of prostate cancer patients treated by less experienced clinicians in facilities other than large teaching hospitals or centres of excellence. [31] Other factors contributing to the differences found in reported side effect rates across studies are differences in the items used to define incontinence and erectile dysfunction, and differing study methodologies [21, 32]. Further, discrepancies between the incidence rates for sexual and urinary dysfunction seem dependant on whether the information is patient or doctor reported, with doctors tending to over-report patients’ sexual and urinary function compared to patient self-reports (by 30% and 13% to 65% respectively). [21, 33, 34]

Clark et al’s (2003) study found that men with prostate cancer (n=540) reported greater urinary, bowel and sexual dysfunction but similar health status when compared to a reference group of men with normal PSA levels and no history of prostate cancer (n=658). Although these findings support previous research it seems a contradiction and suggests that the differences between the two groups may be more complex than the presence, or not, of disease.

It would appear that the incapacitating and frustrating side effects of some prostate cancer treatment modalities are multi-faceted, some outside the patients’ control, i.e. those depending on the skill and
facilities of the health professionals, others a matter of perception of difficulties as seen by the patient. Difficulties with side effects tend to occur in the areas of urinary, bowel and sexual functioning and impact on physical and psychological levels.

The Impact of Urinary Dysfunction

Urinary dysfunction is often associated with surgical and brachytherapy treatment with radical prostatectomy resulting more in symptoms of incontinence such as leakage, and brachytherapy causing irritative urinary symptoms such as frequency and pain on urination. [26] Urinary incontinence is more likely to occur during physical activities requiring exertion, such as exercise, lifting, stretching, rising from a chair, coughing, sneezing and laughing. It may be associated with a full bladder, too frequent voluntary emptying of the bladder, high fluid intake, alcohol consumption and even cold weather. [35] Urinary dysfunction can cause varying levels of distress as men become increasingly anxious about avoiding leakage and hyper-vigilant regarding toilet locations. Men suffering incontinence have reported feeling dirty and concerned about possible urine odour, becoming embarrassed when leakage occurs and uncomfortable wearing pads particularly when the pads become wet. [27, 36] Men also report feeling embarrassed when purchasing pads and finding the constant focus and monitoring required for urinary control a negative, tiring and frustrating experience. [27]

Clark et al found that men who underwent radical prostatectomy reported greater urinary incontinence and sexual dysfunction than those who had other treatments for prostate cancer. However surgical patients reported no difference in the impact of incontinence on their lives to that reported by patients not undergoing surgery. [36]

While urinary difficulties can persist in surgical and brachytherapy patients with their continuing to experience incontinence and urinary irritation or obstruction up to 2 years and possibly beyond that time, post treatment, urinary difficulties in patients who underwent external beam radiotherapy were usually resolved by 12 months after treatment. [31, 37]

The Impact of Bowel Dysfunction

Smith et al (2009) found that all men in their study who had undergone prostate cancer treatment reported some level of bowel disorder [21], with changes in bowel function being a continuing
problem for men who had undergone external beam radiotherapy together with androgen deprivation.

Symptoms following radiation therapy can include rectal urgency, frequency, pain on defaecation, faecal incontinence and bleeding from the bowel. Clark et al (2003) found that men who reported such symptoms were also more likely to report reduced sexual intimacy, reduced marital affection and lowered self esteem. Continuing bowel problems were also more likely to be associated with a greater concern about disease progression and a reduced quality of life. Obtaining data from men with significant bowel problems was difficult and Clark et al argue that that may be due to a low incidence of occurrence or perhaps because men may have greater concerns and embarrassment related to reporting such problems. Bowel problems after prostate cancer treatment were more highly associated with decreased self-esteem than urinary incontinence or sexual dysfunction. [36]

The Impact of Sexual Dysfunction

Sexual dysfunction as a consequence of treatment for prostate cancer may include an inability to achieve and/or maintain erections sufficient for vaginal penetration, absent or decreased ejaculate, less intense orgasms and diminished or absent libido. Changes in sexual function are more commonly assessed in the narrow context of erections and sexual intercourse, with less attention being paid to the reported lessening of desire for, and pleasure from, sexual stimulation and impact on relationship intimacy. [38]

Sexual dysfunction following prostate cancer treatment can have a major impact on some patients and their partners and has been found to have a significant correlation with quality of life.[36, 39] Despite the broad acknowledgement of, and research into, erectile dysfunction following prostate cancer treatment, there is a paucity of information available on men’s recovery process including the impact of the side effects and any dysfunction to relationships.[40] The process of loss of erectile function varies across treatments. Following radical prostatectomy there is immediate loss of erectile function with some recovery, if it occurs, taking more than 2 years in some men, and even then there may be only partial recovery of spontaneous erections. Following radiotherapy, diminished or total loss of erections may take up to two years to occur with little potential for recovery of pre-disease erectile capability. Men treated with androgen deprivation lose erectile function and libido reasonably quickly although recovery may occur in the absence of testosterone suppression where there is no concurrent erectile dysfunction due to other conditions. [40]
Impotence rates following radical prostatectomy have been reported as ranging from 29-75% [31] and have been shown to be comparable with the rates following radiotherapy treatments. Nerve sparing radical prostatectomy does appear to be somewhat superior in terms of preservation of sexual function. [37] That advantage however, according to Schover et al (2002), must be seen in the “context of the generally dismal rates of sexual recovery”. [38]

Prostate cancer treatments can have a dramatic effect on sexual function and even men with good sexual function prior to treatment who regain spontaneous erections sufficient for intercourse, rarely return to their pre treatment physical sexual health baseline. A review of literature indicates that 30-50% of men are experiencing some degree of sexual dysfunction, predominantly erectile dysfunction, at the time of prostate cancer diagnosis and that treatments such as surgery or radiotherapy increase the incidence of sexual dysfunction to about 50-80%. [11] In the same review, androgen deprivation therapy for advanced prostate cancer is reported to result in a sexual dysfunction rate of 80-90%. [38]

In Dalkin et al’s (2008) study only 30% of 116 men with good pre surgical sexual health domain scores, who regained spontaneous erections sufficient for intercourse, returned to pre treatment sexual function scores. Contributing factors for those men not returning to previous sexual function levels may be changes in orgasm, urine leak at orgasm or during foreplay, and loss of penile length, as well as disinclination for sexual activity expressed by their partner [41]

Particular features and the degree of sexual dysfunction vary between individuals [42] with such dysfunction possibly also associated with poorer quality of life and a less positive perception of treatment outcomes. Men with prostate cancer treatment related sexual dysfunction have been found to express reduced quality of sexual intimacy, decreased sexual desire and sexual confidence, impaired feelings of masculinity, lower self-esteem and poorer body image. [36, 39]

Sexual quality of life following prostate cancer treatment can also be affected by age and prostate related factors such as size. [37] Pre treatment sexual quality of life may add some confusion to reported sexual quality of life post treatment, since 17.9% of men in one study reported their sexual function as a “moderate to big problem” prior to their diagnosis of prostate cancer. [31] This suggests some doubt as to causative factors for sexual dysfunction totally resulting from prostate cancer and subsequent treatment procedures. Despite some men’s reports that sexual dysfunction is a “moderate to big problem” there is little consensus as to what that means specifically and what men’s psychosocial experiences are when living with sexual dysfunction. [43, 44]

Men with newly diagnosed prostate cancer may have idealistic and unrealistic expectations of sexual function and competency post treatment. [38] Contrary to some of the published side effect
rates, Schover et al (2002) suggest that these figures may have been overestimating the success of treatments in preserving sexual function and that most men continue to experience varying degrees of sexual dysfunction some time after treatment. In that study, in which respondents were on average 4.3 years post treatment, only 13% of men reported that sexual function had been maintained or had returned and a further 8% stated they could achieve erections only with the use of erectile dysfunction therapies. [38] Smith et al (2009) suggest that better potency rates in some studies may be as a consequence of differences in the definitions used and report that a recent review identified 112 published definitions of incontinence and 79 definitions of erectile dysfunction and, as previously mentioned, there can be a discrepancy between doctor and patient reporting of sexual and urinary function by up to 30% and 13% to 65% respectively. [21]

Clark et al (2003) found diminished sexual quality of life as a result of prostate cancer treatments involved much more than erectile dysfunction. As well as changed sexual function men reported doubts related to their sexual performance and satisfaction. These doubts extended to concern with their ability to satisfy their partners and extended to their relationships with women in general, leaving them feeling tentative about initiating intimacy and with intimacy overall. The loss of libido and their sexual fantasy life lowered their feelings of self worth and reduced their sense of their masculine identity. [36] Hence, post treatment erectile dysfunction and its consequences have been found to be of a greater concern for prostate cancer patients than other side effects.[31, 45]

Discrepancies in definitions of sexual dysfunction and inconsistent reporting by doctors and patients of difficulties found in post surgery patients leading to higher potency rates being reported, may also apply to patients having undergone radiotherapy.

Those men who had good sexual function prior to treatment may be more likely to comment on their current level of sexual functioning and satisfaction, whereas other men may be less likely to comment at all. Thus the patients’ decision to disclose erectile difficulties will influence the estimation of post treatment potency rates.[8] Radiotherapy patients are more likely to have coexisting illnesses than brachytherapy therapy patients, with surgical patients more likely to have the least coexisting health problems. [16] Radiotherapy is indicated for more severe, advanced cancers not amenable to other forms of treatment. Thus men who undergo radiotherapy for prostate cancer are often older, in poorer health and more likely to have pre-existing erectile problems in comparison to men undergoing surgery for prostate cancer. [8]

Sexual dysfunction in patients undergoing radiation treatment can be further compromised by the use of androgen deprivation therapy, an adjuvant therapy often recommended for patients undergoing radiation. [43]\ Bokhour et al (2001) report that patients undergoing brachytherapy and
external beam radiotherapy in conjunction with androgen deprivation therapy, described enduring urinary irritation, bowel irregularities and sexual difficulties as side effects and problems associated with hormone deprivation such as fatigue, weight change, breast swelling and tenderness, depression, hot flushes and problems with overall vitality. [37, 43] The majority of men treated with androgen deprivation therapy cease sexual activity and report poor erectile function. [46]

Better sexual outcomes following treatment for prostate cancer have been shown in patients of a younger age who had not been subjected to any androgen deprivation, had undergone bilateral nerve sparing prostatectomy or brachytherapy and who self reported better mental and physical health on the Short Form Health Survey (SF-36) instrument which is a widely used measure of health related quality of life. [38]

Younger age at treatment has been strongly associated with better sexual outcomes from prostate cancer treatment. [38] Korfage et al (2006) reported the unexpected finding, from their semi-structured interviews of 33 men with prostate cancer that men tended to minimize sexual dysfunction in terms of age, however, age was not a contributing factor when they referred to urinary and bowel dysfunction. Participants explained that decreased sexual function was considered a normal variation associated with increasing age, not a health issue and not considered as part of health related quality of life. [47] A number of men (N=18, between 57-75 years, average age 65 years) interviewed by Fergus et al (2002), regarding their experiences following treatment for prostate cancer, reported that sexual dysfunction would have been more difficult for them had they had been younger. [42]

Whereas physical impediments to sexual functioning may play the more significant role in sexual quality of life, attention also needs to be paid to more emotional and psychological aspects of sexual satisfaction.

Desire and Orgasm

Past research has focused mainly on erectile function as the key component in sexual satisfaction for men without much attention to the relationship between that particular component of sexual function and more subtle components such as desire. [48] Penson et al’s (2003) review of the literature found that sexual function and desire do not necessarily correlate, indicating that men may experience distinctive and decidedly individual reactions to changes in sexual function after treatment. [49] In Canada et al’s (2005) brief counselling intervention for men and their partners following prostate cancer treatment, the authors found that 45% of 1236 men surveyed reported low
sexual desire. Koeman et al (1996) noted that 10 of 18 participants reported diminished sexual desire [20] and also noted that other surveys have reported 50-55% of men to have reduced levels of desire.

Orgasm, the resolution of pleasurable tumescence, occurs when stimuli reach the brain through the sensory fibres of the somatic pudendal nerve and the associated experience of pleasure occurs with a series of contractions of muscles in the genital area and pelvic floor coinciding with the release of dopamine and acetylcholine in the brain.[20] These contractions are variably compromised by treatment interventions. However, most of the research surrounding sexual dysfunction following radical prostatectomy has concentrated on erectile dysfunction with much less attention being given to sensory deprivation, resulting from nerve damage and prostrate removal or prostrate impairment, influencing desire for and the achievement of orgasm during masturbation, intercourse or sexual fantasy. [50]

Following surgical removal of the prostate, the sensations associated with orgasm commonly change as a consequence of the individual no longer experiencing the sensations associated with ejaculation and contractions of the now absent prostate and seminal vesicles. [20, 50] Barnas et al (2004) found that following radical prostatectomy (n=239), 22% of men denied any change in orgasm intensity, 37% reported complete absence of orgasm, 37% reported a decrease in orgasm sensation although 4% of respondents reported a more intense sensation of orgasm than previously experienced. Dysorgasmia (pain during orgasm) was reported by 14% of the 239 men who responded and 33% of those men reported pain always occurred during orgasm with 48% reporting pain occurred frequently or occasionally.[50]

Changes in sexual function associated with prostate cancer treatments are multi-faceted. After treatment men may experience reduced or no desire for sex/ [38] , urine leakage during foreplay and/or climacturia (loss of urine at orgasm, most likely due to the removal of the internal urinary sphincter during surgery). [20, 51] This loss of urine during sexual activity may occur in men who report no urinary incontinence at other times. These changes can all contribute in varying degrees to reduced desire and orgasmic pleasure in this population. This population may also experience compromised or non-existent erections, reduced volume or no ejaculate, reduced sensation or pain at orgasm, plus reduced penile length. [52]

Penile shortening has been found to occur in about 68% to 71% of men following prostatectomy with penile length estimated to be reduced by 1 to 3cm occurring progressively over about 12 months post-operatively. [52-54] Possible causes currently postulated to account for these
phenomena include nerve injury or change subsequent to surgery, changes in penile blood flow resulting in fibrosis and penile tissue atrophy. [53]

Ko et al (2010) report no association between reduced penile length and/or erectile dysfunction and men’s concepts of masculinity. They report that men in their study (n=6) viewed masculinity and the body as separate, therefore enabling them to have a stable sense of masculinity pre and post treatment.[55]. Other studies suggest that men may experience a diminished sense of masculinity following prostate cancer treatment [27, 36, 43], Yet other researchers suggest men may reappraise and adjust their construct of masculinity allowing them to maintain a stable sense of masculinity[42, 56].

The physiological sequelae of prostate cancer treatment includes erectile difficulties, loss of ejaculate, urine loss and pain during sexual activity, reduced penile length and lack of orgasmic contractions previously experienced in the prostate. These physiological changes, possible disease progression and a possible uncertain future can significantly affect men’s sexual experiences and pleasure and may therefore compromise desire and sexual arousal. The more psychological aspects of self-worth, relationships, sexual intimacy with another person and broader aspects of sexual satisfaction and quality of life post treatment, has been somewhat neglected in comparison with those physiological aspects of re-establishing a satisfactory sexual functioning, including the use of erectile aids, for those men with erectile dysfunction. This could indicate that current thought may still be more focused on physical accomplishments for sexual satisfaction at the expense of reforming mental constructs and developing different mental attitudes towards sexual satisfaction.

Use of Erectile Aids/treatments

Although advances in prostate cancer treatments have been made over recent years to enhance the chances of return of erectile function [24, 37, 38] and a variety of treatments have been made available to correct erectile dysfunction, satisfaction rates for men using these treatments and aids is generally reported as low. [37, 57] Treatments include: oral medications (phosphodiesterase type 5 inhibitors), penile injections (see Figure 1), vacuum erection devices (see Figure 2), penile prosthesis (see Figure 3), and psychosexual counselling. [57] The use of erectile treatments is not as medically common as might be expected given the attention to preserving the potential for restoring or maintaining erectile function in first line treatments. [40]

The penis becomes erect following sexual stimulation which causes the release of nitric oxide (NO), resulting in dilation of the blood vessels of the corpus cavernosa via an accumulation of cyclic
guanosine monophosphate (cGMP). An enzyme, phosphodiesterase type 5 (PDE5), that breaks down cGMP can be inhibited and thereby the vasodilatory effect of NO is enhanced. [58] There are currently 3 PDE5 inhibitor oral therapies available in Australia for erectile dysfunction: sildenafil (Viagra™), vardenafil (Levitra™) and tadalafil (Cialis™). [59] All are contraindicated in men with a history of stroke, recent myocardial infarction (heart attack), those using nitrate therapies or with a high risk cardiovascular disease, unstable angina, significant hypotension, uncontrolled hypertension, liver disease and kidney disease requiring dialysis. [58]

The dose is no more than one tablet as prescribed in less than a 24-hour period and effects last for varying times although tadalafil can remain effective for about 36 hours. Alcohol may impair efficacy and although the action of sildenafil may be impaired if taken too soon after eating, both tadalafil and vardenafil can be taken with or without food. All PDE5’s require sexual stimulation for effect. They increase erectile ability not sexual desire. Side effects include headache, facial flushing and nausea and less commonly colour vision changes, photosensitivity, and loss of vision in some cases. Priapism, a painful erection lasting for more than 4 hours, requires urgent medical attention. [60-62]

Alprostadil works by directly relaxing the smooth muscle lining the vascular spaces in the corpora cavernosa. To administer Alprostadil (Caverject Impulse™) men need to be educated in the technique required to insert a hypodermic needle into the corpus cavernosum of the penis to administer the drug. Men need to be reasonably dexterous and educated as to dose titration, treatment of side effects, painful erections [particularly priapism], and side effects related to long term use such as scarring which can cause shortening or curvature of the penis. Erections occur within 5-20 minutes of injection, should last up to one hour and should be used no more than once daily and no more than 3 times weekly. Some men find it difficult to consider injecting themselves, particularly into the penis. [59]

Figure 1. Diagram of Penile injection therapy reproduced from http://www.racgp.org.au/afp/201005/201005smith.pdf

Vacuum erection devices are a non-invasive treatment option for erectile dysfunction. Negative pressure is applied to the penis, engorging the corpora cavernosa which results in an erection. An elastic band is applied for no more than 30 minutes to the base of the penis to maintain the erection.
Some bruising may occur and ejaculation may be interfered with due to the presence of the constriction band.

Figure 2. Vacuum erection device reproduced from http://www.racgp.org.au/afp/201005/201005smith.pdf [58] February 15, 2011

If other treatments are ineffective or patients are not satisfied, a penile prosthesis may be implanted. Implants may be either a semi rigid malleable device which is extended manually when an erection is required or an inflatable hydraulic implant. The latter has paired cylinders which are implanted into the penis and a scrotal pump and reservoir. Some manual dexterity is required for this device. Complications can include corporal and urethral erosion, infection and mechanical failure. Nevertheless, the device is normally well tolerated. [59]


Men who do seek help for erectile dysfunction following prostate cancer treatment are more likely to be of a younger age, have a willing sexual partner, enjoy better physical and mental health, have had nerve sparing radical prostatectomy, be better educated and more financially secure. [40, 63]

In their sample of almost 2,000 men with localised disease Stephenson et al (2005) found similar associations with reported use of erectile dysfunction treatments 5 years post-diagnosis. [57] Schover et al (2002) noted, in a study of 1236 men from one American centre, that the more sexual partners men had in their lifetime the more motivated they were to successfully treat their prostate cancer related erectile dysfunction. Men were also more motivated if they were in newer relationships and/or had a much younger partner, while men who were on androgen deprivation therapy and men with disease progression were less likely to try to restore erectile function. Even if they did try treatment for erectile dysfunction, men in both of these groups were less likely to continue it. [64]

Stephenson et al (n=1977) also found that perceived efficacy of erectile dysfunction treatments varied according to treatments. Whilst approximately half of erectile treatment users perceived
penile prosthesis to be “most helpful” (52%), this type of aid was actually used by only 1.9% of the study sample. Only 12% of men using sildenafil medication (Viagra) reported that the treatment “helped a lot”. Psychosexual counselling was seen as the least helpful (7%). The level of helpfulness of individual treatments from 6 months to 5 years was stable apart from penile injections which, although participants reported that they “helped a lot”, decreased from 43% to 30%. At 5 years, 71% of users perceived both penile prostheses and vacuum erection devices helped “a lot” or “somewhat”, and penile injection, nonsildenafil medication, sildenafil and psychosexual counselling were rated as “a lot” or “somewhat” helpful by 69%, 61%, 47% and 40% respectively. Participants who used more than one treatment for erectile dysfunction described them as less helpful than men who used only one treatment. [31, 57] Although no interpretation of this finding was made by the authors it may be that the men who were prepared to try a second treatment option were more motivated to obtain erections and therefore possibly more likely to experience greater disappointment when the treatment failed. At five years post-treatment, full erections were reported by less than half the users of each aid, whilst the degree of erectile fullness, ability to maintain erections and frequency of sexual activity showed only modest improvement. Frequency of sexual activity was reported as high by men who used vacuum erection devices, penile injection, penile prosthesis and sildenafil (used alone or in conjunction with another therapy). [57]

Sildenafil (Viagra) was introduced in the USA as a therapy for erectile dysfunction in 1997 in the middle of the 5 year duration of Stephenson et al’s (2005) study. Although sildenafil was not found to be as helpful as penile prostheses, vacuum erection devices or penile injection therapy, results from this study suggest sildenafil and other newer, similar medications, vardenafil (Levitra) and tadalafil (Cialis) have now become the most widely used treatment for erectile dysfunction following prostate cancer treatment. [57]

In Canada et al’s (2005) pilot intervention to enhance sexual rehabilitation in couples after treatment for localised prostate cancer, 51 couples were provided with four education sessions about the sexual impact of surgery or radiotherapy, available treatments for erectile dysfunction and their optimal use, plus coping strategies for urinary incontinence during sexual activity and sex-related menopausal symptoms. ex-related menopausal symptoms. The study groups were either couples or men only (partners were not required to attend). Both groups were also instructed in how to perform pelvic floor exercises. At the end of the four sessions, the erectile function of men and sexual function of women in both groups had significantly improved, however sexual functioning in patients and partners had declined slightly at 6 months. Although significant improvements were made in sexual function, sexual satisfaction and greater use of erectile dysfunction treatments
during the intervention, strategies to encourage the continued use of improvement techniques following the intervention, to address the decline in improvement noted 6 months post intervention, were not in place.[63]

Participant’s in Fergus et al’s 2005 qualitative study reported that, even if mechanical erectile aids, including injection therapy, were successful in achieving an erection, they were awkward to use and interfered with spontaneous sexual excitement and performance. [42]

Shover et al (2002) reported that 59% of men with prostate cancer induced erectile dysfunction had tried a treatment for the erectile dysfunction although the perceived low efficacy of treatment resulted in only 30% of those men still using treatment at 4.5 year follow-up. Men who had tried two or more alternatives were more likely to find an effective erectile dysfunction aid. Importantly, literature suggests that men for whom sexual activity after prostate cancer treatment is important are more likely to choose a cancer treatment most likely to preserve sexual function, and they are also more likely to persevere with treatments when spontaneous erectile function is not restored. [64]

Men were more likely to try oral medications, such as sildenafil, although the more invasive treatments, such as penile prosthesis implant or penile injections are known to be the most effective. While oral medications are the most popular, it is important to note that their success rate is commonly linked to cancer treatments which have the least effect on erections, such as nerve sparing surgery and some radiotherapy modalities.[64]

Ideally, erectile dysfunction following prostate cancer is a couple’s problem, however partners are not always included in discussions regarding restoration of function and may in fact suffer as a consequence of men using erectile aids. Potts et al’s (2003) study of women’s experiences of their partners’ use of sildenafil, whilst not looking specifically at couples affected by prostate cancer, highlighted some concerning issues regarding the effect of Viagra use on female partners. [65] Some women described not being interested in sexual activity but tolerated it to improve their partners’ confidence and self esteem. Erectile dysfunction for some couples may result in a sexual repertoire where vaginal penetration is no longer the main priority and women, particularly women who are menopausal/post menopausal or have other disabling health problems, may prefer the resulting sexual non-penetrative activity (e.g. oral sex, mutual masturbation etc.). Women not desiring a return to penetrative sexual activity may experience guilt when their sexual interest and desire for penetrative intercourse does not match that of their partner for whom erectile function has been restored, even if only temporarily. Women may appreciate a closer relationship and intimacy with their partner while not seeking penetrative intercourse and in this study women reported feeling pressured by partners to accommodate their sildenafil-induced sexual capability. In
relationships where the partnership is not equal it may not be possible for women to negotiate sexual activities and frequency. [65]

For many people sexual activity, and any difficulties associated with it, is fraught with social and/or cultural constraints and therefore many men and/or their partners may find it a difficult subject to broach with health professionals. Men may be disadvantaged by cultural restraints in gaining understanding and managing their condition. [40 66] In turn, some health professionals may also feel uncomfortable to discuss this subject with their patients. Referral to an accredited sexual therapist competent in this area is advised in this situation so that all available access to resources is there for the patient and his partner to take advantage of, if they wish.

The ability to achieve an erection is just one feature of sexual function but inability in this area can impact on overall sexual function. Prior to treatment patients need to be informed of the risk of sexual dysfunction occurring as a consequence of treatment. Best practice should also include information about the availability of effective erectile dysfunction treatments, as well as sexual counselling. [48] Informed shared decision-making can then target the most appropriate treatment, together with its possible outcomes, for that patient.

**Treatment Decision-Making**

The diagnosis of cancer and its ensuing treatment can be a major life stressor. [66] Following a diagnosis of prostate cancer the patient and his family are required to understand and consider many options, make decisions on possible life-changing, life-threatening issues in an area they know little about, all at a time when the news of the diagnosis has them overwhelmed.

Clear concise information is required by the patient and his family, moderating that information to fit their level of education, understanding and cultural needs. [67, 68] With the urge to deliver all information and cover all possible angles there is the risk of the health professional dispensing so much information that the patient is unable to absorb most of it and consequently may become more confused and anxious and remember little of it.

Patients are given a comprehensive amount of information by their treatment team and may be encouraged to resource information for themselves as well from other reputable health professionals and websites, decision aides, support groups, cultural and religious organisations etc. In this way they may more comfortably gain information they want in the way they want it. This allows them to bring to the consultations with the specialists and oncologists the questions and concerns most meaningful to them and their family, so that all misunderstanding can be clarified and the most
appropriate treatment regimen agreed upon. Often there is a limited time to resource, absorb and understand all the information required for the patient to feel comfortable in taking part in shared decision-making. The patient has much to contribute to shared decision making by sharing their value systems, hopes needs, fears expectations etc. Knowing which questions to ask if often difficult in these circumstances considering the significant amount of stress the patient is under and does not help him to think straight or remember well. Hence the gaining and retaining of important information can be very difficult. The patient’s statement in hindsight that he was never informed of certain issues may not always in fact be accurate.

Research has shown that patients who reported they were included in decision making stated they were more satisfied with the information provided, emotional support, and overall medical consultations compared to those who reported a limited role in the decision making process. [69]

A shared decision making (SDM) approach, as defined by Charles et al (1997) occurs when both parties share information, are united on the choice of treatment and agree on a treatment plan. [70] A 2006 review of the literature by Makoul et al classified the components of SDM “essential” or “ideal”. Essential components include defining the problem, discussing available treatment options and related risks and benefits, understanding patient values and preferences, discussing the patient’s clinical condition and making a recommendation, checking patient understanding and providing an opportunity to defer the decision. “Ideal” components of SDM are thought to add value to the SDM approach and include provision of unbiased information, clarifying the patient’s role and their desired level of involvement and deciding on a mutually agreed treatment plan. [71]

Patients’ information needs may differ according to what and how much information the individual wants and can absorb [42] and while evidence suggests that SDM results in positive patient outcomes [69], there is some evidence that SDM may not always be a practical approach or a patient preference. [72] While SDM is seen as the “gold standard”, [73] the level of patient involvement in SDM can not be dictated by health professionals and should allow for the differing needs of individuals.

Patients actively involved in gathering their information often feel empowered against their cancer and are more likely to comply with decided treatment options than those who feel disempowered and overwhelmed. The provision of good written verbal and visual information together with support at diagnosis can help reduce anxiety. It has also been shown that the provision of sensory and procedural information and addressing patients’ concerns about treatment options, leads to less pain and distress, more compliance with treatment regimes, as well as shorter hospital stays. [92, 93]
When deciding on a treatment plan men can often think in terms of life-saving rather than quality of life and may feel they are choosing, or making a trade off of, life over side effects including sexual dysfunction. In SDM decision aides can be an invaluable tool in helping patients to prioritise their values, thoughts, needs and wants now and for the future. Discussing these with their health care team can help to lessen a regrettable trade off being made in the heat of the moment. Fergus (2002) reports that “implicit in the trade off” was the “erroneous assumption that sexuality was an isolated function rather than the integral component of the men’s identities and lifestyles that it was” and this could result later in a sense of loss and a need to adjust to a very changed life. [42]

**Quality Of Life Outcomes**

The majority of studies within the prostate cancer setting have concentrated on the risks/prevalence of treatment-related dysfunction [35, 36], with much less consideration having been given to the experience of living post prostrate cancer treatment with the side-effects and subsequent quality of life and relationship disruptions which may occur. [35] The few existing psychosocial and quality of life studies suggest that quality of life is largely unaffected by side effects of prostate cancer treatment, however they argue that this may be because the measures used are insensitive to patients’ actual experience rather than the fact that patients’ quality of life is not affected [27]. Other studies suggest that men do not consider the sexual, urinary and bowel problems experienced following treatment as a health issue impacting on their quality of life and therefore may under-report these difficulties in a health-related quality of life framework. [36, 43, 47]

Clark et al (2003), found that men who live with prostate cancer induced urinary, sexual and bowel dysfunction, particularly in the context of uncertainty about disease progression and dissatisfaction with treatment choices, can experience decreased self-confidence and self-perception. [36] Men commonly experience not only the physical side effects, but also distress and anxiety related to living with the side effects, their impact on them and their personal relationships, as well as concerns about disease progression. The distress experienced may be higher than that which men report [35] and the objective and self-reported estimates of sexual function are not always consistent, suggesting that each man may have a “unique and highly personal” reaction to treatment-induced changes in sexual function. [39]

Since the majority of men diagnosed with prostate cancer are older than 50 years, many may already be experiencing varying degrees of reduced sexual function related to other health issues such as cardiovascular disease, diabetes or antihypertensive medication [20], and therefore be at greater risk of being affected by impairment of sexual function post treatment. whereas others may
be more accustomed to the changes in their sexual life and see this added reduction as less significant.

**Quality of Life: Sexual Wellbeing**

Clark et al (2003) found diminished sexual quality of life as a result of prostate cancer treatments involved much more than erectile dysfunction. [36] As well as changed sexual function, men reported feeling doubts about their sexual performance and satisfaction (their own as well as their partner’s), being less confident in their relationships with women, feeling tentative about initiating intimacy and with intimacy in general, a loss of sexual fantasy life [35, 42] and a reduced sense of their masculine identity. [36, 74] Post treatment erectile dysfunction has been found to be a greater concern for prostate cancer patients than any other side effects. [31, 45]

It has been shown that sexual dysfunction can have a significant impact on the individual and his relationships. [75] Clark et al (2003) found that changes in sexual function resulting from prostate cancer treatment were linked to anxiety regarding intimacy, sexual performance and diminished desire and the overall impact of those changes on men’s relationships with women, including what has been described as an “absence of a sexual element in everyday interaction”. This may be more problematic for men who are not in a monogamous relationship. [43] Some men whose sexual ability has changed following prostate cancer treatment report they experience discomfort with social conversations about sex and a sense of loss related to sexual imaginings now diminished or absent as a result of their changed sexual self-image [27, 76] Fergus et al (2002) reported a participant described “imaginal interruptus” when sexual fantasy is interrupted by the realisation that the individual lacks the sexual capacity required in his fantasy. [20] Some men report that diminished desire and orgasmic pleasure are equal to erectile dysfunction in their sexual dissatisfaction. [38]

The association of sexual function with quality of life outcomes is mitigated by men’s level of sexual desire. Men who report low sexual function but more sexual desire have low scores on relevant quality of life measures but men with low function and low desire have higher quality of life scores. [39] Despite men reporting distress related to their changed sexual function following prostate cancer treatment, some studies suggest that the treatment-related side effects do not have an appreciable or enduring influence on men’s quality of life. [26, 38, 39] However, Dahn et al (2004) found a statistically significant relationship, between sexual function and quality of life in men with prostate cancer (n=91) and argues that dissimilar levels of sexual desire and sexual function will have an adverse affect on men’s quality of life. That is, men who may desire sexual
activity but lack the capability may experience frustration, embarrassment, disappointment and possibly relationship stress, all of which may impact his overall quality of life. [39] On the other hand, Bokhour et al (2001) found differently in their study of perceptions of the impact of erectile dysfunction on 48 men treated 12 to 24 months previously for early prostate cancer. These authors suggest that despite men incurring considerable sexual side effects following treatment, they report overall good quality of life and are generally pleased they have undergone treatment for prostate cancer. [43]

The impact on quality of life from changed sexual function after prostate cancer treatment may be dictated by several factors, such as pre treatment sexual function and desire, and the impact of those changes on quality of life. These different findings may in part be attributable to a positive adaptive response to altered quality of life resulting from ongoing sexual dysfunction, that is, a response shift. [47, 42, 81]

**Quality of Life: Psychological Wellbeing**

The diagnosis of prostate cancer can set in motion a series of potentially life changing stressors (e.g. changes in the individual’s roles and finances) over and above the disease specific issues. [77] Consideration of the financial implications of treatment modalities may not be the area of expertise for health professionals and referral to a qualified professional in that area can do much to ally some anxiety for patients and their families. Men commonly see themselves as the financial provider for the family and changes to this role may be yet another challenge for them to deal with as it impacts their psychological well-being. [81]

The impact of functional changes consequent to prostate cancer can have a negative psychological affect on feelings of sexuality, thus further contributing to reduced sexual function. [75, 77] Cliff and MacDonagh (2000) found almost 21% of men (n=135) reported some level of psychosocial distress after prostate cancer treatment [78] however, Wootten et al (2007) found just over 14% of men (n=167) in their study continued to report psychological distress. This difference in rates of mood disturbance may be attributed in part to disease stage, as men with advanced disease were included in Cliff and MacDonagh’s study but not in Wootten et al. [76]

Men may feel a sense of loss and long for the return of pre treatment feelings of arousal and sexual fantasies that are part of men’s everyday life, monogamous or otherwise. For men who are not sexually active prior to treatment, it has been shown that post-treatment their sense of loss may be equally as strong as that for sexually active men. [43]
Sexual disturbances have been found to be a major contributing factor in men’s difficulty adjusting to altered circumstances following prostate cancer treatment while the perception of social support has been reported as an important protective factor against adjustment difficulties. [76] Wootten et al (2007) reported that men appear to be problem-focused in their management of urinary problems, compared to an emotion-focussed approach to sexual dysfunction. The implication of this may be that patients are not receiving or assimilating adequate information about the practical management of sexual dysfunction which might allow them to be more problem-focused. [76]

Psychological distress may occur after prostate cancer as a result of functional changes and the associated negative impact on feelings of sexuality, potentially resulting in a further decrease in sexual function. [75, 77] Men report a grief response to their feeling of diminishing physical strength following treatment and the loss of sexual function for some men, while significantly affecting their sexual quality of life, can also result in feelings of grief. [35] For many men it was not the lost sexual activity resulting from treatment but the loss of the capacity for sexual activity that men found so difficult – men not sexually active prior to treatment reported similar distress to men who had been sexually active prior to treatment. [42, 43]

Couper et al (2006) reported psychological changes in both men and their partners over a 6 month period in a prospective, observational study of 103 couples where the men had been diagnosed with prostate cancer, either localised or advanced. Interestingly, partners were more distressed at diagnosis than at the second measurement time point of 6 months after diagnosis, with men experiencing the opposite effect, being less distressed at diagnosis and more distressed at 6 months follow-up. The patterns of change did not appear to be influenced by disease stage. The influence of time from diagnosis and treatment was not factored into this study so it is possible that findings would change over a longer time (longer than 6 months). While previous research has identified similarly higher levels of distress in partners than in patients [78], Couper et al (2006) caution that gender differences have been shown to exist in the reporting of symptoms of anxiety and depression, with women being more likely to report symptoms of anxiety and depression than men. [79]

An individual’s underlying disposition may contribute to his quality of life and psychological satisfaction. Men who are generally more optimistic in their outlook on life may view difficulties as less of a problem than more pessimistic individuals, and this would influence his view of himself in the world, informing strategies available to him to overcome difficulties. This individual variable needs to be factored in when assessing men’s adjustment to their situation following treatment for prostate cancer. [80]
Self Perception and Self-Esteem

Bokhour et al (2001) report that sexuality is an integral part of men’s lives and how they see themselves despite changes in sexual function. In the presence of their sexual dysfunction men recalibrate their view of themselves as sexual beings. [43] Side effects of prostate cancer treatments may threaten a man’s masculinity, his identity as a man, worker, partner and family member, as well as negatively impacting on his self esteem. [36, 81, 82] There are many discourses that are one’s life (work, family etc), and men diagnosed and treated for prostate cancer become members of another discourse, the medical discourse. This brings with it the identity of the patient, which may be unchartered territory for many men, and under the banner of which men may feel powerless to varying degrees, providing a further potential assault on their self-esteem. Bokhour et al (2007) argues that after prostate cancer treatment men may “re-collage” their identity by reinforcing their position within other discourses important to them. [82]

Compared to men in the general population, men who are treated for prostate cancer by surgery or radiotherapy tend to report lower levels of sexual intimacy and sexual confidence, anxiety about sexual interaction and difficulties associated with urinary control. [36] Undesirable changes in sexual function may impact on a man’s sense of masculinity and are likely to be associated with lower scores on masculine self esteem measures. [36, 42] Fergus et al (2002) describe urinary continence and erectile function as being “intimately tied to dominant notions of masculinity” which when affected by prostate cancer treatment provide a challenge to men’s sense of masculinity and self-esteem. [42, 82]

Boehmer and Babayan (2004) interviewed 21 men, diagnosed with prostate cancer prior to treatment, and 13 women identified by the men as a “trusted other”. The men’s perception was that treatment-induced erectile dysfunction in some way would compromise their masculinity. Compared to the men who reported good sexual function prior to diagnosis, men already experiencing erectile problems at diagnosis or for whom sex was not of great importance were less concerned about post treatment dysfunction.[82]

After prostate cancer treatment many patients describe themselves as “changed” or no longer “whole” men. The sense of diminished masculinity or the humiliation of having lost control of some bodily functions can have a negative effect on self esteem in some men. [34] In the Boehmer and Babayan (2004) study, the researchers focused on the reaction of men and their “trusted other” (i.e. female partner) to the possible loss of sexual function. Female partners saw sexual activity as only a part of their overall relationship and were not as concerned about erectile dysfunction as men but were concerned about their partner’s concerns regarding the impact of treatment on erectile
function and subsequently on the relationship. Men were aware that sexual function was not as important to their partners as it was to them, however, both men and women expressed concerns about the effect of impotency on their relationship. Both men and women in this study tended to consider interventions to achieve erections rather than adapting their sexual repertoire to include sexual activity which did not require an erection. [83]

Men with post treatment urinary incontinence that interferes with a return to more physical activity may experience lowered self esteem due to the incontinence. If, in lieu of more physical work, men take on less physical roles identified by some as “woman’s work” their self esteem may be further adversely affected. [74] It has been shown that even in the presence of high levels of both urinary and sexual dysfunction men are more likely to report more dissatisfaction associated with sexual dysfunction as well as lower self-esteem. [76].

Men with prostate cancer induced sexual dysfunction may have difficulty relating to women, particularly in social situations, because of an associated loss of self confidence. [43, 74]

Prostate cancer treatment can affect many aspects of men’s lives including their roles within the family and the work-place, sporting hobbies and social activities, all of which can impact on self confidence. Managing the changes in their life can be a challenge for some men.

Coping With Post-Treatment Changes

Radical prostatectomy patients, despite reporting reduced quality of life due to urinary and sexual dysfunction, reported trouble related to the dysfunctions as only a “small” problem. Smith et al (2009) found that although 12% of men who had undergone radical prostatectomy reported prolonged incontinence at 3 years post-treatment, less than 50% of the sample described this as a “small” problem. In the same study ongoing erectile dysfunction was also described as a “small” problem by 48%. [21, 84]

Generally, patients who undergo non nerve sparing prostatectomy report worse sexual outcomes than those who have undergone a nerve sparing procedure. However, Smith et al (2009) found that the former patients reported being less bothered by loss of sexual function than men who had undergone the nerve sparing operation. The authors suggest this may be due to the fact that men undergoing nerve sparing surgery have a higher expectation of regaining sexual function and failure to achieve this may be more of a problem for those individuals. In some men, unrealistically high expectations of post treatment function may be a consequence of poorly presented information being provided or information given being based on data from high volume surgeons and centres of
excellence, not necessarily reflective of the post treatment outcomes in the broader community. [31] It needs also to be noted that not all information given relating to sensitive issues is perceived or remembered accurately, instead patients’ high unrealistic expectations may be ‘remembered’ as fact more often.

It is also suggested that some men may experience a phenomenon called response shift and accept the changes in their sexual function by accommodating their changed health related quality of life. [21] Response shift may occur as the result of a positive adaptive reaction to altered health-related quality of life either by changing one’s concept of quality of life or reprioritising specific quality of life domains or personal standards. [47]. In the presence of the life disruption of ongoing sexual dysfunction men may re-evaluate their narrative to enable them to carry on with their life with the least amount of distress.[42, 82]

Fergus et al (2002) reported that men start using coping strategies prior to treatment by focusing on preventing sexual dysfunction post-treatment, or by endeavouring to adapt to that dysfunction. However they suggest the latter is more a consequence of wanting to overcome the sense of lost masculine identity associated with the change in function rather than the desire for sexual pleasure. The authors also report that men used coping strategies to “contain the loss” such as humour, whereby redefining the significance of the changed function and embracing sexual activity other than penetrative intercourse to express affection. [42].

Men also tended to adapt to their changed sexual function by understanding that they were not responsible for this outcome but rather these changes were a result of treatment. Some also accepted the unwelcome side effects of their treatment for prostate cancer as being a trade off for being free of the cancer whereby their surviving prostate cancer was more important than preserving their erectile function [42, 74]. This strategy can be challenged by subsequent disease progression. For some men, the significant cancer treatment-induced changes in sexual function are more acceptable when sexual function is reappraised in terms of no longer being necessary because they do not wish to father more children.[74]

Men may use normalizing strategies to interpret changed sexual function following treatment as normal and not affecting their masculine identity. Men’s age, other health problems or their partner’s response were helpful in normalizing erectile dysfunction. Men may also balance hope for a return to normal function with what they regard as a temporary acceptance of function as it now is [74, 85].

Men also described engaging in hobbies and work as a method of distraction from their altered quality of life after prostate cancer treatment. However, it is important to note that since physical
activity may induce urinary leakage its use as a distraction technique may be limited. [35, 42, 86, 87]

Two distinct coping strategies, emotion-focused and problem-focused, have been identified as those which individuals use to mitigate stress. [88] Emotion-focused coping occurs when the individual tries to manage stressful emotions and uses strategies such as distancing, self-control, escape-avoidance and positive reappraisal. Problem-focused coping is used when trying to manage one’s environment or external factors and includes seeking help and being task-oriented to achieve a satisfactory level of control. [77] Wootten et al (2007) reported that men appear to be predominantly problem-focussed in their management of urinary side-effects whilst they tend to use an emotion-focussed approach to manage sexual dysfunction. The implication may be that patients are not receiving adequate information concerning amelioration of, or feel uncomfortable about practical management of, sexual dysfunction. [76]

Studies show that men with better quality of life scores are more likely to minimise their illness-related stress compared to those with poorer quality of life scores [77]. Further, men who experience ongoing urinary incontinence seem better able to cope with sexual changes following prostate cancer treatment [42], perhaps because they avoid sexual activity [80] or experience a response shift to accommodate their changed quality of life. [21]

Men’s response to changed sexual and urinary function after prostate cancer varies between individuals, ranging from tolerance to actively seeking to manage the changed functions and gain a feeling of control.[35] Maintaining a sense of control over one’s body, or life in general, by continuing to go about daily activities, such as work and other routines, can be very important to some men when adjusting to life after treatment for prostate cancer. [89]

Men may adapt to sexual dysfunction and diminished sexual intimacy and sexual confidence resulting from treatment by over-compensating in other positive aspects of their life such as high levels of marital affection. Clark et al (2003) found that men treated with radical prostatectomy or radiotherapy reported marital affection scores similar to those of men without cancer[43]. Better quality of life was more likely to be reported in men who experienced good social support and had higher self esteem. [74, 87]

Some men coped with the diagnosis of prostate cancer by trying to adjust to their changed life situation and see the adjustment process as a step towards a new life. Three post-treatment adjustment strategies were identified in the study by Hedestig (2005): i) living in the present, ii) focusing on the curative intent of their treatment, and iii) reappraising the importance of aspects of their life which would improve their quality of life. [35] Hervouet et al (2005) and others report
men found it helpful to tell others of their diagnosis and to plan for the future. Since they hoped to be cancer-free, these strategies assisted these men in dealing with their disease related anxiety and concerns. Many men however coped by not divulging their concerns to others preferring to keep them to themselves [35, 82, 86]

Living after treatment for prostate cancer may involve adjusting to a “new fractured identity” [82] and the discordance of a life affected by illness [90] and men need to reframe their lives, including the changes and losses illness has wrought, within the illness narrative.

**Effect of Diagnosis and Treatment on Relationships**

The consequences of treatment for prostate cancer such as urinary, sexual and bowel dysfunction can negatively impact men not only physically but also influence their intimate and social relationships with men and with women, their sexual fantasies and their perception of themselves as men. [43]. As noted in studies with women with breast cancer and their partners, there can be a major personal cost for men diagnosed and treated for prostate cancer with a flow-on effect to partners [43, 79].

The changes in sexual function experienced by men following prostate cancer inevitably affect their partner. Without the ability to engage in penetrative intercourse, some men limit or cease other forms of intimacy, such as touch, as it is seen as a form of intimacy which is incomplete unless it leads to penetrative intercourse. As a consequence of diminished sexual contact and intimacy such men and their partners may experience difficulties in their relationship such as a sense of distancing and alienation. [43] Reduced sexual confidence related to satisfying their partner or being satisfied themselves may cause men to avoid or limit attempts at intimacy of any kind including sexual intimacy. [43, 91]

Couples’ successful adjustment to the changes in their intimate relationships brought about by prostate cancer treatment may be more dependent on how well the couple related verbally and sexually prior to the diagnosis of prostate cancer and how well they integrate the cancer into their lives rather than seeing disease related problems.[92] Couples who can communicate about many issues including the disease related side-effects may be better able to accept changes in their relationship resulting from a cancer diagnosis and work together to adjust to those changes.
Information Needs

Many types of information are necessary for the better adjustment and management of life following treatments for prostate cancer. Not all information is found in pamphlets, books, and on the internet. Help organisations such as support groups, psychologists, counsellors, and recovered patients all have a wealth of information and strategies to impart. [90 91]

The need to be confident, complying and vigilant with treatment regimes once decided, can impose a high level of strain on most patients and their families. Psychosocial clinical practice guidelines, providing evidence-based procedures to assist in improving cancer associated distress, are now available in Australia and the United States of America to guide the care of people affected by cancer. However, as yet these psychosocial guidelines have not been widely implemented as part of standard clinical practice. [66] Patients and their families may not be aware of such support and even when offered such support may not consider psychosocial issues an essential part of the immediate treatment plan. Thus the valuable information available from professionals in such clinics is not accessed. Possible quality of life issues long term may be ignored until treatments are complete and some degree of normalcy re-established. By this time valuable opportunities for implementing practices to ameliorate difficulties both physically and psychologically may have passed.[93, 94]

It has been shown that patients who lack information about their condition and its treatment with its possible side effects, or feel overwhelmed by too much ‘jargon’ information, can feel disappointed, fearful and angry. [95, 96], [69] This frame of mind can impede recovery and block access to receiving valuable strategies for improvement.

Provision of appropriate information regarding prostate cancer, possible treatments, side-effects, recovery rates, recovery strategies, likelihood of disease progression, all have been shown to assist men in adjusting to post treatment side effects. [89] Knowing how much information to give, in which form, at what depth, in which sensitive culturally appropriate way at what time is an highly specialised skill. Merely dispensing information is no indication that it has been heard, understood in context, or will be remembered. Men who feel they were given the information necessary for them to make an informed treatment decision are less likely to feel frustrated with their doctor or angry about side effects. [89] Conversely, men who feel confused and overwhelmed by information may later regret the treatment option they chose which may result in difficulties adjusting to the post-treatment functional changes. [97]

Steginga et al (2001) found that for 25% of participants in their study of supportive care needs in 206 men with prostate cancer, there was a moderate to high need for information related to the
Some men report they were unaware of the side effects of treatment. This may be a consequence of appropriate information not being given, or the recognised phenomenon of denial following a diagnosis of cancer. However high levels of anxiety, often present at the time information is given, can impact negatively on the patients’ understanding of what is said and on their ability to process, retain and recall that information in context at a later date. Hence the statement by the patient that he was never told such information may not be in fact true but appears true to him, since he did not retain that information neither can he recall it.

Patients have been found to be less satisfied with doctor-patient communication relating to information if they experience long term side effects of treatment and feel they did not understand the potential for side effects or their impact on quality of life. Again at times of great stress and anxiety the assimilation of information can be seriously compromised, Hence effective ways of disseminating information particularly that related to choosing a treatment option, and being reassured that the patient, his family and/or care-giver accurately understands that information, is vital. Age, cultural and educationally appropriate written and visual information able to be kept by the patient, has been shown to prevent various misconceptions down the track. In this context a decision aid booklet can be a valuable non-directive tool to help patients take a more active role in important clinical decisions. Decision aids are designed to help people make deliberate choices between options, including the status quo, by providing information on options and outcomes relevant to a patient’s health. They typically contain relevant evidence-based information about options and outcomes very clearly in both written and graphical form, and lead patients through a process of clarifying their values and weighing up the pros and cons of the options prior to decision-making.

Patients often report that their need for information does not cease when their contact with their treatment team ends. In fact it is often at this time that more doubts and questions arise about their condition. In some cases the longer some men survive without resolution of incapacitating side effects the less they feel they were well prepared or given the right information prior to treatment and consequently may not have chosen the right treatment option. Access to on-going information may alleviate this feeling and resentment.

Up-dating appropriate information regarding their present state of recovery and addressing current needs can be difficult and time consuming. Knowing how to access the information and knowing which organisations, websites etc are reliable vehicles to deliver that information can be
overwhelming. Joining a support group for sufferers of prostate cancer can really be of help at this time. The group has access to current trends and understanding of treatments and strategies for enhancing quality of life. [101].

There is evidence that resourcing as much information as possible does not necessarily equate with being better informed, since the quality of some information may be suspect or out of date which may lead to ambiguity, confusion, unrealistic expectations, and greater dissatisfaction with the current situation. [97] Recourse to general practitioners and other health practitioners is still the most reliable way to access accurate information.

While patients’ concerns have remained essentially unchanged for over a decade[102, 103], the quantity and quality of information now available has changed since that time, with new techniques and technologies and evidenced based treatments readily available on-line for health professionals making the provision of up to date information by clinicians, more accessible. [102, 103]

Feldman-Stewart et al (2009) surveyed 2 groups of men diagnosed with prostate cancer within the previous 2 years. One group was surveyed 10 years prior to the other group (1996, n=38 and 2005, n=130). The authors found that men newly diagnosed with prostate cancer want to know i) what the options are if the initial treatment is not successful and ii) if the prostate cancer is not treated will the patient die from it, how fast will it spread and how will the patient be affected? Feldman-Steward et al encourage patients to be given take-home information to not only increase their knowledge base, but also to refer to as questions arise or issues need clarification. Take home information also allows the patient to take in information at a rate that suits his needs. [103]

Despite wide access to the Internet, research has shown that doctors continue to be the main source of information for patients. [97] Men who feel well informed tend to be more satisfied with their interactions with their doctor [97] It has been shown that patient satisfaction with doctor-provided information diminishes over time if men continue to experience enduring, but initially unexpected, side effects of prostate cancer treatment. [97]

Men can often find it difficult to ask for information or practical help in managing their sexual dysfunction. Knowing when and how to offer appropriate information is to some extent dependent on the man’s willingness to ask for such help, particularly when formal contact with their treatment team has stopped. Offering such information well in advance may not be sufficient since each situation is unique and needs to be dealt with in the context of all variables at that time. Only so much can be anticipated in advance and remembered when needed. Merely providing appropriate information at some time is not as efficient as providing that information at the time it is actually needed. [76]
Many men and their partners, may not be used to discussing personal and sensitive issues such as sexual functioning even between themselves and may find it difficult to address sexual side effects in any detail with health professionals. Treatment and support for changed sexual function may be further compromised if health professionals are uncomfortable with in depth discussion of sexual side effects and their management. However this should seldom be the case since referral to experts in the field of sexual functioning particularly related to gender cancers, is always an option. [40, 76]

Summary

This research focuses on the sexual adjustment and self-perception of men following treatment for prostate cancer.

Many men can be tested for prostate cancer in the absence of any symptoms and there is currently varying opinions about whether aggressive treatment is appropriate in some men with very early disease. There are a number of treatments available for localised prostate cancer which are curative in intent but can result in substantial morbidity due to urinary, bowel and sexual side effects. There is a substantial amount of information to absorb in order to ultimately decide on the most appropriate treatment option. The decision is often made more difficult when taking into account the relevant possible side effects of each option since there are inconsistencies in reported rates of side effects and their severity. These inconsistencies may be attributed to methodological issues or discrepancies in reporting between doctors and patients.

In the context of a prostate cancer diagnosis and sequelae, obtaining the right amount of appropriate information for their particular needs can be quite a challenge for men and can be an ongoing process even after treatment as men endeavour to adjust to their changed life.

The functional changes associated with prostate cancer may be short term or chronic. Men who experience side effects of treatment report varied impact on their quality of life. This may be due to individual differences in men or because, despite some men experiencing significant side effects, they do not perceive them as a health-related problem.

Changes in urinary, bowel and erectile function can impact on sexual functions such as desire and orgasm, and all may contribute to a diminished quality of life and some deterioration in personal relationships. The impact of these functional changes can have a negative psychological impact on a man’s sense of his sexuality and may cause further problems with sexual function.
There are a variety of treatments available for the treatment of erectile/sexual dysfunction, however many men do not respond to oral medications and may find injection therapy or mechanical devices either too invasive, too awkward to use, or both. In the absence of good information and support, many couples stop using erectile aids (although this is not the only reason their use is stopped) and for some, sexual activity and even displays of affection cease in the absence of erections.

Obtaining information and support for sexual dysfunction may be quite challenging for men and their health care team. More patient-specific information and appropriate clinical and psychosocial support is required to assist men in obtaining sufficient and relevant information to make an informed treatment decision, undergo that treatment, adjust to the changes in their life and limit the impact of those changes on their quality of life. With all these facilities in place there is still the issue of encouraging men and their partners to actively seek such help and information and actively engage in using it in the recovery process.

The changes in urinary, bowel and sexual function men experience following treatment for prostate cancer may impact on a man’s masculine identity as well as other identities such as a partner or worker, thus having the potential to lower self esteem. Men may use a number of different strategies to cope with their changed lives such as reconstructing their self-identity or undergoing a response shift whereby they reprioritise previously important aspects of their life, such as erectile function, in order to adjust to life after prostate cancer treatment.

**Study Aims**

This study aims to explore the experiences of men previously diagnosed with, and treated for, prostate cancer, particularly with regard to their sexual function, intimate relationships, sense of masculinity and overall self-perception.

The ultimate goal of the current research is to improve understanding of the adjustment process men undergo in the area of sexuality and self perception following their prostate cancer treatment.

**Justification**

All treatments for prostate cancer are known to result in possible short-term or more enduring side-effects which may have an effect on a man’s relationships [27] and quality of life [26]. Despite the growing body of literature which highlights the potential for significant side-effects following treatment, there is minimal research available relating to the experience of living with treatment-
related side-effects and the resulting disruptions to quality of life and relationships which may emerge.

To redress the currently limited research further investigation of men’s experience of treatment induced side-effects is required to gain a greater understanding of these experiences thereby informing the development of tailored interventions to assist men in coping with changes in sexual function and activity, as well as self-identity, after treatment.

**Significance**

It is expected that by a timely provision of information and support to men newly diagnosed with prostate cancer, they will have a better understanding of the potential impact of side effects, particularly relating to sexual function, on their personal and social relationships, their body image, self esteem and sexuality.

It has been found that patients continue to need information even after the cessation of the acute stage of treatment at which time contact with the treatment team ends. [100] It may be at this time that they experience further concerns about their condition [36] and in some instances the longer some men live with ongoing incapacitating side effects the less they feel they were well prepared or given the right information prior to treatment and may therefore question their choice of treatment. [78] Access to on-going information may alleviate this feeling and resentment.

By identifying the issues early and providing relevant information and support, men in a similar situation in the future will be better equipped to adjust to a new normal sexual function that will emerge as a result of their treatment.
CHAPTER 2

METHOD

Ethical Considerations

Ethics approval was obtained from the University of Sydney and Concord Repatriation General Hospital (see Appendices 1 and 2).

To maintain confidentiality, all participants were given a code number so that their name would not appear on the questionnaire or computer database. Responses were held in strict confidence and were not disclosed to any medical staff treating the patient. Questionnaires were kept in a locked cabinet to which only the investigator had access. A list of patient names linked to their IDs have been kept on a separate sheet, stored in a separate filing cabinet, in case clarification is sought on any issues. In accordance with the National Statement on the Ethical Conduct in Research Involving Humans issued by the National Health and Medical Research Council (2002), all questionnaires will be kept for seven years and then disposed of by shredding.

The possibility was considered that some patients may experience some issues or concerns as a consequence of their participation in the study as it was dealing with a very personal and sensitive subject. A reference to that effect was included in the Information sheet, with a suggestion that they contact the investigators or Ethics Officer if they had any issues or concerns. No patients contacted the researcher during the study to report increased distress related to their participation in either the questionnaire’s completion or the interview.

Participants

Eligible participants were those who had been treated for prostate cancer within the past 5 years. Excluded from participation were males younger than 18 years, with insufficient English to understand and give informed consent, complete the questionnaire or participate in the interview and having concurrent malignancy (of another type) and/or a psychiatric disorder (e.g. psychotic illness). For further information regarding participants please refer to Table 7, “Demographic characteristics of participants” on page 61.

Previous studies have shown that sample sizes of 20 participants are sufficient to reach theoretical saturation in qualitative studies (Guest, Bunce and Johnson, 2006), and to provide clear trends on quantitative measures. In the current study, data saturation (i.e. a point at which no new themes emerge from the data) was achieved at the sample size of 21.
Study Design

Most of the current findings in prostate cancer treatment side-effects research relate to their incidence rather than men’s experience of living with those side-effects, their adjustment to functional changes and the impact those changes have on self-perception and personal relationships.

The current study employs a predominantly qualitative approach supplemented by quantitative measurements. Qualitative methods have the potential to capture wide-ranging information about responses, thoughts and feelings about particular issues which may not be targeted by quantitative measures and gives more meaning to the data than what is obtained by quantitative measures alone. [103] The use of both qualitative and quantitative methods results in a more comprehensive analysis of the impact of side-effects than may have resulted by using one method only. Further comments regarding the use of both quantitative and qualitative research methods are found in Chapter 5, Limitations and Strengths of the Study pp. 141-3.

Recruitment process

An advertisement was placed in the newsletter of the Concord Hospital Prostate Cancer Support Group inviting men, diagnosed and treated for prostate cancer in the last five years, to participate in the study. Men interested in participating were asked to call the number provided in the advertisement to register their interest. During that phone call the researcher screened for eligibility (participants were required to be male, over 18 years of age, fluent in reading and speaking English and less than five years since treatment) and explained the study in more detail to eligible participants.

It was anticipated that twenty to thirty men would be recruited to the study. It was expected that both early and advanced disease and the three main types of treatment (surgery, radiotherapy including brachytherapy and hormone treatment) would be represented.

Procedure

During the screening phone call it was explained to the men that they could choose to complete a questionnaire and/or participate in a face-to-face interview. Potential participants at that time were informed of the confidential nature of their participation and responses, and of their option to withdraw from the study at any time without any repercussion. They were also advised that the
questionnaire would take approximately 35 minutes to complete and the interview was expected to take between 30 minutes to an hour.

At the time of the initial phone call the researcher obtained verbal consent to complete the questionnaires and consenting participants were then mailed a package containing the study information sheet, consent form and the questionnaire. Participants were asked to return the signed consent form and completed questionnaire within a week of receiving them in the reply-paid envelope provided. Men who agreed to participate but who failed to return the signed consent form and the questionnaire within the established time frame were to be telephoned as a prompt however all participants responded within the time frame as did the 3 men who opted not to proceed thereafter.

Measures

The questionnaire sent to participants was comprised of a number of validated measures described below. Cronbach’s alphas to assess the internal consistency of the measures used in the study sample were run using SPSS 15.0. Customary ranges for consistency were used: acceptable (0.60 to 0.69), good (0.70 and 0.79) and high (0.80 to 1.0) levels.

*Functional Assessment of Cancer Therapy - Prostate (FACT-P) scale (Esper et al., 1997)*

Quality of life was assessed as it represents a key personal issue for patients receiving cancer treatment and incorporates physical and psychosocial wellbeing consequential to both prostate cancer diagnosis and its treatment. The FACT-P is a well-validated multidimensional measure of quality of life with subscales assessing: Physical Wellbeing (PWB; 7 items), the Social/Family Wellbeing (SWB; 7 items), Emotional Wellbeing (EWB; 6 items), Functional Wellbeing (FWB; 7 items) and Prostate Cancer (PCS; 12 items) subscales. The FACT-P Total Score is the sum of all 5 subscales. Each item is rated on a 0 to 4 Likert type scale and then combined to produce subscale scores for each domain and a global QOL score. The FACT-P Total score ranges from 0-156, with higher scores indicating better outcomes.

The inventory has been used extensively in the prostate cancer population (e.g. Wei et al., 2002) and it appears sensitive to changes in the patient’s clinical status over time (Esper et al., 1997). The FACT-P has good internal consistency with Cronbach’s alpha coefficient of 0.89 for the total score and subscale Cronbach’s alpha coefficients ranging from 0.62 to 0.83 (see Table 1).
Using the current sample, the Cronbach’s alpha was high for Social/Family Wellbeing (SWB, 0.85) and Functional Wellbeing (FWB, 0.90). Good internal consistency was found for the Prostate Cancer Subscale (PCS) and FACT-P Total Score (Cronbach’s alpha= 0.74 and 0.74). The internal reliability for the Emotional Wellbeing (EWB) subscale and FACT-G Total Score was acceptable (Cronbach’s alpha=0.69 and 0.64). The Cronbach’s alpha coefficient in this sample for the PWB subscale (0.58) reflected relatively poor internal consistency. Using the SPSS function “scale mean if item deleted”, the reduction of items did not show any significant increase in the alpha coefficient.

*Functional Assessment of Incontinence Therapy – Urinary symptoms (FAIT-U) subscale* (Cella D, http://www.facit.org)

FAIT-U is a symptom-specific subscale measuring concerns related to urinary incontinence. Although to date there is no documented validation of this tool, the FAIT-U belongs to the FACIT suite of scales which has rigorous protocols for developing questionnaires. The FAIT-U is the sum of all 4 FACT wellbeing subscale scores (see previous measure) plus the Urinary Incontinence Subscale (UIS) score. The total score ranges from 0-152, with higher scores indicating better outcomes.

In the current sample, the internal consistency of UIS was good (Cronbach’s alpha =0.75) and FAIT-U Total Score was acceptable (Cronbach’s alpha=0.69).

<table>
<thead>
<tr>
<th>Scale/subscale</th>
<th>Undimensionality</th>
<th>Cronbach’s alpha</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>(Internal consistency)</td>
<td>Current study</td>
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<tr>
<td>Social/Family Wellbeing</td>
<td>High</td>
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<tr>
<td>Functional Wellbeing</td>
<td>High</td>
<td>0.90</td>
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<tr>
<td>Prostate Cancer Subscale</td>
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<tr>
<td>FACT-P Total Score</td>
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<td>Emotional Wellbeing</td>
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<tr>
<td>FAIT-U Total Score*</td>
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<tr>
<td>Physical Wellbeing</td>
<td>Poor</td>
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*As noted in text, there is currently no documented validation for FAIT-U scale
The Expanded Prostate Cancer Index Composite (EPIC) (Wei et al., 2000)

The Expanded Prostate Cancer Index Composite (EPIC) is a robust prostate cancer health-related quality of life instrument measuring a broad spectrum of urinary, bowel, sexual and hormonal symptoms (Wei et al., 2000). It was selected to assess the long-term impact of prostate cancer treatments and associated toxicities on these specific quality of life domains, which are not comprehensively assessed by the FACT-P. The EPIC was developed from the UCLA Prostate Cancer Index health related quality of life measure and includes items assessing irritative and obstructive urinary symptoms, function-related bother, effects of androgen deprivation and related bother. The Urinary Domain is comprised of two subscales, Urinary Incontinence and Urinary Irritative/Oblstructive Symptoms. The responses for each item are first standardized to a 0 to 100 scale, and then summed to generate domain summary scores. Higher scores represent better health-related Quality of Life.

Although the longer form of EPIC was used in the battery of questionnaires, only the 26 items which comprise the EPIC SF26 were scored. Responses to those items and the remaining unscored items are described in the Results section of this document.

Internal consistency for EPIC urinary, bowel, sexual, and hormonal subscales are high (Cronbach’s Alpha > 0.81, Wei et al., 2000). Cronbach’s alpha coefficients for the EPIC HRQOL Domains in the current study are reported in Table 2 below. In the current study the Cronbach’s alpha for Urinary Incontinence subscale and Sexual domain were high (0.88 and 0.93 respectively). Internal consistency for the Urinary Irritative/Oblstructive Symptoms subscale was poor (Cronbach’s alpha =0.55).

TABLE 2 Reliability of the Expanded Prostate Cancer Index Composite (EPIC-26) in the current study and in the validation study (Wei et al., 2000)

<table>
<thead>
<tr>
<th>HRQOL Domain Summary Score</th>
<th>Undimensionality (Internal consistency)</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Current study</td>
<td>Current study</td>
</tr>
<tr>
<td>Urinary Incontinence</td>
<td>High</td>
<td>0.88</td>
</tr>
<tr>
<td>Sexual</td>
<td>High</td>
<td>0.93</td>
</tr>
<tr>
<td>Hormonal</td>
<td>Good</td>
<td>0.72</td>
</tr>
<tr>
<td>Bowel</td>
<td>Acceptable</td>
<td>0.66</td>
</tr>
<tr>
<td>Urinary Irritative/Oblstructive Symptoms</td>
<td>Poor</td>
<td>0.55</td>
</tr>
</tbody>
</table>
**Men’s Sexual Self-Schema scale (Andersen et al., 1999)**

Men’s Sexual Self-Schema is an unobtrusive measure assessing sexually relevant cognitive domains. The schema arises from previous sexual experience, is evident in their present sexual behaviour and impacts on sexual experiences in the future (Andersen et al., 1999). It consists of 3 dimensions: passionate-loving, powerful-aggressive, and open-minded – liberal traits. The scale has a discrete and unobtrusive item format that is not vulnerable to the types of participation bias and measurement errors seen in other sexuality methodologies and measures. The internal consistency for the full scale and each factor is adequate to desirable (full scale: Cronbach’s alpha=0.86; Factor 1: Cronbach’s alpha = 0.89; Factor 2: Cronbach’s alpha = 0.78; and Factor 3: Cronbach’s alpha = 0.65). Test-retest reliability (9 weeks) was 0.81, reflecting the stable characteristic of individual difference measures. The item ratings for the undergraduates and older men were identical or differ by less than 1 point (<0.75), indicating generalisability of the sexual self-schema construct in older male populations. The Men’s Sexual Self-Schema Scale has convergent yet incremental validity with other individual difference approaches, including measures of general relevance (e.g., self-esteem), as well as measures of specific relevance to sexuality (e.g., extroversion or neuroticism), (Andersen et al., 1999).

Men are described along a continuum from sexually “schematic” (high scorers) to sexually “aschematic” (low scorers). In other words, higher ratings indicate greater descriptive relevance, with lower ratings being not at all descriptive of a sexual man (Andersen et al, 1999).

**TABLE 3  Reliability of the Men’s Sexual Self-Schema Scale (MSS) in the current study and in the validation study (Andersen et al., 1999)**

<table>
<thead>
<tr>
<th>MSS Scale</th>
<th>Unidimensionality (Internal consistency)</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Current study</td>
<td>Current study</td>
</tr>
<tr>
<td>Factor 1: Passionate-Loving</td>
<td>Good</td>
<td>0.76</td>
</tr>
<tr>
<td>Factor 2: Powerful-Aggressive</td>
<td>Good</td>
<td>0.76</td>
</tr>
<tr>
<td>Factor 3: Open-Minded-Liberal</td>
<td>Acceptable</td>
<td>0.66</td>
</tr>
<tr>
<td>Total Score</td>
<td>Acceptable</td>
<td>0.60</td>
</tr>
</tbody>
</table>
**Male Sexual Health Questionnaire (MSHQ) scale (Rosen et al., 2004)**

As sexual function is known to be a fundamental aspect of an individual’s quality of life and sexual problems can contribute to diminished life satisfaction, mood and relationship quality (Rosen et al., 2004), the Male Sexual Health Questionnaire (MSHQ) was included to assess the key domains of sexual function and satisfaction in aging men with urogenital and sexual health concerns. The MSHQ Likert-type scale is comprised of 3 subscales: ejaculation (7 items), sexual and relationship satisfaction (5 items) and erection (3 items). For the purposes of the current study, only the Ejaculation and Sexual satisfaction subscales were used, since the assessment of erectile function was assessed within the EPIC scale. The relevant items for the two subscales used in the current study are readily identified in the results section (page 70) and the MSHQ component of the questionnaire can be found in Appendix 5, Section 3 Part A, page 170.

This measure is designed to be culturally sensitive, age appropriate and unbiased regarding sexual preferences (Rosen et al., 2004). MSHQ is a psychometrically robust questionnaire, with all subscales having good internal consistency (ranging from 0.81 to 0.90) and test-retest reliability (ranging from 0.86 to 0.88). Data obtained from this questionnaire were analysed descriptively.

**Self-esteem and Relationship (SEAR) questionnaire (Cappelleri et al., 2004)**

As sexual dysfunction is a well known side-effect of prostate cancer treatments and sexual dysfunction can have a significant impact on one’s overall quality of life via its impact on self esteem and relationships, the SEAR was included to assess the effect of erectile disorders on sexual, relational and emotional wellbeing. The 14-item Likert-type scale, ranging from almost never/never (1) to almost always/always (5), includes two domains: Sexual Relationship (items 1-8) and Confidence (items 9-14). The Confidence domain is further subdivided into two subscales: Self-esteem (items 9-12) and Overall Relationship (items 13 and 14). The SEAR component of the questionnaire can be found in Appendix 5, Section 3 Part B, page 172.

The scale possesses strong psychometric properties that support its reliability and validity for measuring sexual relationship, confidence, and self-esteem in men with erectile dysfunction (Cappelleri et al., 2004). Questions 8 and 11 are reverse scored. Each domain score, subscale score and overall score is transformed onto a 0-100 scale, with a higher score identifying a more favourable response.
The internal consistency reliability for each of the Sexual Relationship domain, Confidence domain, Overall Relationship subscale and Total score was high and the Self-Esteem subscale demonstrated good internal consistency using Cronbach’s alpha analysis.

**TABLE 4**  Reliability of the Self-esteem and Relationship (SEAR) questionnaire in the current study and in the validation study (Cappelleri et al., 2004)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Unidimensionality (Internal consistency)</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Current study</strong></td>
<td><strong>Current study</strong></td>
</tr>
<tr>
<td>Sexual Relationship</td>
<td>High</td>
<td>0.86</td>
</tr>
<tr>
<td>Confidence</td>
<td>High</td>
<td>0.84</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>Good</td>
<td>0.74</td>
</tr>
<tr>
<td>Overall Relationship</td>
<td>High</td>
<td>0.86</td>
</tr>
<tr>
<td>Total Score</td>
<td>High</td>
<td>0.91</td>
</tr>
</tbody>
</table>

_Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983)_

The HADS is a 4-point, 14-item self-assessment measure of emotional disturbance, with 2 sub-scales measuring sub-clinical and clinical levels of anxiety and depression among physically ill patients (Zigmond & Snaith., 1983). The HADS does not include any somatic items found in the usual psychiatric instruments assessing anxiety and depression, and this aptitude has been broadly confirmed in breast cancer by a factor analysis that found all items to load more strongly onto a psychological than somatic factor [104].

Subscale scores range from 0 (no distress) to 21 (maximum distress). A score for each subscale can be divided into three categories indicating the severity of depression or anxiety. Scores of 11 and higher indicate “probable” clinical cases of anxiety and depression, whilst scores of “possible” cases range from 8-10 and “non-cases” are indicated by a score of 7 or less. An Australian study investigating the diagnostic efficacy of HADS in early stage breast cancer patients found that these recommended cut off points may result in under-reporting of psychiatric morbidity in similar samples (Love, Kissane, Bloch & Clarke, 2002). In their sample, optimal accuracy of the scale (i.e. specificity and sensitivity) was achieved when the cut-off scores for the caseness were reduced to 5.
Therefore the current study used the cut-off score of 5 with the following subcategories: non-cases (0-5), subclinical (possible) cases (6-10), and clinical (probable) cases (11-21).

The HADS has been found to be a useful screening tool for both anxiety and depression in a cancer setting and with general population (Bjelland et al 2002 found 747 papers referring to HADS in Medline, ISAI and PsycINFO indexed journals to May 2000). Psychometric properties of the scale are found to be robust across a wide spectrum of populations. Bjelland et al (2002) found the HADS has good test-retest reliability and internal consistency reporting Cronbach’s alpha for the anxiety and depression subscales between 0.68 to 0.93 (anxiety) and.67 to 0.90 (depression). The psychometric robustness of the HADS inventory was confirmed in the current study, with both anxiety and depression subscales demonstrating Cronbach’s Alphas in the desirable range ($\alpha_{\text{Anxiety}} = 0.81$; $\alpha_{\text{Depression}} = 0.72$).

TABLE 5  Reliability of the Hospital Anxiety and Depression Scale (HADS) in the current study and in the validation study (Bjelland et al 2002)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Unidimensionality (Internal consistency)</th>
<th>Current study</th>
<th>Current study</th>
<th>Validation study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>High</td>
<td>0.81</td>
<td>0.68 to 0.93</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>Good</td>
<td>0.72</td>
<td>0.67 to 0.90</td>
<td></td>
</tr>
</tbody>
</table>

**Supportive Care Needs Survey Short Form 34 (SCNF-SF34) (Boyes et al, 2009)**

This 34-item needs assessment survey was selected to assess the perceived needs of patients with cancer (Boyes et al, 2009). SCNF-SF34 is a shorter version of the original 59-item instrument which has been developed and validated in Australia. This tool assesses unmet needs of adults with cancer in the following domains: a) psychological, b) health information, c) physical and daily living, d) patient care, and e) sexuality. Respondents are asked to indicate their level of need for help over the last month in relation to their cancer diagnosis and treatment using the following five response options (1 [No Need (Not applicable)], 2 [No Need (Satisfied)], 3 [Low Need], 4 [Moderate Need], 5 [High Need]).
All subscale domains have high internal consistency (Cronbach’s alpha ≥ 0.86 to 0.96) (Boyes et al., 2009). The original SCNS-SF34 has good convergent validity (Boyes et al, 2009). Subscale scores are obtained by summing the individual items, with higher scores indicating higher levels of need (CHERP, 2003).

In the current study there was high internal consistency in Psychological, Health Systems Information, and Daily Living domains. The Cronbach’s alpha for the Patient Care and Sexuality domains reflected good internal reliability.

**TABLE 6**  Reliability of the Supportive Care Needs Survey (SCNS-SF34 in the current study and in the validation study (Boyes et al, 2008)

<table>
<thead>
<tr>
<th>Domains</th>
<th>Unidimensionality (Internal consistency)</th>
<th>Cronbach’s alpha</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Current study</strong></td>
<td><strong>Current study</strong></td>
</tr>
<tr>
<td>Psychological</td>
<td>High</td>
<td>0.94</td>
</tr>
<tr>
<td>Health Systems Information</td>
<td>High</td>
<td>0.97</td>
</tr>
<tr>
<td>Daily Living</td>
<td>High</td>
<td>0.80</td>
</tr>
<tr>
<td>Patient Care and Support</td>
<td>Good</td>
<td>0.77</td>
</tr>
<tr>
<td>Sexuality</td>
<td>Good</td>
<td>0.78</td>
</tr>
</tbody>
</table>

**Semi-Structured Interviews**

The semi-structured interviews were designed by the researcher based on existing literature and researcher’s experience working with men diagnosed with prostate cancer over a period of ten years. Cognisant of the sensitive nature of the topics to be addressed in the interviews the researcher gave significant consideration to the interview questions so that they would encourage participants to disclose information as openly as possible regarding their continence status, sexual function and their intimate relationships, without coercion. The semi-structured interview format was adopted as this was thought to be the most likely way to elicit individual interviewee’s perception of their life after prostate cancer treatment. The interviewer had a varied professional relationship (as a nurse or a support group co-facilitator) with all but 2 of the 21 interviewees (these 2 men did not attend support group meetings but were on the group’s newsletter mailing list).
Following receipt of a participant’s signed consent form, the researcher telephoned the participant to arrange a convenient time for a semi-structured face-to-face interview. Twenty of the 21 semi-structured interviews were conducted by the (female) researcher in the “Quiet Room” in the Urology Department, Concord Hospital and one was conducted by the Associate Supervisor (also female) in the School of Psychology at the University of Sydney as that particular participant felt he knew the researcher too well from his ongoing care at Concord Hospital and thought he would feel more comfortable being interviewed by someone with whom he was not familiar. Each interview commenced with an introduction which was read to the participant thanking him for agreeing to participate and explaining again the aims of the study. The interviewer detailed the process of the interview which explained the need for all participants to be asked the same questions (some of which may not be seen as relevant to the individual). Participants were also reminded that the interview would be audio taped and that the interview could be stopped at any time. Interviewees were reassured throughout the interview that the information they provided would remain confidential and they would not be able to be identified.

The semi-structured interview included 14 questions (see Appendix 5) which covered: knowledge of treatment side effects prior to treatment, discussion of side effects before treatment, interest in sex and sexual activity prior to treatment and at the time of interview, changes in sexual activity (function) since treatment, management of changes in sexual activity post treatment, effects of treatment on quality of life, impact on existing relationship or on ability of single men to seek a relationship, coping strategies and information provision prior to treatment.

Following the interviews the participants were offered access, if they wished, to a Clinical Psychologist and if partner sexual issues had arisen as part of the interview, information was given regarding referral to the Female Sexual Medicine Clinic in the Department.

Data Analysis

Quantitative Data

All data analyses were conducted using the Statistical Package for the Social Science (SPSS) Version 15.0. Prior to conducting statistical analyses, the data set was closely inspected to assess the accuracy of input, plausibility of means and standard deviations, out-of-range values and missing values. This preliminary data inspection revealed that the pattern of missing data was random with less than twenty five percent of data missing. Consequently, missing values were estimated using group mean substitution as outlined by Tabachnik & Fiddell (1996). [105] Descriptive statistics
including the means, standard deviations, and percentages were used to describe the sample.

Qualitative Data

All interviews were conducted, audio-taped and transcribed by the researcher. The reliability of interview transcripts was checked against the original audio recordings for accuracy. The contents of interviews were repeatedly sorted, coded and compared, in line with a thematic analysis approach. In this report we have omitted word repetitions and speech hesitation such as “um” and “ah”. The presence of three consecutive dots (...) indicates a portion of the quote has been removed although in no circumstances was that done to change the meaning of a quote. Quotations from the interviews were used to illustrate a typical expression of a certain view shared by more than one participant or an important experience expressed by an individual participant.

The present study utilized a qualitative approach to investigate men’s experiences following prostate cancer treatment. Qualitative methods are well utilized when endeavouring to understand the significance and implications of peoples’ experiences of a specific phenomenon (Strauss & Corbin, 1998), as they produce detailed information about people’s responses, thoughts and emotions relating to specific events which quantitative methods may fail to capture. Qualitative data analysis is for the most part inductive, resulting in meaning to emerge from the data (Kuper, Reeves, & Levinson, 2008), in contrast to the hypothesis testing of quantitative methods.

As the present study sought to understand men’s sexual self-perception, thematic analysis, defined as a method for identifying, analysing and reporting patterns (themes) within the data, was chosen as the best method to analyse the data (Braun & Clarke, 2006). As outlined by Braun and Clarke (2006) there are six phases of thematic analysis: i) familiarisation with the data, ii) code generation, iii) searching for themes, iv) reviewing themes, v) defining and naming themes, and vi) producing the report. In accordance with these stages, the researcher transcribed the interviews in full, read the individual interview transcripts, carefully noting initial thoughts and ideas. At various stages throughout the analysis the researcher met with the primary supervisor (Dr Juraskova) to discuss the key features of the data thus enhancing researcher sensitivity and overcoming selective inattention.

The qualitative data underwent the first two of the three stages of constant comparative analysis or coding. In the first stage or open coding, the data was grouped into smaller segments with a descriptor or “code” attached to each segment. In the second stage, axial coding, the codes were grouped into similar categories. The third stage of constant comparative analysis, selective coding,
i.e. the process through which theory can be created out of data, was not deemed necessary in the current study.

When a new feature of the data emerged it was added as a sub-theme to the coding frame. These features were checked for emerging patterns, variability and consistency and commonality across participants until saturation, when analysis produced no new themes or categories. This final version of the Coding Tree, with its themes and sub themes, is shown in the Results section (see Figure 4, page 78).
CHAPTER 3

RESULTS

Thirty (30) men self-selected by responding to an advertisement about the current research published in the Concord Hospital Prostate Cancer Support Group newsletter. Of these, three men did not meet the eligibility criteria as they were more than 5 years post treatment and 27 men gave consent to participate during the initial telephone screening interview. Of the 27 eligible men, three opted to withdraw from the study after receiving study documents, citing reasons of partner’s reluctance for them to participate (n=2) and feeling they could not provide any useful information, despite being reassured this was unlikely to be the case (n=1). Therefore, the final response rate was 90%. Of the 27 eligible participants, 24 (89%) completed the questionnaire and 21 (78%) completed the interview. It is of note that despite the considerable distance from the research centre, three participants arranged to travel from their rural homes for the interview. For stratification of participants and participation mode by treatment type and time since treatment see Table 8 (Clinical characteristics of sample).

Demographic and clinical characteristics of the sample

Demographic characteristics of the sample are summarised in Table 7. Participants were on average 61 years old (range: 51-69) at the time of interview and on average 59 years of age at the time of treatment (range 49-66). The majority were married (n=17, 71%) with an average length of marriage between 26 and 48 years. However, one man, whilst still living with his wife, reported that his marriage had failed since his treatment and he was soon to move out of the marital home to live with another woman. One man identified himself as homosexual but not currently in a relationship. University or TAFE qualifications were held by 14 participants (7 per each category). Fourteen participants (54%) were employed in some capacity with the majority of those being employed full-time (46%). Nine (9) participants were retired and one was permanently unable to work (see Table 7 on page 61).

Clinical characteristics of the sample are shown in Table 8. Prior to treatment all 24 participants had been diagnosed with localised prostate cancer amenable to treatment with curative intent. Twenty two (92%) participants underwent surgery (radical prostatectomy). Of those, 19 individuals participated in the interview and questionnaire and 3 completed the questionnaire only. Two participants (8%), both of whom completed the questionnaire and interview, were treated by high dose rate brachytherapy (HDRB) with neo-adjuvant hormone deprivation therapy (ADT).

At study entry, 4 participants had undergone further treatment for localised disease progression. Two of those 4 had undergone radiation therapy (RT) and one of whom was continued to be treated
with ADT. At the time of completing the questionnaire a further 2 participants were being treated with ADT alone following failure of surgical treatment.

Of the 2 participants who had undergone HDRB one had completed associated ADT and the second participant was soon to complete the associated ADT.

As shown in Table 8, of the 21 men interviewed, 6 were within the first 12 months since their initial treatment and 13 were between one and 3 years from initial treatment. The 3 men who completed the questionnaire only were 5 years or less from treatment (see Table 8 on page 62).

The question asking which form(s) of prostate cancer treatment participants had undergone provided 3 radical prostatectomy options: i) with bilateral nerve sparing; ii) with unilateral nerve sparing and iii) with no nerve sparing. There was no option of “unsure regarding nerve sparing” however 8 (36%) participants marked one or more of the specific radical prostatectomy items and indicated, either by a handwritten note (e.g. “I think”) or symbol (?), that they were uncertain regarding the nerve sparing aspect of their radical prostatectomy.

Five participants reported they were currently on medication for anxiety or depression.
Table 7  Demographic characteristics of participants (*n=24*)

<table>
<thead>
<tr>
<th></th>
<th>Total sample (n=24)</th>
<th>Questionnaire &amp; Interview (n=21)</th>
<th>Questionnaire only (n=3)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Current Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>8 (33.3%)</td>
<td>8 (38.1%)</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>15 (62.5%)</td>
<td>13 (61.9%)</td>
<td>2 (66.7%)</td>
</tr>
<tr>
<td><strong>Age at treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 49</td>
<td>1 (4.2%)</td>
<td>1 (4.8%)</td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>12 (50%)</td>
<td>11 (52.4%)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td>60-69</td>
<td>10 (41.6%)</td>
<td>9 (42.9%)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>2 (8.3%)</td>
<td>2 (9.5%)</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>2 (8.3%)</td>
<td>2 (9.5%)</td>
<td></td>
</tr>
<tr>
<td>Relationship (not living together)</td>
<td>2 (8.3%)</td>
<td>1 (4.8%)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td>Married</td>
<td>17 (70.9%)</td>
<td>16 (76.2%)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td><strong>Sexual Orientation</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>22 (91.6%)</td>
<td>20 (95.2%)</td>
<td>2 (66.7%)</td>
</tr>
<tr>
<td>Homosexual</td>
<td>1 (4.2%)</td>
<td>1 (4.8%)</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year 10/equivalent or less</td>
<td>7 (29.15%)</td>
<td>7 (33.3%)</td>
<td></td>
</tr>
<tr>
<td>Yr 12/equivalent</td>
<td>1 (4.2%)</td>
<td>1 (4.8%)</td>
<td></td>
</tr>
<tr>
<td>TAFE</td>
<td>8 (33.3%)</td>
<td>7 (33.3%)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td>University degree or higher</td>
<td>7 (29.15%)</td>
<td>6 (28.6%)</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td><strong>Employment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time (incl. self employed)</td>
<td>11 (45.8%)</td>
<td>11 (52.4%)</td>
<td></td>
</tr>
<tr>
<td>Part-time</td>
<td>9 (37.5%)</td>
<td>7 (33.3%)</td>
<td>2 (66.7%)</td>
</tr>
<tr>
<td>Retired</td>
<td>1 (4.2%)</td>
<td>1 (4.8%)</td>
<td></td>
</tr>
<tr>
<td>Unable to work</td>
<td>1 (4.2%)</td>
<td>-</td>
<td>1 (33.3%)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*the percentages do not add up to 100 due to missing data*
Table 8. Stratification of participants by treatment and participation mode (n=24)

<table>
<thead>
<tr>
<th>Treatment</th>
<th>Questionnaire &amp; Interview (n=21)</th>
<th>Questionnaire only (n=3)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Radical Prostatectomy</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bilateral nerve sparing</td>
<td>10 (42%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>unilateral nerve sparing</td>
<td>3 (12%)</td>
<td>-</td>
</tr>
<tr>
<td>no nerve sparing</td>
<td>5 (21%)</td>
<td>1 (4%)</td>
</tr>
<tr>
<td>pt unsure re nerve sparing</td>
<td>8 (33%)</td>
<td>-</td>
</tr>
<tr>
<td><strong>High Dose Brachytherapy + androgen deprivation therapy</strong></td>
<td>2 (8%)</td>
<td>-</td>
</tr>
</tbody>
</table>

| Failed Radical prostatectomy | | |
| + radiotherapy | 1 (4%) | - |
| + radiotherapy + androgen deprivation therapy | 1 (4%) | - |
| + androgen deprivation therapy | 2 (8%) | - |

| Time since treatment | | |
| ≤ 5 months | 2 (8%) | - |
| 5-12 months | 4 (16%) | - |
| ≤ 2 years | 6 (25%) | 1 (4%) |
| ≤ 3 years | 3 (12%) | 2 (8%) |
| ≤ 5 years | | |
QUANTITATIVE RESULTS

Quality Of Life

FACT-P and FAIT-U

The Functional Assessment of Cancer Therapy – Prostate scale (FACT-P) and Functional Assessment of Incontinence Therapy – Urinary Symptoms subscale were used in the current study to assess physical, functional, emotional, and social wellbeing as well as prostate cancer concerns. Means and standard deviations of the FACT-P and its subscales in the current sample are reported in Table 9 below.

Means and standard deviations for the current study were found to be comparable with the validation study across all subscales. There is currently no validation (normative) data available for the FAIT-U subscales for comparison however this tool belongs to the FACIT suite of scales which has rigorous protocols for developing questionnaires (see http://www.facit.org).

TABLE 9  Functional Assessment of Cancer Therapy-Prostate instrument (FACT-P): Means and Standard Deviations in the current study. Means and standard deviations in brackets are for the validation study (Esper et al., 1997)

<table>
<thead>
<tr>
<th>Scale/subscale</th>
<th>Current study</th>
<th>Validation study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Sexual Wellbeing</td>
<td>21.08 (5.6)</td>
<td>20.8 (5.0)</td>
</tr>
<tr>
<td>Functional Wellbeing</td>
<td>20.58 (6.1)</td>
<td>22.4 (4.3)</td>
</tr>
<tr>
<td>Prostate Cancer Subscale</td>
<td>33.25 (8.6)</td>
<td>34.4 (6.7)</td>
</tr>
<tr>
<td>Emotional Wellbeing</td>
<td>18.75 (3.7)</td>
<td>16.3 (3.0)</td>
</tr>
<tr>
<td>Physical Wellbeing</td>
<td>24.04 (3.6)</td>
<td>25.5 (3.6)</td>
</tr>
<tr>
<td>FACT-P Total Score</td>
<td>117.71 (22.2)</td>
<td>126.1 (18.8)</td>
</tr>
<tr>
<td>FACT-G Total Score</td>
<td>84.46 (15.0)</td>
<td>91.5 (13.5)</td>
</tr>
<tr>
<td>Functional Assessment of Incontinence Therapy-Urinary Symptoms (FAIT-U)*</td>
<td>31.92 (9.3)</td>
<td>-</td>
</tr>
<tr>
<td>FAIT-U Total Score*</td>
<td>116.37 (21.1)</td>
<td>-</td>
</tr>
</tbody>
</table>

*As noted in the Method section, there is currently no documented validation data for FAIT-U

Just over half the participants (14, 58%) reported they “were not at all” bothered by treatment side effects and the majority reported having “quite a bit/very much” emotional support from family (n=22, 92%) and friends (n=18, 75%). Ten (10, 42%) men reported they were “quite a bit/very much” content with their current quality of life and half the participants (12, 50%) reported being “a little bit/somewhat” content.
In contrast to the report by the majority that they were “not at all” bothered by treatment side effects, just over two-thirds of the participants (17, 71%) reported they were “not at all” able to have and maintain an erection and 9 (38%) participants reported they were “not at all” satisfied with their sex life with one third (8, 33%) only “a little bit or somewhat” satisfied. The majority (n=19, 79%) reported they had to limit their sexual activity “a little bit” to “very much” because of their condition. In spite of this 19 (79%) participants said they were “quite a bit/very much” close to their partner/main support person and just over half the participants (n=13 54%) reported being able to feel like a man “quite a bit” to “very much” with “a little bit/somewhat” reported by 10 (42%) men.

Almost two-thirds of participants reported they urinate “a little bit” to “very much” more frequently than usual (n=15, 62%) and half (12, 50%) reported trouble controlling their urine “a little bit” to “very much” - one participant did not mark an answer but wrote “artificial sphincter” beside the question indicating he had undergone a surgical procedure to treat his incontinence. Ten (10, 42%) participants reported they were afraid to be far from a toilet “a little bit” to “very much”, and over half (13, 55%) noted they needed to urinate frequently to avoid leaks however only one-third (8, 33%) of the men reported they wore protection for urine leakage “a little bit” to “very much”. Problems with urination limited physical activity “a little bit/somewhat” for 8 (33%) participants and “quite a bit/very much” for 3 (13%) with half (12, 50%) of the men reporting they were “a little bit” to “very much” embarrassed by their condition.

Two thirds of participants (16, 67%) reported they were “a little bit” to “very much” sad and half (12, 50%) reported feeling “a little bit” to “very much” nervous. Two thirds of the participants (16, 67%) worried “a little bit” to “very much” that their condition would worsen and 7 (29%) participants reported they were losing hope in the fight against their illness.

The majority of participants (n=17, 71%) denied any pain although the majority of participants reported feeling a lack of energy (n=17, 71%). Almost all participants (23, 96 %) reported feeling “a little bit” to “very much” satisfied with how they were coping. Seventeen (71%) men accepted their illness “quite a bit/very much” and two-thirds (16, 67%) reported they were “not at all” worried about dying, enjoyed usual fun things they like to do “quite a bit/very much” (n=16, 67%) and were “quite a bit/very much” able to enjoy life (n=16, 67%) with just over two-thirds (19, 79%) of participants reporting they were “quite a bit/very much” able to work.
<table>
<thead>
<tr>
<th>Item</th>
<th>n</th>
<th>Not at all</th>
<th>A little bit/ Somewhat</th>
<th>Quite a bit/very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of energy</td>
<td>24</td>
<td>7 (29%)</td>
<td>11 (46%)</td>
<td>6 (25%)</td>
</tr>
<tr>
<td>Pain</td>
<td>23</td>
<td>17 (71%)</td>
<td>4 (17%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Bothered by treatment side effects</td>
<td>24</td>
<td>14 (58%)</td>
<td>5 (21%)</td>
<td>5 (21%)</td>
</tr>
<tr>
<td>Emotional support from family</td>
<td>24</td>
<td>1 (4%)</td>
<td>1 (4%)</td>
<td>22 (92%)</td>
</tr>
<tr>
<td>Support from friends</td>
<td>24</td>
<td>1 (4%)</td>
<td>5 (21%)</td>
<td>18 (75%)</td>
</tr>
<tr>
<td>Close to partner/main support</td>
<td>24</td>
<td>1 (4%)</td>
<td>4 (17%)</td>
<td>19 (79%)</td>
</tr>
<tr>
<td>Satisfied with sex life</td>
<td>22</td>
<td>9 (38%)</td>
<td>8 (33%)</td>
<td>5 (21%)</td>
</tr>
<tr>
<td>Feel sad</td>
<td>23</td>
<td>7 (29%)</td>
<td>12 (50%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Satisfied how I am coping</td>
<td>24</td>
<td>1 (4%)</td>
<td>8 (33%)</td>
<td>15 (63%)</td>
</tr>
<tr>
<td>Losing hope</td>
<td>24</td>
<td>17 (71%)</td>
<td>5 (21%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Feel nervous</td>
<td>24</td>
<td>12 (50%)</td>
<td>10 (42%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Worry about dying</td>
<td>24</td>
<td>16 (67%)</td>
<td>6 (25%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Worry condition will worsen</td>
<td>24</td>
<td>8 (33%)</td>
<td>12 (50%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Able to work</td>
<td>24</td>
<td>2 (8%)</td>
<td>3 (13%)</td>
<td>19 (79%)</td>
</tr>
<tr>
<td>Able to enjoy life</td>
<td>24</td>
<td>1 (4%)</td>
<td>7 (29%)</td>
<td>16 (67%)</td>
</tr>
<tr>
<td>Accepted illness</td>
<td>24</td>
<td>2 (8%)</td>
<td>5 (21%)</td>
<td>17 (71%)</td>
</tr>
<tr>
<td>Enjoy usual fun things</td>
<td>24</td>
<td>3 (12%)</td>
<td>5 (21%)</td>
<td>16 (67%)</td>
</tr>
<tr>
<td>Content with current QOL</td>
<td>24</td>
<td>2 (8%)</td>
<td>12 (50%)</td>
<td>10 (42%)</td>
</tr>
<tr>
<td>Able to feel like a man</td>
<td>24</td>
<td>1 (4%)</td>
<td>10 (42%)</td>
<td>13 (54%)</td>
</tr>
<tr>
<td>Urinate more frequently than usual</td>
<td>24</td>
<td>9 (38%)</td>
<td>7 (29%)</td>
<td>8 (33%)</td>
</tr>
<tr>
<td>Able to have and maintain an erection</td>
<td>24</td>
<td>17 (71%)</td>
<td>4 (17%)</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Trouble controlling urine</td>
<td>23</td>
<td>11 (46%)</td>
<td>9 (38%)</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Afraid to be far from toilet</td>
<td>24</td>
<td>14 (58%)</td>
<td>8 (34%)</td>
<td>2 (8%)</td>
</tr>
<tr>
<td>Have to limit physical activity</td>
<td>23</td>
<td>12 (50%)</td>
<td>8 (34%)</td>
<td>3 (13%)</td>
</tr>
<tr>
<td>Have to limit sexual activity</td>
<td>24</td>
<td>5 (21%)</td>
<td>6 (25%)</td>
<td>13 (54%)</td>
</tr>
<tr>
<td>Embarrassed by condition</td>
<td>24</td>
<td>12 (50%)</td>
<td>7 (29%)</td>
<td>5 (21%)</td>
</tr>
<tr>
<td>Must urinate frequently to avoid leaks</td>
<td>24</td>
<td>11 (46%)</td>
<td>9 (38%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Wear protection for urine leaks</td>
<td>24</td>
<td>16 (67%)</td>
<td>2 (8%)</td>
<td>6 (25%)</td>
</tr>
</tbody>
</table>
EPIC

The Expanded Prostate Cancer Index Composite (EPIC) was used in our study population to measure urinary, bowel, sexual and hormonal function and bother as well as the long-term impact of prostate cancer treatments on these specific quality of life domains. Higher scores represent better health-related Quality of Life. Means and standard deviations of the EPIC measure and its subscales in the current sample are reported in Table 11.

The mean scores for all the HRQOL Domains in the current study were not appreciably different from those reported for the EPIC validation cohort (Wei et al., 2000) although on average the current study population fared worse in the Urinary Incontinence, Sexual and Hormonal subscales. The means for the Urinary Incontinence, Sexual and Hormonal domains were lower than those for the validation cohort however for the Urinary Irritative/Obstructive Symptoms and Bowel domains the mean was higher than for the validation study population.

<table>
<thead>
<tr>
<th>HRQOL Domain Summary Score (n=24)</th>
<th>Current Study</th>
<th>Validation Study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Urinary Incontinence</td>
<td>78.96 (24.3)</td>
<td>83.2 (22.9)</td>
</tr>
<tr>
<td>Urinary Irritative/Obstructive Symptoms</td>
<td>89.06 (14.5)</td>
<td>79.7 (18.5)</td>
</tr>
<tr>
<td>Bowel</td>
<td>90.62 (12.2)</td>
<td>86.6 (15.7)</td>
</tr>
<tr>
<td>Sexual</td>
<td>30.06 (29.7)</td>
<td>33.1 (23.6)</td>
</tr>
<tr>
<td>Hormonal</td>
<td>82.17 (18.6)</td>
<td>86.6 (13.8)</td>
</tr>
</tbody>
</table>

Half the participants (12, 50%) reported they “rarely/never” had a problem with urinary leakage however almost half (48%) reported some degree of leakage with 5 (23%) reporting leakage “once a day/more than once a day”. None of the participants reported any bleeding associated with urination. Two (2, 8%) participants reported pain or burning on urination “about once or more than once a week” and 1 (4%) reported pain or burning on urination “more than once a day”. One (1, 4%) man described pain or burning on urination as a “big problem”.

One (4%) participant reported having “no urinary control” and just over half (13, 54%) reported “frequent or occasional dribbling” of urine however more than two-thirds of the men (19, 79%) reported wearing no pads for protection against urinary leakage but 1 (4%) participant reported
using 3 or more pads per day. This result is comparable to a similar item in the FAIT-U measure. It is noteworthy that one man during the interview, while describing significant urinary leakage, reported that he did not wear incontinence pads but rather wore dark trousers in an attempt to disguise any wetness.

In contrast to the number of participants who reported wearing no incontinence pads only 10 (42%) reported they had no problem with urine dripping or leaking. Three (3, 12%) men reported leaking as a “moderate or big problem” and almost half (11, 46%) reported leaking as a “small or very small problem”.

Eleven (11, 46%) participants reported that needing to urinate waking them at night was a “small to very small” problem” and 4 described it as a “big to moderate problem”. Eleven (11, 45%) participants reported a problem of daytime urinary frequency ranging from “very small to big” and overall urinary function was reported as a “very small” to “big” problem by 15 (62%).

Almost all participants (23, 96%) reported overall bowel function as “small to no problem” and the majority (21, 91%) reported hot flushes occurring “about once a week”, “rarely” or “never”.

Sexual desire was reported as “poor or none” by 2 (9%) participants, “poor or fair” by over one-third (9, 39%) and “good” to “very good” by half (12, 50%). Half the participants (12, 50%) reported their level of sexual desire as “no problem” but almost half (11, 48%) described it as ranging from “small to big problem”. Fifteen (15, 65%) men reported their ability to orgasm as “fair” to “none” and over half (14, 61%) reported their inability to orgasm as a “very small” to “big” problem. Nineteen (19, 83%) participants described their ability to have an erection as “fair” to “none”, less than one quarter (5, 22%) reported their erections were firm enough for intercourse and only 1 (4.3%) reported he was able to get an erection whenever he wanted with two-thirds (16, 70%) of the men reporting they were never able to get an erection. The inability to have erections was rated by two-thirds (16, 69%) of participants as a “moderate” to “big” problem. More than half (14, 61%) of the men reported no sexual activity at all in the previous 4 weeks and sexual function was described as “very poor” to “none” by more than one quarter (6, 26%) of respondents with a further 13 (57%) reporting sexual function as “fair” or “poor”. Sexual function was reported by 17 of 22 (77%) responding participants as a “moderate” to “big” problem.

Participants reported experiencing depression “about once a week to more than once a week” (n=9, 37%) and “about once a day/more than once a day” (n=4, 17%). Feeling depressed was reported by more than half the participants (13, 56%) as a “very small” to “big” problem. Reports of lack of energy were similar in number to those reported in the FACT-P measure with 5 (21%) reporting lack of energy “about once/ more than once a week” to “once a day/more than once a day” (n=7,
30%) and lack of energy was reported as a “very small” to “big” problem by over half (13, 56%) of participants.

| TABLE 12  The Expanded Prostate Cancer Index Composite (EPIC): Categorised responses to individual items |
|-------------------------------------------------|-------------------------------------------------|-------------------------------------------------|-------------------------------------------------|
| **Item (in the last 4 weeks)**                  | **n***                                          | **Never/Rarely**                                | **About once a week/ > once a week**            | **About once a day/>once a day**                  |
| Leaked Urine                                    | 23                                             | 12 (50%)                                       | 6 (25%)                                        | 5 (23%)                                         |
| Pain or burning on urination                    | 24                                             | 21 (88%)                                       | 2 (8%)                                         | 1 (4%)                                          |
| Urinary control                                 | 24                                             | 1 (4%)                                         | 13 (54%)                                       | 10 (42%)                                        |
| Adult diapers required per day                  | 24                                             | 1 (4%)                                         | 4 (17%)                                        | 19 (79%)                                        |
| Leaking urine                                   | 24                                             | 3 (12%)                                        | 11 (46%)                                       | 10 (42%)                                        |
| Waking up to urinate                            | 24                                             | 4 (17%)                                        | 11 (46%)                                       | 9 (37%)                                         |
| Need to urinate frequently                      | 24                                             | 3 (12%)                                        | 8 (33%)                                        | 13 (55%)                                        |
| Overall urinary function                        | 24                                             | 3 (12%)                                        | 12 (50%)                                       | 9 (38%)                                         |
| Sexual desire                                   | 23                                             | 2 (9%)                                         | 9 (39%)                                        | 12 (50%)                                        |
| Able to have erection                           | 23                                             | 15 (66%)                                       | 4 (17%)                                        | 4 (17%)                                         |
| Able to orgasm                                  | 23                                             | 5 (22%)                                        | 10 (43%)                                       | 8 (35%)                                         |
| Quality of erections                            | 23                                             | 16 (69%)                                       | 2 (9%)                                         | 5 (22%)                                         |
| Frequency of sexual activity                    | 23                                             | 14 (61%)                                       | 7 (30%)                                        | 1 (4%)                                          |
| Sexual Function                                 | 23                                             | 6 (26%)                                        | 13 (57%)                                       | 4 (17%)                                         |
| Level of sexual desire                          | 23                                             | 3 (13%)                                        | 8 (35%)                                        | 12 (52%)                                        |
### Able to have erection

- 23 participants answered: 16 (69%) able to have erection, 3 (13%) able to have erection but not always, 4 (18%) not able to have erection.

### Able to have orgasm

- 23 participants answered: 9 (39%) able to have orgasm, 5 (22%) able to have orgasm but not always, 9 (39%) not able to have orgasm.

### Sexual function (or lack)

- 22 participants answered: 17 (77%) sexual function normal, 1 (5%) sexual function difficult, 4 (18%) sexual function absent.

### Felt depressed

- 23 participants answered: 10 (42%) felt depressed, 9 (37%) felt slightly depressed, 4 (17%) felt no depression.

### Lack of energy

- 23 participants answered: 11 (46%) felt lack of energy, 5 (21%) felt slightly lack of energy, 7 (30%) felt no lack of energy.

### Feeling depressed

- 23 participants answered: 6 (25%) felt depressed, 7 (30%) felt slightly depressed, 10 (42%) felt no depression.

### Lack of energy

- 23 participants answered: 5 (22%) felt lack of energy, 8 (34%) felt slightly lack of energy, 10 (42%) felt no lack of energy.

*Total number of participants that answered each item.

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**Sexual Function and Relationship**

**MSHQ.**

For the purposes of the current study, only the Ejaculation and Sexual satisfaction subscales were used therefore findings for the MSHQ will be described using frequency data only.

One participant failed to answer any of the items in this measure and all items had at least one “not applicable” response which may be explained in part by the fact that 2 men described themselves as single, 2 were divorced or separated and the partner of one of the married participants was in the final stages of a terminal illness. Almost all (17, 71%) of 20 participants reported they were never able to ejaculate when having sex with their partner and 1 participant (4%) reported being able to ejaculate a few times only. Of 19 responses 13 (55%) participants reported they took too long to ejaculate “a few times” to “always”.

Five (5, 21%) of 16 respondents reported experiencing pain when ejaculating ranging from a few times to always. Three-quarters (15, 63%) of 20 respondents answered that they lost no fluid when they felt they were ejaculating and 12 (50%) of those participants reported the frequency as “most times/always”. Six (5, 21%) of 18 respondents described the strength of their ejaculation as “good” to “very good” while 6 (25%) reported it as “poor/none”. Sixteen (13, 54%) participants reported the volume of ejaculate as “poor”
Ten (10, 42%) of only 11 participants who answered the question comparing current physical pleasure at ejaculation to that experienced prior to diagnosis reported that it had decreased. Twelve men declined to answer that question.

The overall sexual relationship with their partner was rated “a little bit/somewhat” satisfactory by 12 (50%) of respondents and 6 (25%) rated it as “quite a bit/very much” satisfactory. Of 21 respondents, 11 (46%) reported they were “a little bit/somewhat” satisfied with the quality of their sex life with their main partner and a further 7 (29%) reported they were “quite a bit/very much” satisfied with the quality of their sex life with their partner.

Sixteen (11, 46%) of participants reported they were “quite a bit/very much” satisfied with the way they and their main partner show affection during sex and 7 (29%) of participants said they were “quite a bit/very much” satisfied with the way they and their main partner communicate about sex.

### Table 13 Male Sexual Health Questionnaire (MSHQ) scale

<table>
<thead>
<tr>
<th>Item</th>
<th>n*</th>
<th>Never</th>
<th>A few times/Sometimes</th>
<th>Most times/always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Able to ejaculate#</td>
<td>20</td>
<td>17 (85%)</td>
<td>1 (5%)</td>
<td>2 (10%)</td>
</tr>
<tr>
<td>Pain when ejaculating#</td>
<td>16</td>
<td>11 (69%)</td>
<td>2 (12%)</td>
<td>3 (19%)</td>
</tr>
<tr>
<td>Feels like ejaculating but no fluid#</td>
<td>20</td>
<td>5 (25%)</td>
<td>3 (15%)</td>
<td>12 (60%)</td>
</tr>
<tr>
<td>Take too long to ejaculate#</td>
<td>19</td>
<td>6 (32%)</td>
<td>3 (16%)</td>
<td>10 (53%)</td>
</tr>
<tr>
<td>Overall satisfaction with sexual relationship</td>
<td>21</td>
<td>3 (14%)</td>
<td>12 (57%)</td>
<td>6 (29%)</td>
</tr>
<tr>
<td>Overall satisfaction with quality of sex life</td>
<td>21</td>
<td>3 (14%)</td>
<td>11 (52%)</td>
<td>7 (33%)</td>
</tr>
<tr>
<td>Satisfaction with frequency of sex~</td>
<td>21</td>
<td>5 (24%)</td>
<td>9 (43%)</td>
<td>7 (33%)</td>
</tr>
<tr>
<td>Satisfaction with affection during sex~</td>
<td>21</td>
<td>3(14%)</td>
<td>7 (33%)</td>
<td>11 (52%)</td>
</tr>
<tr>
<td>Satisfaction with communication with partner about sex</td>
<td>21</td>
<td>5 (24%)</td>
<td>9 (43%)</td>
<td>7 (33%)</td>
</tr>
<tr>
<td>Strength of ejaculation#</td>
<td>18</td>
<td>6 (33%)</td>
<td>7 (39%)</td>
<td>5 (28%)</td>
</tr>
<tr>
<td>Volume of ejaculate#</td>
<td>18</td>
<td>13 (72%)</td>
<td>4 (22%)</td>
<td>1 (6%)</td>
</tr>
<tr>
<td>Physical pleasure when ejaculating#</td>
<td>11</td>
<td>10 (91%)</td>
<td>1 (9%)</td>
<td></td>
</tr>
</tbody>
</table>

*Total number of participants that answered each item.

# ejaculation subscale items (7), ~ sexual and relationship satisfaction subscale items (5)
Psychosocial Well-being and function

*MSS*

The Men’s Sexual Self-Schema (MSS) was used in our study to assess the 3 sexually relevant cognitive domains of *Passionate-Loving, Powerful-Aggressive* and *Open-Minded – Liberal* traits. Using a 7-point scale ranging from 0=not at all descriptive to 6=very much descriptive of me participants were requested to choose a number for each adjective to indicate how accurately the adjective described them. Items for each of the 3 Factors are shown below in Table 14. Higher scores are associated with more sexually schematic men while sexually aschematic men score lower.

<table>
<thead>
<tr>
<th>TABLE 14 Male Sexual Self-Schema Scale Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor 1: Passionate-Loving</td>
</tr>
<tr>
<td>Compassionate</td>
</tr>
<tr>
<td>Warm-hearted</td>
</tr>
<tr>
<td>Passionate</td>
</tr>
<tr>
<td>Loving</td>
</tr>
<tr>
<td>Sensitive</td>
</tr>
<tr>
<td>Feeling</td>
</tr>
<tr>
<td>Romantic</td>
</tr>
<tr>
<td>Soft-hearted</td>
</tr>
<tr>
<td>Sensual</td>
</tr>
<tr>
<td>Arousable</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

Means and standard deviations of the MSS measure and its subscales in the current sample are reported in Table 15 (page 72). The means and standard deviations for the study population across all 3 Factors were comparable to the normal population (Andersen et al., 1997) indicating the participants were similar in their sexual self schema to men who have not been treated for prostate cancer.
TABLE 15 The Men’s Sexual Self-Schema (MSS): Means and Standard Deviations in the current study. *Means and standard deviations in brackets are for the validation study (Andersen et al., 1997)*

<table>
<thead>
<tr>
<th>MSS Scale</th>
<th>Current Study</th>
<th>Validation Study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Factor 1: Passionate-Loving</td>
<td>47.46 (7.3)</td>
<td>46.23 (8.0)</td>
</tr>
<tr>
<td>Factor 2: Powerful-Aggressive</td>
<td>47.83 (10.5)</td>
<td>49.10 (9.3)</td>
</tr>
<tr>
<td>Factor 3: Open-Minded- Liberal</td>
<td>16.12 (3.6)</td>
<td>14.72 (4.1)</td>
</tr>
<tr>
<td>Total Score</td>
<td>111.42 (17.1)</td>
<td>109.93 (16.2)</td>
</tr>
</tbody>
</table>

Results for the 27 items used to assess Men’s Sexual Self Schema are reported in Appendix 7. The majority of men described themselves as conservative (23, 96%) and reserved (21, 87%) although open-minded (24, 100%), broad-minded (24, 100%) and liberal (24, 100%). The majority also saw themselves as independent (24, 100%), loving (24, 100%), passionate (24, 100%), warm-hearted (22, 92%), arousable (21, 87%) and sensitive (24, 100%). Twenty-three (23, 96%) identified themselves as romantic and spontaneous. Half the participants (12, 50%) described themselves as domineering and more than half self-reported as powerful (20, 83%) and aggressive 15 (62%).

**SEAR**

The Self Esteem and Relationship (SEAR) questionnaire assesses the sexual, relational and emotional impacts of erectile dysfunction, a well documented side-effect of prostate cancer treatment which can affect self esteem and relationships and therefore overall quality of life. It was included in this study to assess the emotional toll of erectile dysfunction (ED) on participants. Descriptive statistics for the SEAR items are reported in Table 17 (page 74) and means and standard deviations of the SEAR and its subscales in the current sample are reported in Table 16 (page 73).

In the Total Score the study sample fared somewhat worse than the ED population in the validation study. The measure includes two domains: Sexual Relationship (items 1-8) and Confidence (items 9-14), with the Confidence domain compromising two subscales: Self-esteem (items 9-12) and Overall Relationship (items 12 and 14). For SEAR component of questionnaire please see Appendix 5, Section 3 Part B, page 172. Study participants also scored lower than the validation study population in their perception of their sexual relationship and confidence, particularly in the subscale measuring self-esteem. Men in the study were similar to those in the validation study in their confidence with their overall relationship.
Table 16  Self-esteem and Relationship (SEAR) questionnaire: Means and Standard Deviations in the current study.  *Means and standard deviations in brackets are for ED population in the validation Cappelleri et al, 2004*)

<table>
<thead>
<tr>
<th>Domain</th>
<th>Current Study</th>
<th>Validation Study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Sexual Relationship</td>
<td>39.9 (25.0)</td>
<td>47.3 (26.5)</td>
</tr>
<tr>
<td>Confidence</td>
<td>51.5 (26.6)</td>
<td>61.4 (24.4)</td>
</tr>
<tr>
<td>Self-esteem</td>
<td>48.0 (25.7)</td>
<td>60.7 (25.9)</td>
</tr>
<tr>
<td>Overall Relationship</td>
<td>58.5 (35.2)</td>
<td>62.9 (27.8)</td>
</tr>
<tr>
<td>Total Score</td>
<td>44.9 (24.5)</td>
<td>53.4 (23.4)</td>
</tr>
</tbody>
</table>

The majority of respondents reported they never or only sometimes felt confident their erection would last (20, 91%), never or only sometimes felt satisfied with their sexual performance (19, 86%), never or only sometimes felt like a whole man (17, 77%) and never or only sometimes felt satisfied with their sex life (15, 68%). The majority of the participants also reported they were never or only sometimes confident about performing sexually (14, 64%) and felt sex could be never or only sometimes be spontaneous (19, 87%). More than half the participants (12, 55%) reported never or only sometimes feeling relaxed about initiating sex and more than half (13, 59%) reported never or only sometimes being likely to initiate sex. Half the participants (11, 50%) who responded reported they never or only sometimes had good self esteem while half (11, 50%) reported having good self esteem most times or always.

Despite reporting problems associated with maintaining erections, sexual performance, feeling like a whole man, sexual spontaneity and sex life satisfaction, the majority of participants (21, 95%) reported they never or only sometimes felt like a failure and half (11, 50%) reported they were satisfied with their relationship in general most times or always. Also despite the problems associated with their sexual function, performance and sex life satisfaction more than two-thirds (15, 68%) participants reported their partners were satisfied with their relationship in general and the majority (19, 86%) reported that their partners were never or only sometimes unhappy with the quality of their sexual relationship.
<table>
<thead>
<tr>
<th>Item</th>
<th>Never</th>
<th>Few times / Sometimes</th>
<th>Most times / Always</th>
<th>Current study</th>
<th>Validation study*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Relaxed re initiating sex</td>
<td>7 (32%)</td>
<td>5 (23%)</td>
<td>10 (45%)</td>
<td>2.8 (1.6)</td>
<td>3.1 (1.4)</td>
</tr>
<tr>
<td>Confident erection would last</td>
<td>18 (82%)</td>
<td>2 (9%)</td>
<td>2 (9%)</td>
<td>1.6 (1.4)</td>
<td>2.5 (1.3)</td>
</tr>
<tr>
<td>Satisfied with sexual performance</td>
<td>11 (50%)</td>
<td>8 (36%)</td>
<td>3 (14%)</td>
<td>1.9 (1.2)</td>
<td>2.6 (1.3)</td>
</tr>
<tr>
<td>Felt sex could be spontaneous</td>
<td>7 (32%)</td>
<td>12 (55%)</td>
<td>3 (13%)</td>
<td>2.3 (1.2)</td>
<td>2.7 (1.3)</td>
</tr>
<tr>
<td>Likely to initiate sex</td>
<td>6 (27%)</td>
<td>7 (32%)</td>
<td>9 (41%)</td>
<td>2.9 (1.6)</td>
<td>3.1 (1.4)</td>
</tr>
<tr>
<td>Confident about performing sexually</td>
<td>7 (32%)</td>
<td>7 (32%)</td>
<td>8 (36%)</td>
<td>2.6 (1.6)</td>
<td>2.7 (1.4)</td>
</tr>
<tr>
<td>Satisfied with sex life</td>
<td>9 (41%)</td>
<td>6 (27%)</td>
<td>7 (32%)</td>
<td>2.4 (1.5)</td>
<td>2.8 (1.4)</td>
</tr>
<tr>
<td>Partner unhappy with quality of sexual relations</td>
<td>13 (59%)</td>
<td>6 (27%)</td>
<td>7 (32%)</td>
<td>4.1 (1.2)</td>
<td>3.6 (1.3)</td>
</tr>
<tr>
<td>Had good self esteem</td>
<td>7 (32%)</td>
<td>4 (18%)</td>
<td>11 (50%)</td>
<td>2.9 (1.5)</td>
<td>3.5 (1.3)</td>
</tr>
<tr>
<td>Felt like a whole man</td>
<td>12 (54%)</td>
<td>5 (23%)</td>
<td>5 (23%)</td>
<td>2.4 (1.5)</td>
<td>3.3 (1.3)</td>
</tr>
<tr>
<td>Inclined to feel like a failure</td>
<td>8 (36%)</td>
<td>13 (59%)</td>
<td>1 (5%)</td>
<td>4.0 (1.0)</td>
<td>3.7 (1.3)</td>
</tr>
<tr>
<td>I felt confident</td>
<td>5 (23%)</td>
<td>9 (41%)</td>
<td>8 (36%)</td>
<td>2.7 (1.4)</td>
<td>3.7 (1.3)</td>
</tr>
<tr>
<td>Partner satisfied with relationship in general</td>
<td>3 (14%)</td>
<td>4 (18%)</td>
<td>15 (68%)</td>
<td>3.6 (1.4)</td>
<td>3.4 (1.2)</td>
</tr>
<tr>
<td>Satisfied with relationship in general</td>
<td>6 (27%)</td>
<td>5 (23%)</td>
<td>11 (50%)</td>
<td>3.1 (1.6)</td>
<td>3.6 (1.2)</td>
</tr>
</tbody>
</table>

*Means and standard deviations are for Erectile Dysfunction (ED) population in the validation study (Cappelleri et al, 2004)
Anxiety and Depression

HADS

The Hospital Anxiety and Depression Scale (HADS) was used in the current study to assess participants for sub-clinical and clinical levels of anxiety and depression. Using the validated five point (0-4) subscale scores (Love, Kissane, Bloch & Clarke, 2002) the majority of participants (13, 54%) were non cases with a further 6 (25%) of participants assessed as sub-clinical or doubtful with regard to Anxiety. Five (5, 21%) were found to be within the definite clinical levels of Anxiety category.

According to the data there were no definite cases of Depression amongst the 24 participants and only 4 (17%) scored in the “doubtful” range.

It is noteworthy that in the demographic section of the study questionnaire, 5 participants reported they were currently taking antidepressant medication.

| TABLE 18  Hospital Anxiety and Depression Scale (HADS): Means and Standard Deviations in the current study. Means and standard deviations in brackets are for data in a comparative study (Bisson et al., 2002) |
|---|---|---|
| Subscale | Current Study | Validation Study |
| | Mean (SD) | Mean (SD) |
| Anxiety Total Score | 6.66 (3.7) | 4.96 (3.82) |
| Depression Total Score | 4.37 (3.0) | 1.95 (2.5) |

Table 19  HADS – Anxiety and Depression Cases  Descriptive statistics (n=24)

<table>
<thead>
<tr>
<th></th>
<th>ANXIETY subscale</th>
<th>DEPRESSION subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Non cases (0-5)</td>
<td>13 (54%)</td>
<td>20 (83%)</td>
</tr>
<tr>
<td>Subclinical cases (8-10)</td>
<td>6 (25%)</td>
<td>4 (17%)</td>
</tr>
<tr>
<td>Clinical cases (11+)</td>
<td>5 (21%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>
Unmet Needs

Supportive Care Needs Survey (SCNS-SF34)

The 34-item Supportive Care Needs Survey (SCNS-SF34) was administered in the current study to measure the participants’ perceived unmet needs across five domains: psychological (10 items), health system and information (11 items), physical and daily living (5 items), patient care and support (5 items), and sexuality (3 items).

Means and standard deviations of the SCNS-SF34- and its subscales in the current sample are reported in Table 20.

The means derived for the current study in the Psychological, Health Systems Information and Physical and Daily Living were lower than those for the population in the validated study (Boyes et al, 2008). Standard Deviations for these domains were lower than those reported in the validation study, particularly in the Physical and Daily Living domains.

For the Patient Care and Support and Sexuality domains, the study means were higher than the validation study means. The standard deviation for the Patient Care and Support domain was lower than that for the validation study and for the Sexuality domain it was slightly higher.

TABLE 20 Supportive Care Needs Survey (SCNS-SF34): Means and Standard Deviations in current study. Means and standard deviations in brackets are for the validation study (Boyes et al, 2008).

<table>
<thead>
<tr>
<th>Domains</th>
<th>Current Study</th>
<th>Validation Study</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Psychological</td>
<td>23.64 (24.52)</td>
<td>39.1 (29.1)</td>
</tr>
<tr>
<td>Health Systems Information</td>
<td>16.21 (23.29)</td>
<td>39.0 (29.0)</td>
</tr>
<tr>
<td>Daily Living</td>
<td>13.33 (17.55)</td>
<td>36.6 (26.6)</td>
</tr>
<tr>
<td>Patient Care and Support</td>
<td>34.78 (13.98)</td>
<td>25.3 (24.0)</td>
</tr>
<tr>
<td>Sexuality</td>
<td>34.34 (28.81)</td>
<td>22.6 (27.1)</td>
</tr>
</tbody>
</table>

SCNS-SF34 items demonstrating some need are shown in Table 21 (page 77). In all items in all 5 domains the majority of participants reported “no need” however “some need” was reported in all items in all domains, particularly in the Psychological and Sexuality domains. When items identified as requiring “some need” were ranked, the first 8 were all within either the Psychological or Sexuality domains.
Unmet needs in the Sexual domain ranked highest. “Some need “was reported for changes in sexual feelings by 11 (48%) participants and 10 (43%) reported unmet needs related to changes in sexual relationships. Unmet needs for information about sexual relationships were reported by 7 (29%) of participants.

The most frequently ranked unmet need in the Psychological domain related to fears about the cancer spreading and was reported by 9 (39%) of participants, followed by unmet needs related to feeling down or depressed (n=8, 33%) and feelings of sadness (n=8, 35%).

“Concerns about the worries of those close to you” (n=8, 35%), and “uncertainty about the future” (n=7, 30%) were reported by participants. Anxiety and learning to feel in control of your situation were reported as areas of need by 5 (22%) participants.

<table>
<thead>
<tr>
<th>Rank</th>
<th>SCNS Dimension</th>
<th>SCNS Need Item</th>
<th>N*</th>
<th>Frequency of responses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Sexuality needs</td>
<td>Changes in sexual feelings</td>
<td>23</td>
<td>11</td>
<td>47.8</td>
</tr>
<tr>
<td>2</td>
<td>Sexuality needs</td>
<td>Changes in your sexual relationships</td>
<td>23</td>
<td>10</td>
<td>43.5</td>
</tr>
<tr>
<td>3</td>
<td>Psychological needs</td>
<td>Fears about the cancer spreading</td>
<td>23</td>
<td>9</td>
<td>39.1</td>
</tr>
<tr>
<td>4</td>
<td>Psychological needs</td>
<td>Feel down or depressed</td>
<td>24</td>
<td>8</td>
<td>33.3</td>
</tr>
<tr>
<td>5</td>
<td>Psychological needs</td>
<td>Feelings of sadness</td>
<td>23</td>
<td>8</td>
<td>34.8</td>
</tr>
<tr>
<td>6</td>
<td>Psychological needs</td>
<td>Concerns about the worries of those close to you</td>
<td>23</td>
<td>8</td>
<td>34.8</td>
</tr>
<tr>
<td>7</td>
<td>Sexuality needs</td>
<td>To be given information about sexual relationships</td>
<td>24</td>
<td>7</td>
<td>29.2</td>
</tr>
<tr>
<td>8</td>
<td>Psychological needs</td>
<td>Uncertainty about the future</td>
<td>23</td>
<td>7</td>
<td>30.4</td>
</tr>
</tbody>
</table>

*Total number of participants that answered each item.
QUALITATIVE RESULTS

Figure 4. Model of psychosexual adjustment following the prostate cancer treatment depicting main themes and subthemes that emerged from the qualitative analysis.
QUALITATIVE RESULTS
Three main themes arose during the interviews which could be further divided into a number of sub-themes as illustrated in Figure 4 (page 78). The three main themes were change in self-identity, communication and support and the adjustment process. These themes are reported according to both the frequency with which they were reported and the importance placed on them by participants in the semi-structured interviews.

THEME I: CHANGE IN SELF-IDENTITY
Within the overall “Change in Self-Identity” theme there were five sub-themes, related to Physical Changes, Changes in Self-Perception, Psychological Adjustment, Existential Issues and Changes in Relationships.

a) Physical changes
Physical changes reported by participants following treatment for prostate cancer included erectile dysfunction, urinary incontinence, urine leakage during arousal or at orgasm, reduced penile size, lack of or reduced ejaculate, change in intensity of orgasm, reduced desire and pain.

i) Erectile Dysfunction
Erectile dysfunction was noticed immediately by the men who underwent radical prostatectomy but was a more gradual process for those who underwent brachytherapy or radiation therapy. The inability to achieve an erection and therefore have penetrative intercourse precluded some of the participants from sexual intimacy with their partners, as they viewed sexual interaction as involving only penetrative intercourse and, as a couple, they were unable to discuss such matters. Some men noticed that unlike previously when erections had been spontaneous, they now consciously thought about what was happening during arousal (which in itself had a negative impact on arousal), thinking about how long the erection would last, what he needs to do, what his partner is thinking and whether he will “perform”.

“...minimal erections so there’s no penetration. The major issue has been around penetration and the inability to be able to get an erection...” [ID 21, age 65]

“You do think about (is the penis becoming erect) a bit...kind of checking-in ...you do think about it and that probably takes away from the moment.” [ID 29, age 59]
Men recovering from treatment reported being anxious to regain erections, either spontaneously or with assistance, and commented it was difficult if their partner was not as motivated about his sexual rehabilitation as he was. One man reported his wife, who he described as being supportive and who accompanied him when he attended a doctor with a view to exploring options for erectile rehabilitation, as not being “impressed” with penile needles and seemed to use his wife’s discomfort to justify his decision not to proceed.

Some men who were found to have disease progression reported ongoing difficulty adjusting to continued side effects of treatment such as erectile dysfunction particularly if that treatment had been performed with curative intent.

“The realisation that the cancer wasn’t cured was sort of a double whammy because, well that sort of dragged me back to where I was 3 years previously and wrestling with these issues (impotence)” [ID 9, age 62]

ii) Urinary incontinence

Urinary incontinence was a significant issue for a number of men, particularly in the early weeks and months after radical prostatectomy. Lifestyle issues such as not being able to comfortably go to the beach because of urinary leakage caused distress for some individuals however for most men with ongoing leakage, the longer they lived with it, the better they seemed to accept it. One notable exception was one participant who just over 12 months post surgery with ongoing stress leakage (urine leakage on coughing, sneezing, exertion etc), refused to use pads and wore only dark pants so that wet patches would be less noticeable. A lack of understanding about, or compliance with, practical strategies to minimise leakage was apparent in some participants although they had been provided with information regarding regular pelvic floor exercises and management of continence problems. The participant mentioned above failed to do pelvic floor exercises or pursue investigation of his ongoing continence problems despite encouragement and refused to wear pads yet he described embarrassment and frustration as a consequence of the ongoing problems with urine leakage. A few of the men who reported being acutely aware of the impact of alcohol or other behaviours on urinary leakage chose to ignore the potential for embarrassment and continued on occasion to consume significant amounts of alcohol. Over time, despite their failure to improve, some men started to accept the continuing nature of some side effects however at least one man underwent surgery to implant an artificial urinary sphincter which greatly improved his quality of life.
“Yeah, I had trouble urinating in as much as that when I went to relieve myself I’d wet myself prior to getting my penis out and that was annoying because I had no feeling whatsoever and I wasn’t knowing that I was wetting myself until I looked down so I had no feeling in my genital area.” [ID 7, age 61]

“(Urinary incontinence) stopped me…before I used to do a lot of walking. But one of the things it really inhibited was going for a swim. Because you can’t swim with a pad on and you can’t go to the beach with your pants starting to get wet all the time.” [ID 1, age 62]

“I haven’t probably done the pelvic exercises as well as I should have and that’s a bit silly but by and large unless I go and have a few beers, say 5 or 6 beers on a Friday night, there’ll be severe leakage whereas on a day to day basis the leakage is minimal. So much so that, for example, today I haven’t got a pad on and I’m quite comfortable with that”. [ID 15, age 59]

iii) Urine loss during foreplay and orgasm

Urine leakage during arousal and/or at orgasm was a difficult problem for some participants following radical prostatectomy although it did not necessarily occur each time sexual activity took place. One man reported that leakage occurring during arousal stopped the activity whilst another described it as embarrassing for him but more so because it upset his wife who withdrew from the activity. A gay participant described the difficulties he encountered when, with a new partner (often not well known to him), he needed to use injection therapy to get an erection and then suffered the embarrassment of urine leakage during arousal or orgasm. Prior to his diagnosis this participant frequented gay venues with the specific intention of meeting men (usually previously unknown to him) for sex – the embarrassment he felt because of erectile dysfunction and urine leakage led to reduced socialising and significant reduction in the frequency of his sexual encounters.

“…a couple of times it happened and (my wife) got so angry, she jumped up and went and had a shower and I felt terrible…she refused to even talk about sex anymore…can’t blame my wife and I couldn’t blame myself because you just can’t control it…” [ID 9, age 58]

“When I do get an erection the discharge seems to be mainly urine…I just give up because it won’t go any further.” [ID 8, 69]

“It was really strange because when I had the orgasm, urine came out…like sperm used to come out. You take headache tablets before the Caverject and …have a wee…and have a towel in bed. It’s always been spontaneous…pick someone up and go home with them…I can’t go to their place…I’ve got to think of what I’ve got to do so they can’t see what I’m doing.” [ID 11, age 67]
iv) **Reduced penile length**

A number of participants described a reduction in the size of their penis following radical prostatectomy or androgen deprivation therapy (ADT). Some men, particularly those who underwent surgery, were unaware this might occur and in some instances felt health professionals were unable or even perhaps unwilling to clarify why it occurred and that it was a normal effect in some men following prostate cancer surgery.

“...urologists, some of them say it doesn’t happen but on internet prostate cancer sites I have seen descriptions of it happening - that size decreases.” [ID 1, age 62]

“...and, don’t think I’m brash, I went from about I suppose 6 or 7 inches down to about 4 inches.” [ID 7, age 61]

“Not that I was ever big but I’m like half the size.” [ID 3, age 60]

v) **Effects of hormones**

Of the twenty-two participants, five had received or were continuing to receive androgen deprivation therapy. During the interviews they reported common side effects of this hormonal treatment which they found very hard to accept and deal with, namely, decreased genitalia size, increased breast tissue, reduced body hair and depression, as well as significantly reduced or extinguished libido and erectile dysfunction during the time of treatment.

“I lost everything except my pubic hair... but everything is shrunk and they said that’s normal.” [ID 3, age 60]

“I’m just putting on weight...and after two years I’m sort of growing breasts... I’m shaving less frequently, I don’t have female tendencies... but it just gets me down. I don’t know whether to go off them or not.” [ID 7, age 61]

“The hot flushes and the night sweats, they were horrific to me.” [ID 10, age 66]

vi **Changes to orgasm**

After prostate cancer treatment a number of men reported a reduced intensity of orgasm or even absence of orgasm. A number of the men, when describing negative changes in the physical sensations associated with orgasm also described negative changes in the emotional experience of orgasm. Although some men reported a reduced intensity of orgasm others described a more intense feeling than prior to treatment.
“And the last few times I noticed, I felt the sensation and you feel you have come but there’s nothing. If you put a tissue there there’s nothing but later on, you find that it’s...because I still wear a pad to work but at home I don’t really, but you can feel that it has come afterwards. I don’t know whether that’s normal or not.” [ID 3, age 60]

“The whole thing of sex that ends in intercourse and the build up to it is an emotional experience and that is a deep thing, it was for me at least, and that’s not there.” [ID 2, age 54]

“... the actual activity of sex has for the initial part of it, a lot less feeling. You feel a bit detached... It’s a bit like doing it with someone else’s dick. But then... it starts to build up and then the actual orgasm is probably about the same as before but because you’re building up from a lower point I think it feels stronger but I think it’s probably really the same thing... At the end of it, the feeling dies off quickly and there’s no sort of “afterglow” like there was before... the erection tends to die off a bit quickly now, more quickly than it did before.” [ID 20, age 59]

vii) Pain

A few of the participants described penile or perineal pain post surgical or brachytherapy treatment. One man had ongoing pain upon sitting for some time post operatively and although it resolved after some months no specific cause was identified. Another participant described ongoing but unexplained pain and, although soon after surgery he was diagnosed with disease outside the prostate, on scanning there was no metastases at or near the site of his pain. Two men in this study population who underwent high dose brachytherapy also reported pain - one experienced ongoing significant pain or “burning” on urination and the other described pain related to erections and orgasm. When pain was associated with sexual activity it had a negative impact on libido.

“When I get an erection, it is) very painful at the perineum area which translates up to the head of the penis and that starts mind games on me...I hold back.” [ID 12, age 51]

“I have not gone to the toilet now for 2 years without burning... I don’t think it was like this at the start. I’ve conditioned myself; I’d rather it not get blocked. I cannot stand the treatment when they have to go up through the penis. I hate it. Just the thought...” [ID 3, age 60]

“I have a pain now in my right testicle. It’s just like an ache, just a constant ache. Well that’s been going on since the day that I had the operation.” [ID 7, age 61]

"Whenever you’ve got pain your sexual desire seems to go fairly much out the window.” [ID 17, age 58]

viii) Reduced Libido/Desire
A number of the men described reduced sexual desire since undergoing treatment for prostate cancer. For these men the lack of erections sufficient for penetration and/or the “trouble” they had to go to in order to get and keep such an erection (medications, injections, devices) removed the spontaneity from sexual intimacy. Some men reported that urinary leakage, the inability to achieve an erection despite treatment, or pain resulted in reduced interest in sexual interaction and intimacy. Reduced self-esteem and self-confidence were also reported as a consequence of changed sexual function which in turn impacted on desire.

For participants who were able to achieve an erection with treatment, the effort and the planning, plus the non-refundable expense, now required for penetrative intercourse in many cases significantly reduced sexual desire. One man summed it up by commenting that the negative change in sexual activity since his treatment had resulted in diminished enthusiasm for sexual activity.

“I don’t have sexual difficulties because I don’t have any sexual urges. When I say that, my wife and I aren’t intimate, we cuddle but that’s about it, cuddle and kiss.” [ID 7, age 61]

“The want is still there but it seems further away now than it ever was because of the operation because of my inadequate being. Not being able to respond quickly and naturally to a female’s response.” [ID 8, age 69]

“…when it does come to having, coming close to…whether it be penetration or just physical foreplay, whatever, I get very tense and just lose interest completely.” [ID 12, age 51]

“…severe drop in actual sex, this could be because I’m now living by myself but even as far as masturbation or any of that goes (erections are painful) so interest has declined… And that starts mind games on me.” [ID 12, age 51]

ix) Aids and their side-effects

Medications, penile injections and vacuum devices are the most common treatment for erectile dysfunction, a common side effect of treatments for prostate cancer. Unfortunately these therapies can produce side effects of their own such as headache, visual disturbances, indigestion and prolonged erections. Participants also commented on the fact that the medications and aids used to treat erectile dysfunction are expensive and no pharmaceutical reimbursement can be claimed. In other words, while taking measures to treat the side effects of their cancer treatment many men are subjected to further distress as a consequence of using those treatments, resulting in further diminished sexual desire.
A number of men commented on the lack of spontaneity in their sexual relationships as a consequence of requiring medication or devices to attain an erection. For many of the men the side effects of medications or injection therapy to achieve an erection were sufficient to stop their use of them and for some the aids did not work.

“The Viagra that they gave me doesn’t work, makes me sick. It just doesn’t do anything at all. I feel really crook.” [ID 5, age 60]

“I have tried a range of physical aids ... the most successful is to use something like Viagra or one of those. I can actually partly engorge my penis, in a crouching position ... and I bought myself parts of those vacuum kits, with the rubber bands so I can ... achieve enough of an erection to have penetrative sex but it’s a bit of a production...you make a booking”. [ID 9, age 62]

“The cost is the thing. It’s out of hand. Like a tablet is $12 a time (and that’s discounted). The injection is about the same. You got to this company and they say ‘we’ll give you a capsule for your needles and that’s $750 which will last you 6 months’. Where do I get $750 just out of your life...The people that need it, who’ve had the operation, should be looked after. That’s what sort of annoys you. I’d like to see it lower (in cost).” [ID 21, age 65]

“I get indigestion from some of those tablets ... I tried the needles – they’re alright but I might have sort of overused the needles in the sense that I started to get that Peyronie’s disease, the bend. So I sort of backed off that – these are the sort of things that put you back. That’s what lets you down.” [ID 21, age 65]

x) Lack of sexual intimacy

Some men were quite resistant to using medication or devices to achieve erections either because of what they had heard about possible side effects and/or concerns about injecting themselves in the penis. Renegotiating sexual intimacy with their partner after treatment was difficult for some participants even if men were willing to try forms of non penetrative sexual activity partners were not always willing to participate, particularly if such activities had not been part of the couple’s pre-prostate cancer sexual repertoire.

“I can bring her to orgasm occasionally, only after I’ve had the needle though.” [ID 6, age 58]

One man who was unable to achieve spontaneous erections reported he would not consider non-penetrative sexual intimacy and therefore he and his partner did not engage in any form of physical intimacy.

“I’m not comfortable with the pumps or things like that. I’m not comfortable with that.... No I couldn’t come at putting a needle in it... (outercourse, manual stimulation or oral sex) is not an option.. No, not at this stage.” [ID 7, age 61]
b) Changes in Self-Perception

A number of the participants described changes in how they saw themselves as a response to the physical changes such as urinary difficulties, sexual issues and reduced penile size that they had experienced following treatment. A number of the men were quite articulate about their feelings but most struggled to find a concrete term for what they experienced.

"I think my impression of myself now as a man (is) a bit lower than before I had that operation." [ID 5, age 60]

"It’s very hard to put (the effect of changes in sexual function) into words... it’s part of your self image, your self confidence...when it happens it really does change you." [ID 2, age 54]

Many of the men reported that the physical changes had a negative affect on how they saw themself in the world, that is, on their self-perception and sense of self-esteem. Some described feeling less confident about their ability to engage in sexual activity, particularly in the case of men without partners, and some men reported a negative impact on their perception of their ability to participate in non sexual but stereotypical male behaviour. One man reported the broader effect of surgically induced impotence on his confidence to go four-wheel driving in the same “aggressive” manner as he did prior to treatment.

“I don’t sort of feel confident to be with someone sexually now” [ID 11, age 67]

“It’s changed how I see myself (in the world) a little. It’s one of those ethereal things that you just can’t really put your finger on ...you feel wounded, a bit less than what you were... if I had been 20 years older and I’d sort of faded away in that respect I imagine I’d feel totally different. But I was as good as gold and then BANG, gone!” [ID 2, age 54]

“The self esteem gnaws away at you in really unusual situations ......I love four-wheel driving, I try not to take unreasonable risks but the extent to which you might take the risk is just.... for some reason ... diminished by your lack of confidence...self esteem and self confidence are really knocked around. Sexuality is important but self esteem and self confidence tend to hang off that issue.” [ID 9, age 62]

Some of the men who reported having a good response to medical therapy to achieve an erection commented on the additional benefit of the restoration of their confidence in themselves as males.

“Since having the needles it’s given me a lot more confidence...It’s a lovely feeling, you feel very proud of yourself. You put the needle in and everything’s working again. Being a selfish male and my ego...” [ID 6, age 58]
Despite the changes men felt in their self-confidence they usually managed general social situations without difficulty. Some single men meeting new people reported they chose not to become involved in social interactions likely to lead to intimacy because of their loss of sexual self confidence. Some men involved in a partnership also experienced problems with self-esteem due to changes in their sexual function.

“One of my friends has been through this, he said ‘I’m happily married but what if I wanted to have an affair with somebody’. I’d never thought of it that way and thought “who wants to” but I know what he means. You’re suddenly a different, non-performing... you’re almost like ...the eunuchs ... you feel like you’ve been neutered almost. A normal healthy, heterosexual male as far as I know, feels that’s a powerful thing for him and to have it taken away takes a bit of you away.” [ID 2, age 54]

“... meeting someone new you haven’t got the confidence that you had before...Oh it has slowed me down and makes me a bit wary if I’m meeting someone new or something like that, you know. If I think there’s potential there I sort of have a lack of confidence.” [ID 15, age 59]

“(When I lost the erection the first time I was with a particular girl she said) “oh yeah, don’t worry about it” and got up and left, and I’ve never seen her since after going out with her for about 3 or 4 months, and I had known her for about 11 years down the nudist beach just to say hello to... no communication whatsoever now. Yes that was a bit of an affront on my masculinity and it was a deadset head job - not that sort!” [ID 12, age 51]

“And I can shut out the issue when I’m in social situations. That’s not a problem, it doesn’t bear down on me to the extent that I’m a social misfit but it bears down on me more particularly in my own self esteem and my own relationship with my wife.” [ID 9, age 62]

Some men reported they now felt inadequate as a result of changes in sexual function and reduction in the size of their genitalia. This aspect of self-esteem was compounded for some as they sought to overcome erectile problems and even obstructed their uptake of possible management options. One participant was put off by the information DVD for injection therapy, which showed a well-endowed man, clearly not suffering with reduced penile size following treatment for prostate cancer.

“The bloke in the demonstration film was built like a bloody horse so he had plenty to poke the needle into and I just got depressed about it... and the vacuum pump, it was built for a bloody horse, it was massive and it was just too depressing so I didn’t pursue that.” [ID 9, age 62]

Not all men viewed themselves differently as a consequence of side effects of treatment. One participant reported he was adapting to erectile dysfunction and urinary incontinence but did not feel his masculinity was affected. Two participants had already adapted to changes in their
sexual relationships prior to experiencing erectile problems post surgery; one as a consequence of erectile dysfunction prior to a diagnosis of prostate cancer and one as a consequence of his partner’s low libido. They continued to cuddle and enjoyed infrequent sexual intimacy without penetration and reported no effect on his feelings of masculinity.

“You’ve got to learn to live with the side effects. But I wouldn’t walk around worrying about losing my manhood and things like that.” [ID 15, age 59]

“I still feel that I’m a man.” [ID 4, age 63]

The time spent as a patient, reliant on young, inexperienced staff in an unfamiliar environment when feeling physically weak was also reported as difficult. A man who described himself as normally strong enough to be assertive about his needs described feeling helpless while in hospital and that remained as an unpleasant memory about 2 years post surgery. As a patient, unwell, in bed and in pyjamas, one man described feeling more vulnerable and less of the person than he normally felt himself to be and recalling that time and how he felt moved him to tears. Surgery left men feeling physically weaker than previously but they also described feeling unable to speak up for themselves and articulate their concerns and preferences, which was very different after years of feeling like a strong male in control of situations.

“There were a couple of occasions when I felt in the ward that I was being left alone when I needed help. I was under the control of a student at the time and she was good and I’m not knocking what she did but she left me and I didn’t know what I was doing.” [ID 16, age 66]

“...by then I had been through the surgery and I had been in the hospital and I had had the disempowering experience of hospital for over a week and I didn’t have the fight in me.” [ID 10, age 66]

“... coping with 5 grandchildren (visiting) at the one time and I think it would have been important for me to say to my family, it’s good I know you’re interested but just one or two, which was difficult at times.” [ID 16, age 66]

Some men reported being aware that, as a result of the physical changes which followed their treatment for prostate cancer, they now had a level of self awareness previously not experienced. This self-perception seemed to have allowed them to accept the changes and the impact of those changes on their lives and this in turn had allowed them to “move on” to a new “normal.”

“...there was a realisation at one stage...I guess prior to this experience it (sex) may have been mechanical to a degree. I mean that’s a hard thing for a man to admit. You have a mindset about exactly what it is.” [ID 18, age 53]
Some participants reported a detrimental impact on self-esteem and self confidence related to discrepancy in desire for sexual rehabilitation, when partners who had been otherwise supportive in terms of diagnosis and treatment exhibited considerably less or no interest in resumption of erections and penetrative intercourse and the interventions this required. Such discrepancies and the effects on self-esteem and self confidence made it difficult for some men to accept the changes in their sexual function. For some participants, side effects of prostate cancer treatment exacerbated existing issues in their life and/or relationship which in turn led to a negative impact on self-esteem.

“I began to get some sort of realisation of self which I’d never ever had before.” [ID 10, age 66]

“But I thought that the fact that I couldn’t make love properly anymore had affected my wife. She says it didn’t but you know. She even, she asked her sister how many times they make love. They make love twice a week and I’m thinking, that was an issue... see how it’s preoccupying a lot of things even though you try not to make it, it does. It’s part of your life.” [ID 6, age 58]

“I think my impression of myself now as a man (is) a bit lower than before I had that operation. Even as a husband, I think that’s changed entirely... Definitely changed.” [ID 5, age 60]

“Well, I ‘rattle it up’ and she says ‘alright, come on’ but that’s not the way I want it. I don’t want the ‘let’s do it’ because I’ve ‘rattled it up’...It’s getting her at the right moment, getting her in the right mood. Before (treatment) it was a couple of times a week but now it’s nil, very low, rare, very rare.” [ID 21, age 65]

c) Psychological adjustment

At the time of diagnosis most of the men had no symptoms relating to prostate cancer so it was difficult to comprehend that there was anything wrong and most described a feeling of shock when they were first diagnosed. Living with the consequences of prostate cancer treatment was difficult for many of the participants, a number of whom reported experiencing emotions such as anger, depression, disappointment and a sense of loss associated with changes in sexual function, penile shortening and loss of libido. A number of the men also described recurring feelings of anxiety around the time they have a repeat PSA test as part of their ongoing follow-up after treatment for prostate cancer.

“You’ve got no problems except urinating was slow (before the diagnosis) ... I felt perfect apart from that. So when I got told it was a huge shock.” [ID 19, age 64]

“My penis goes inside my body and that annoys the crap out of me.” [ID 7, age 61]

“You get pretty angry at times... feeling pretty shitty.” [ID 9, age 62]
“I hate going back (for review) and I hate the PSA readings because you worry, “oh what’s this going to be?” and it’s always nothing there.” [ID 6, age 58]

The use of ADT either alone or in conjunction with another therapy such as radiation, and its associated mood swings in some of the men, was reported as exacerbating negative emotions already being experienced. One participant being treated with ADT with its related loss of libido, described feeling jealous of his wife when he became aware that she masturbated.

“My wife has had to put up with a lot of shit from me...my mood swings and when I get tired from the hormones and things like that. I think she puts up with it real well.” [ID 7, age 61]

“I felt a little bit jealous if I knew she was masturbating.” [ID 3, age 60]

Some men reported feelings of disappointment and even depression at the way life was for them now.

“And it’s hard, sometimes, some days it’s very hard. And you get disappointed but you know, you’ve got no choice.” [ID 6, age 58]

“I don’t have crying fits, I used to but I don’t now.” [ID 7, age 61]

A number of the men described feelings of sadness or sorrow associated with a sense of loss as a result of changes in sexual function and some, particularly those with progressing disease, reported such feelings associated with a change in the expectation of what they thought their life would be in the future.

“I used to wake every day with a hard-on and I miss all that.” [ID 11, age 67]

“The whole thing of sex that ends in intercourse and the build up to it is an emotional experience and that is a deep thing, it was for me at least, and that’s not there.” [ID 2, age 54]

“I can remember the earlier days and you’d see an elderly couple together and feeling quite sort of jealous and angry about it and thinking ‘that’s not going to be me.” [ID 1, age 62]

A number of the men were diagnosed around the time they were to retire or soon after retirement. One man described trying to manage both changes, which occurred around the same time, as being quite difficult and acknowledged that the prostate cancer had made his retirement, normally seen as a
significant life change, seem insignificant in relation to being treated for prostate cancer. He commented that life with prostate cancer was not the way he had expected his retirement to be.

“Managing either one at one time is difficult, managing both together was quite difficult although the retirement sort of sank a bit into insignificance in relation to the prostate cancer. In your quiet moments now you still think this wasn’t exactly what I intended out of retirement.” [ID 9, age 62]

Despite the difficulties he had encountered since diagnosis one man was also able to see a positive outcome from all he had been through in terms of his relationship with his daughter.

“There’s a lot of positives out of it. It’s bought me closer to my daughter, and it’s bought me more closer to my daughter than I ever thought (possible).” [ID 7, age 62]

d) Existential issues

Death from prostate cancer was not seen to be likely in the immediate future, possibly because most participants had been diagnosed with early prostate cancer and were given a good prognosis. The concerns for most participants with localised disease, after the initial shock of diagnosis, generally seemed to surround the side effects of treatment rather than the risk of dying as a consequence of this disease. The men living with progressive disease were particularly aware of their reduced life expectancy and had a heightened sense of the importance of time and how they used it. One man wanted his wife to spend more of her time with him while another, perceiving that his wife was possibly trying to encourage him to get the most of the time left to him, wanted on occasion to be left to his own devices and to choose what he wanted to do with that time.

“I really think the major issue is the reduced life expectancy. I think following the surgery we were getting through a lot of the issues and dealing with them reasonably successfully and you sort of get to a stage where you think I’m probably right now and then it turns out you’re not. I think that was really very, very difficult to take on board. That was probably the most difficult, the most difficult day.” [ID 9, age 62]

“(My wife is)... of course, supportive, you know, enormously but now consumed with caring (for other aged and infirm relatives), and, you know, at times I find myself a bit resentful about that because I think, well gee, I haven’t got all that long left either, you know. And I think that’s a pretty normal response in any relationship.” [ID 1, age 62]

“(My wife) is enthusiastic and encouraging which in itself can be a bit of a problem. I just want to sit down and enjoy a cup of coffee today but I feel if I’ve only got 10 years left I don’t really feel as if I’ve got to run around and do everything tomorrow.” [ID 9, age 62]
e) Changes in Relationships

Most, but not all, of those men who were married reported that a diagnosis of prostate cancer had an impact on their relationship with their wife.

“I couldn’t say that it’s having a detrimental effect on our relationship or our life generally.” [ID 13, age 64]

Some men reported they had taken the opportunity to re-evaluate their life, particularly the intimate aspect of it, and some managed to see the positives therein. They reported that despite the problems associated with treatment their relationship had survived and in many cases had been strengthened, sometimes despite being unable to resolve issues, such as changed sexual function, in a manner satisfactory to both.

“There are a number of changes to be managed and sort of negotiated... oral sex... the lifetime horizon... we’re both no longer working and spend a lot more time together... the key message is that you’ve got to expect there will be changes...but none of those changes have been for the worse.” [ID 9, age 62]

“You’ve got to be able to say ‘well this is an investment in each other’... one or other of us can say ‘not tonight dear’ and not be offended by it and not be upset about it. The quality of the relationship is really important where bruised egos aren’t going to happen.” [ID 18, age 53]

“I do feel that I’m in a very loving relationship and I am very well loved. I think that has always been the case but it is probably more so after the operation.” [ID 9, age 62]

“It is not just the sexual stuff... it’s about your feelings for each other...as a man... it’s not just about satisfying yourself but it’s about making sure that you’re satisfying each other... that’s with the sexual aspect, the emotional aspect, the communication. I find myself cuddling my wife a lot more often. I find myself being very considerate and watching her and anticipating...I’m more in tune with maybe how she’s feeling or how she’s responding.” [ID 18, age 53]

The problems associated with prostate cancer treatment seemed to highlight communication difficulties related to feelings or sexual issues which may have been present but not addressed or resolved prior to diagnosis, and these increased in magnitude for some men/couples, as they tried to cope after treatment. For some men the issues were in the marital relationship itself, but for others it was life situations that had been managed prior to diagnosis but had a greater impact now when living with prostate cancer. For single men, side effects of treatment were reported as inhibiting their ability to seek a relationship.

“I don’t think the feelings have changed, I think the rejection has sort of got stronger. If I try and instigate any sort of sex at all and she just rejects it, then I just turn over and don’t say nothing. I just go to sleep and forget about it. Next day I won’t talk then you start to talk a
little bit later and then I think she starts to realise what happened 2 nights before and then things sort of go alright for that next night and things go their merry way again” [ID 5, age 60]

“I’ve hidden myself away. I don’t feel confident ...I’ve felt more comfortable once I’ve got inside my little door... I don’t go to any of the bars. I don’t go anywhere that I used to go to meet other people.” [ID 11, age 67]

Partners were all described as being very supportive in terms of diagnosis and treatments even if issues related to treatment side effects were problematic. Some men described themselves as being angry or moody and were aware their partner was usually the target of their ill-temper but all who did so reported that their wife “put up with” their husband’s bad temperament. As reported earlier regarding self perception, some men reported conflict in their relationship when their wife was supportive in terms of their diagnosis and treatment but had significantly less interest, if any, in the resumption of erections and penetrative intercourse.

“She has been excellent. Actually sometimes I get very irritable and cranky and I know I shouldn’t.” [ID 3, age 60]

“My wife is not as interested (in sexual activity) now as she was because of the incontinence... she has been very supportive but now I think she’s decided that it’s been 2 years so get over it. We’re still happy to do the other things... without penetrating... you’re still able to get the feel of ejaculating even though nothing happens...it mustn’t be much fun for my wife...you’re just climbing on top and rolling around.” [ID 6 age 58]

Some men reported ongoing difficulties in their relationship, and one man reported that his marriage of over 30 years failed following treatment. Another man who had a loving but sexless relationship had discussed his increased sex drive following treatment with his wife and reported she had assented to his pursuing his sexual needs outside the marriage and yet another man, while declaring that he still loved his wife despite long-term and ongoing sexual difficulties between them, indicated he would now like to live alone although he stated he did not think his wife was aware of this.

“(Prior to the operation) I had a very high interest in sex but the interest didn’t necessarily equate to the activity. I had a specific treatment to try and maintain (sex function) ... things worked from time to time after the operation with my wife... I thought she might understand...then it was sort of no good. There was other stuff going on... I’ve met another lady... there is still a fair bit of drama but my interest is good and everything seems to be working out.” [ID 20, age 59]

“I really want to be by myself now. I’ve spoken to her about it and I’ve got no reply of course, “do you think you can love someone but not want to live with them” and she just looks at me and “what are you getting at?” and I walk away. Yeah, she’s helped me a lot too. I’ve got to get out of this and move on and see that comes back to what I was saying before. You’re manhood, its rejection.” [ID 5, age 60]
For men without partners the absence of that significant other or close, supportive friend seemed to be felt more intensely at a time of crisis or need, such as arises with a diagnosis of cancer.

“... even though I was told, I still had to let it sink in. I had to read it and read it and read it and read it but I needed someone to read it with me and discuss it with me but there was no-one there to do it.” [ID 11, age 67]

THEME 2: COMMUNICATION AND SUPPORT

Within this theme there were six sub-themes relating to communication and support: Doctor-patient, Partner-patient, Other Health Professionals-patient, Other Men with Prostate Cancer and Support Group-patients and Information Needs and Recommendations for the Future.

Men who reported they had good communication with their partner, doctor and other health professionals, and those who had access to good information, seemed better prepared for treatment, particularly with regard to side effects. They also reported being better prepared for post-treatment changes and were able to more readily adapt to ongoing side effects of treatment.

a) Doctor-patient communication

With hindsight and the benefit of experience some of the participants reported they now realise that some of the doctors involved in their care had not provided sufficient information or explanation at the time of diagnosis to allow the men to process and understand what they had been told. Some men reported only seeing an Urologist who explained the different treatment options rather than being referred for specialist information regarding radiation options. Men reported that with hindsight they consider the risk of side effects was minimised in some instances, which left them feeling now that they should have been given more information about potential side effects, likely risk that they might occur and how they could be managed.

A number of the men described receiving what, with the benefit of experience, appeared to be insufficient information. However, they seemed to accept this because of the trust they had in their doctor, and in the early phase of a prostate cancer diagnosis many men did not know enough about the disease and its effects to know what questions to ask their doctor. Some men who saw more than one specialist commented on the differences in how doctors provided information.
“He’s a wonderful doctor and he was an excellent surgeon but he virtually said to me “don’t worry, everything will be right. You’re young.” and I felt very confident that nothing would go wrong and eventually it would fix up anyway. “But I’ve got to tell you there’s a 2% this and a 2% that” and I thought “oh well, it won’t affect me” and everything did. Two percent of everything - that made me think, “oh I was 2% of everything” and even things that weren’t a percentage I got.” [ID 6, age 58]

“I think they gave me enough information. They didn’t go into details and I think the Urologist is very quiet – if you ask him he’s very good and knowledgeable but he’s very quiet.” [ID 3, age 60]

“The Urologist was good, I like him, and to me he’s the old style doctor. He tried to keep you focussed and he doesn’t like telling you the bad things. The Radiation Oncologist, when I first met him, said ‘if you don’t have this and if you don’t do this and this, you’re going to die’. I said ‘can you cure it’ and he said ‘I don’t think so’. He was straight to the point, what I like.” [ID 7, age 61]

Some men noted that they felt uncomfortable talking about sexual issues and if their doctor did not raise the subject, neither did they. Some also noted that at the time treatment options and side effects were being discussed they were unaware, because of their limited knowledge of prostate cancer, what to ask their doctor. A number of participants noted that their doctor raised the topic of sexual function often which was appreciated particularly if the man was uncomfortable having that particular conversation.

“He didn’t tell me the after effects and to be quite honest I didn’t ask.” .” [ID 7, age 61]

“Honestly, my urologist said ‘why I keep bringing it up is because some people won’t talk about it (sexual side-effects) ’ and I suppose that’s right.” [ID 4, age 63]

Some men reported that doctors sometimes used euphemisms for sexual changes which, in light of their initial lack of knowledge about the disease and associated issues, men failed to understand. For example, one participant who was told “you’ve finished with having any more family” thought his doctor was telling him he’d be infertile after treatment which was not a problem for him – unfortunately the participant at the time did not understand this to mean impotence or lack of other sexual function.

“My urologist, I’ll use his words said ‘that you’ve finished with having any more family.’ That was the words he used.” [ID 7, age 61]

Men reported a great sense of trust in doctors who provided them with information and gave them the opportunity to ask questions. They reported that a doctor’s good “bedside manner” provided much needed and appreciated reassurance.
“I’m lying in the room outside the theatres...a bit nervous...and the urologist walked in ...he
looked down and patted me on the shoulder and said ‘you’re in good hands.’ When I woke up
the first person I saw was him, leaning over me and he said I’ve phoned your wife and
everything’s gone well’... it really helped.”  [ID 4, age 63]

“I wrote all the questions and asked him when I went in there and he said ‘don’t worry about
the other people in the waiting area you’re in here now and I will take the time to answer all
your questions’ and he did.” [ID 8, age 69]

However, the lack of empathy from doctors (and other health professionals) also resonated in the
men’s discourses. One man reported he was still not sure he wanted to proceed with surgery as
late as being in the anaesthetic bay outside the operating theatre. According to the participant,
despite his concerns and a request to speak to his urologist before proceeding it seems a brief
pre-operative check by the anaesthetist (with no opportunity to express his concerns) may have
been occurring at the same time as he was being sedated and when he was next aware of his
surroundings the operation had been completed.

“I was very undecided about having it (the operation) and the anaesthetist walked in and
introduced himself, said ‘do you know your name, yes. How old are you, yes. Do you know
what you’re having, yes? I’m the anaesthetist and my bill’s ‘something.’  I looked at the
nurse, a bloke, and he said something about the cannula and I woke up at 6.30pm. I even
told the bloke I really wanted to talk to the doctor and I think we were interrupted by the
anaesthetist.  Yeah, I really wanted to... I was asking all the different things, I told him I
wasn’t real sure, whether I’d have it or not. I’m not sorry I had it, not now.”  [ID 7, age 61]

“The surgeon that actually did my operation was the Registrar. He’s lovely but when I was in
hospital I didn’t know who he was when he was coming round to see me. He should have said
I’m Dr X, I’m the one who cut you open and we did this and this...and I thought he would but
he didn’t.  I didn’t know who he was.” [ID 11, age 67]

“There is has very unsympathetic... the doctor had no bedside manner, no feeling
whatsoever.  I was quite disappointed in and don’t think I’d ever want to see that doctor
again.” [ID 15, age 59]

A number of the men in this study reported they had not been referred for psychosocial assessment
or provided with other opportunities for information and support, other than through their GP and
treating clinician. Some men reported their doctors did not address psychological issues and failed
to pick up on the cues patients were giving about their emotional distress. One participant reported
that, despite feeling extremely distressed and regularly seeing his GP regarding this, he had to ask
for a psychiatric referral rather than being offered it in the first instance.

“I don’t think in my case if the facility to explore the impact of the outcomes was available that
it would have changed my decision but it may have helped change the effect of those impacts on
me. You get pretty angry at times so maybe that would sort of help modify the onset of feeling pretty shitty. I only spoke to the psychologist after I started coming to the clinic about 3 years after diagnosis (and 18 months after recurrence of disease).” [ID 9, age 62]

“With the resultant depression I became extremely distressed and morose and ... I asked my GP to refer me to a psychiatrist which he did quite readily.” [ID 10, age 66]

Many of the participants reported that their cancer specialists appeared to be more focused post-treatment on monitoring of the cancer and impotence and in some cases, incontinence, seemed of much less importance.

“I was always confident ... ‘cause (the doctor) would say ‘Oh, you’re not better yet.’ In other words, you’re going to get better soon... my physiotherapist said ‘it takes 1 1/2 years before you’re back to normal’ and I’m thinking, ‘Oh, it will improve.’ but I just know it won’t. It’s gone. It would have been good if ...at the beginning ... they had explained what you could do.” [ID 6, age 58]

“I would hate to think that all men think it’s just about sex. It’s about your life.” [ID 19, age 64]

“ I didn’t know about Viagra or anything like that. It was just in passing one day (the doctor) said to me, ‘Oh, why don’t you try this drug. It’s better than Viagra’ and of course it had no effect. And then about a year later he said ‘oh, why don’t you try the Caverject.’” [ID 6, age 58]

b) Partner-patient communication

Men reported varying degrees of communication in their relationships, particularly related to sexual activity. Some couples had difficulty discussing the changes that had occurred and the various management options. Some men reported they were not prepared to explore the options of penile injections, vacuum pumps or medication to achieve an erection, which some considered to be a requirement for sexual intimacy because they defined this as penetrative intercourse.

“It doesn’t worry me not having (sex) - we’ve discussed it that there’s nothing we can do (tried Viagra but won’t think of injections or pumps etc) so there’s no sex life in our place...there’s no sexual intimacy...we hug and we kiss and do all that but other than that there’s no intimacy whatsoever.” [ID 7, age 61]

“I think my missus would be absolutely shocked if it she knew. I think that deep down when she found out I was taking these tablets (Viagra), she wasn’t happy with that, and I think if she found out I was having injections – geez. I haven’t told her about the injections, I’ve sort of kept that one to myself.” [ID 5, age 60]
"As people get older ... they have certain views of what’s normal and what’s achievable and what’s not achievable, so while I’d be desperate to try some other activities such as oral sex ... my partner is not ... how the hell do you change your partner’s view on this." [ID 9, age 62]

Some men reported they were aware that how they had interacted in general as a couple prior to diagnosis clearly impacted after treatment on their ability or inability to work through issues.

"Well, what you get afterwards is only a product of what’s been going on beforehand isn’t it." [ID 2, age 54]

For some participants, communication strategies which had been adequate in the past were no longer suitable, particularly when couples had to adjust to living with side effects affecting their sexual life. For some of these couples sexual activity became an item of trade rather than a mutually acceptable negotiation. It would seem from some of the responses made by the participants that some female partners did not have the same interest in resuming sexual activity and had developed strategies to avoid it. Other participants who were part of a couple which had communicated well on difficult issues in the past reported they continued to communicate well on the difficulties associated with life after prostate cancer treatment.

“She says “ I don’t want to talk about it, let’s not talk about it”” ... she doesn’t want it to lead to anything... sometimes it’s almost condescending when she says ‘we’ll make love next Friday. If you’re nice and if we don’t fight in the meantime and I’m feeling alright’ I think ‘well, to hell with you, I’d rather not do it then.’ Sometimes I feel like that. Whereas that never happened before.” [ID 6, age 58]

“There’s lots of communication if there’s an issue... and basically that’s continued.” [ID 18, age 53]

One couple who had been experiencing difficulties in their relationship for about 5 years prior to his diagnosis and treatment eventually separated after about two years. He is now with someone new with whom he has been able to discuss the effects of his treatment and who he says is very supportive.

“... even though I talked about the treatment and what I was going through, wanting to find the doctor that could ensure erections after the operation, we didn’t actually talk about what will happen after the operation. She (wife) knew what I was going through, she knew why I was going to see all these different doctors and all this, but we didn’t actually sit down and say “ok, when the operation takes place and whatever happens afterwards, what’s it going to be like?” We didn’t talk about that.” [ID 20, age 59]
c) Communication with /support from Other Health Professionals

A number of the men reported receiving good support from health professionals other than their doctors, and the interactions the men had with them since their diagnosis were mentioned frequently during the interviews.

“...doctors, they’re very clinical...all coming from a technical point of view. I think talking with the nurse was really good, that was really the first time I’d spoken to somebody about it because it was all that fresh to me. That was very helpful.” [ID 2, age 54]

“The psychologist talked about “future loss”, and that was the thing that really got me, still does a bit. But giving it a name that was quite helpful... I think that helped my wife too.” [ID 1, age 62]

“...my gratitude for the nurse at the hospital. She absolutely got me through the hard time. Some of the little things she did for me while I was in hospital helped me greatly. I think she does it with everybody not just me. She’s very professional and made me relax that much more.” [ID 19, age 64]

“...knowing (the nurse) personally was good because I could speak to her personally from meeting her in the hospital and that. That’s why I feel so relaxed because I know that I can speak to (the nurse) about everything without feeling embarrassed or things like that. With a complete stranger I don’t know that I would have been so open. I have a lot of confidence in her.” [ID 6, age 58]

“Talking to the nurse at the hospital and the staff from the Cancer Council Telephone Support Group, talking to the psychologist ...‘there is light at the end of the tunnel, there is hope’. That’s the people part of it; I think it is really important. That hope factor today is not necessarily the way it’s always going to be and each person is different.” [ID 18, age 53]

Failure in coordination of care was noted by two men who had experienced significant delays in referral for management of erectile dysfunction.

“I’m waiting for someone to tell me (the appointment is organised), the doctor’s supposed to have sent the fax through to them, and I’m waiting and waiting and ok they’re busy, they’re busy, so after about 6 weeks or so I phoned up and said ‘what’s happened?’ ‘Oh we sent the fax’ and they find no one’s got anything so no appointment gets set up and then months go by and finally we get it sorted out and the appointment is about 3 months ahead.” [ID 2, age 54]

d) Support from Other men with Prostate Cancer and Prostate Cancer Support Groups

From the discourses all the men welcomed support and information from sources other than their health professionals or partner. A number of men attended a support group after treatment and although some men did not want to participate in groups they reported that they liked to receive ongoing information relating to their cancer, treatments etc via the support group’s newsletter.
The men who had attended a support group described it as a reliable avenue for gaining further information and a confidential and safe opportunity to talk about any concerns they may be having.

”The newsletters … they’re good because they tell us things and there’s somebody still interested in you rather than saying “look, we’ve done all we can for you.” [ID 2, age 54]

“My friend who’d been through it, he and I had a very frank talk and he was able…because he’d never been able to talk to anybody. He had it done elsewhere and didn’t have any of this support stuff and was a bit agog at the amount of support that was available here …he didn’t have any of that. I gather he was just left to his own devices.” [ID 2, age 54]

“I’d heard about the Support Group and I opted to go to that straight away to find out what it was like and I was so impressed the first time that I’ve been every time since except when I’m away. I think they’re very good, I’d recommend them” [ID 8, age 69]

“Those meetings are pretty good. I understood more about things…I learned a lot really. And it’s good to hear other people’s problems and what they had and all those sort of things”. [ID 3, age 60]

“The coordinators say ‘everything that happens in this room stays in this room’ so you just open your heart and you talk and it’s just for this room, it’s confidential’. And that’s understandable. It’s personal and you just glean what points are relevant to you.” [ID 8, age 69]

Although some men had never attended the group or had in the past but no longer did, they reported they derived reassurance knowing that it was there if they needed to access it for any reason.

“…knowing it (the Support Group) is there…I don’t make a lot of contact … knowing it’s there is good.” [ID 2, age 54]

e) Information needs and recommendations for future

Of the 24 participants only 9 had been referred to another health professional (not a doctor) for support at the time of diagnosis. During their interviews, while discussing their experiences following a diagnosis of prostate cancer, a number of the men made suggestions for improving the provision of information and support which they felt would have helped them through their experience of diagnosis, treatment and living with side effects. Some men noted that, from their experience, information provision and support from other health professionals should begin as soon as possible.

“I think … when the doctor diagnoses a person with prostate cancer there should be some mechanism that they then refer, say to the Cancer Council or direct to the likes of (a prostate nurse)...and then …the person is given the opportunity of coming to a Support meeting or talking to people”. [ID 7, age 61]
A number of men reported that when the word “cancer” was used it was difficult for them to accept let alone comprehend much information relative to their diagnosis - some men commented that patients should be encouraged to bring someone with them to appointments, particularly when attending to get test results such as prostate biopsies.

“When somebody says you’ve got cancer you do go blank.” [ID 6, age 58]

While some of the men reported being given minimal information after diagnosis other than a book to read by their specialist, others reported their doctor had been willing to answer their, sometimes numerous, questions. With the benefit of hindsight some of the men commented that more information and explanation may have helped them adjust to the changes, physical and emotional, that they underwent as a consequence of treatment for prostate cancer.

“The urologist gave me a book to read and said come back and ask any questions you like. I went back with a foolscap page and a half of questions and he was not concerned ...and he kept saying “any more, any more”. He was very good actually. He went right to the bottom and he answered every one and I picked up another couple of questions out of his answers.” [ID 8, age 69]

For some the time frame between diagnosis and treatment did not allow for much exploration, understanding and discussion of information.

“The discussions were really more about managing the battle rather than the peace. The focus was really on getting through the treatment, how we’d deal with that but understanding that there were some physical aids available. That (potential side effects and their treatment) sort of all paled into insignificance just in relation to getting through the biopsy, the surgery, the recuperation and all that sort of stuff.” [ID 9, age 62]

“I was in hospital the next week (after diagnosis - not allowing much time to explore options or what the future might hold.)” [ID 6, Age 58]

A number of men indicated a need for more in depth information from the beginning although their experience of the prostate biopsy was only mentioned by a few men. One man described the biopsy as a very unpleasant experience which, in his case, was followed by septicaemia - he reported that he did not have enough information preceding the biopsy, what to expect at the time of the biopsy and afterwards. Another felt he had missed out on practical information regarding bleeding and “do’s and don’ts” following the procedure. Men commented that clear explanation and reassurance regarding procedures and treatments may have helped to allay their concerns.
“(The biopsy) was a really bad experience. I just felt that the advice and the preparation I got, was very unsuitable. I think patients need to be more aware of what the treatment involves and the extent to which it might impact you afterward. It was probably the most painful and unpleasant procedure I’ve ever had and that was not what my perception of it was going into the procedure.” [ID 9, age 62]

“...as far as the biopsy thing goes, there should be a bit more talk on “oh well you may pass some blood when you ejaculate or urinate for a couple of days or a week later” but I was actually receiving oral (sex) at that time and luckily the person pulled their head away because, I’ll put it this way, it looked more like a very heavy period than ejaculate. “ [ID 12, age 51]

Most of the men indicated that, to assist in reducing anxiety and improving understanding of what men were going through in general, more information should be given regarding exploring the feelings men and their partners may experience at this time as well as procedures and side effects.

“The information about the feelings is missing. There’s plenty of information about the changes to erections, plenty of information about the possibility of incontinence.” [ID 20, age 59]

One man when questioned as to whether he thought, in hindsight, that the information he’d been provided was sufficient, replied with a very definitive “no”. However he also went on to say that he had only read a few pages of the information he’d been given, although he later searched the Internet. A few of the men reported that when first diagnosed they did not want to access more information and in some instances chose not to read what they had been given.

“I got the book from my urologist. I read about 6 pages and put it down. I just said “oh, this is a load of crap” because I just want to go in....my attitude was, I want to go in, cut it out, do the time and go back to normal living.” [ID 7, age 61]

Nonetheless, it was clear that a number of men felt they had time to go over the information so they could better understand the situation and potential problems. Men also appreciated being given an opportunity to comprehensively discuss the information they were given with one or more of the following: specialist, GP, specialist nurse, partner or someone who had been treated previously.

“Sharing the literature... the stuff that was sent to me talked about erectile function post operation and both of us sitting and reading those then talking about it. And some of that stuff bathes over you in the next sexual experience so that it adjusts your expectations. It helps the better informed you are and the more time that you’ve got to be able to sit and read the literature, the more time you’ve been able to discuss what’s personally happening and how you are feeling about it and saying “you’re going to be alright, you’re better than what you were before.” [ID 18, age 53]
“(My doctors) are easy to talk to and they were people you could talk to and you knew that they knew what they were about... I don’t think I could have got any better help and support along the way and information”. [ID 13, age 64]

Information for some men appears to have been provided in a trickle down form and for some most of the information was gained after their treatment.

“When I went back to the doctor (after the surgery) I just asked him straight out and he just said that that was part and parcel of the operation- the incontinence, the loss of libido and the sexual function and he explained it all to me after the operation.” [ID 7, age 61]

“It was after I had the operation that I sat down and my wife and I had a long, serious talk about it ... We weren’t prepared for the aftermath of what happened. We weren’t prepared for that.” [ID 7, age 61]

The same participant, who admitted he had not read much of the information provided by the Urologist and had not sought a second opinion regarding treatment options, suggested that newly diagnosed men should be referred to other men who have been treated for prostate cancer so they can ‘tell them ‘this is what’s going to happen to you’. He commented that making the decision regarding which treatment option to pursue had been very difficult for him and he would have preferred the doctor to have made that decision.

“I don’t like doctors saying that “we can’t tell you what to do... If a doctor says you’ve got to do this, “this is what I suggest” instead of saying “well, these are the options” to you. They’re leaving the options open to the person. I think the doctors from the GP up, have got to be able to tell the patient but there should be more support for the person.” [ID 7, age 61]

Men felt that better preparation prior to treatment regarding living with potential side-effects after treatment would have assisted in their adjusting to life with side-effects. Better preparation was seen as being better informed before treatment about what management options were available in the event of side-effects occurring, e.g. couples being encouraged and supported to explore sexual activities other than penetrative intercourse, such as oral sex.

“I’m just saying to you that (issues surrounding exploring previously untried sexual practices (e.g. oral sex ) is a problem that may not have been really explored in any of the discussions with either the surgeon that treated me or the psychologist afterwards or any of the people demonstrating the sex aids.” [ID 9, age 62]
Early intervention for side-effects was also viewed as important and the early intervention should include appropriate and well-coordinated referrals

“This injection thing was supposed to be arranged some time ago but a simple thing like a cock up with some facts that somebody didn’t get means that this (appointment to trial penile injections) got delayed 4 or 5 months.” [ID 2, age 54]

There is so much to take in at the time of diagnosis and when undergoing and recovering from treatment that some men reported they did not consider the likelihood of disease recurrence.

“Do you know what might happen to me if I didn’t have this (brachytherapy) done? What would happen to me, I never actually asked that question before.” [ID 3, age 60]

One man who was found at surgery to have more extensive disease than originally thought, commented on the marked discrepancy between himself and the doctor regarding the timing of information, how much to provide and when. The doctor wanted to postpone discussion of “what to do next”, possibly because he knew that further treatment could be delayed in the short term however the patient, once aware there was a problem, wanted early information and a treatment plan.

“I was led to believe quite clearly ... when I was heading for surgery that it was going to be a beautiful clean-up job... everything had been identified as being contained... it proved to be quite the contrary and I had to extract that information. I got the impression (the doctor covering my specialist’s leave) didn’t really want to get involved.” [ID 10, age 66]

Men commented on the difficulty of really understanding the potential outcomes of treatment at the time of diagnosis and while undergoing treatment.

“I don’t think you really envisage what it’s going to be. It’s very hard to take it on board because you’re dealing with a life saving issue compared to a quality of life issue and the one does sort of swamp the other.” [ID 9, age 62]

“If I knew what the outcome was going to be, that the procedure wasn’t going to stop the continuation of the cancer I may well have made another decision to have no treatment at all but I accept that’s not foreseeable...” [ID 9, age 62]

Although men seemed to appreciate that too much information may be viewed as” frightening” by someone newly diagnosed with prostate cancer, some felt strongly that the risk and realities of possible side-effects of treatment, and the potential for the disease to progress despite initial treatment, should not be minimised
“Better preparation by way of information and less emphasis on minimising concern, and clearer warning about the potential for the tumour to go beyond the boundary of the capsule. As far as possible introduce all the potentials and do not gloss over anything.” [ID 10, age 67]

“If they’d said, don’t count your chickens before 5 years then maybe on the one hand that makes you quite on edge for 5 years but it does avoid the false expectations so I guess that’s a difficult balance to get. You don’t want to make people feel depressed for 5 years but...” [ID 9, age 62]

“I think a lot of education... if a person is diagnosed or any type of cancer, they should be referred then to (a health professional in a support role,) that type of person. Somebody gets in touch... something to put the person’s mind at ease.” [ID 7, age 61]

“I just don’t think you’re actually told enough by the doctors – I think you need a classroom or sit down with somebody that’s been there and ‘this is what’s going to happen’ and sit there with your wife.” [ID 5, age 60]

Men not in a relationship were very aware that there needs were somewhat different to men in a relationship in terms of information and support. As well as the impact that the side effects of prostate cancer treatment have on single men with regard to future relationships, these men may not have the opportunity to discuss their concerns surrounding the quite intimate nature of potential side effects.

“People that are by themselves probably need a bit more input...I don’t mean to hold their hand but just to make sure they’re not going down the wrong path, maybe tapping into them a bit more often.” [ID 12, age 51]

One man who was not referred to allied health professionals for pre-treatment support reported he was quite anxious and still undecided as to whether to proceed when admitted for surgery. He commented on what he sees as the importance of receiving good information early from more than one appropriate source. A number of the men made comments regarding the benefits they perceived of having access to other health professionals besides their treating doctor, and the opportunity of meeting with other men who have experienced the same diagnosis. Men seemed to feel that the majority of information given was relevant to treatments and what side effects might occur. However, after treatment the interval between specialist appointments lengthens and it is often during these intervals that men experience concerns related to ongoing side effects of treatment, so access to other health professionals at that time would be helpful.

“There’s one second in your life when you don’t know and five seconds later you do know so you can’t avoid that, it can’t happen gradually. There’s got to be a moment of realisation and I’m sure different people will react quite differently to that news and they probably need
some pretty strong support when that news breaks. I think people do need good support at that time.” [ID 9, age 62]

“I think there probably does need to be an opportunity, away from the surgeon, for discussion about those physical details in more detail than I received. I don’t think it would have changed my decision.” [ID 9, age 62]

“I don’t think the environment of a doctor’s surgery is a really good one, even one on one, to explain it all. You tend to be not all that relaxed. I’d recommend another form of educational tool like a presentation to a group who have been diagnosed. You know ‘this is what’s going to happen, what they’re going to do, the side effects of all of those.’ I think in that environment I would probably function a little bit better than one on one in a doctor’s surgery and ... having to get back to work...” [ID 17, age 58]

It was noted that provision of good information and support is also difficult when patients come from and return to regional areas where such support is less likely to be locally available.

“There should be some way for the doctor to interact with a prostate nurse, or in a regional area there should be some way a doctor can get somebody or can tap into his computer if there’s anyone around there who has had prostate cancer...whether or not they’re cured so that person can go to the person who’s been diagnosed and tell them ‘this is what’s going to happen to you’. The thing that worried me more than anything else was that I sat in the hospital and didn’t know what was going to happen to me. It’s alright to say “oh, you’re going to have an operation” but what does it mean.” [ID 7, age 61]

One participant commented that a higher level of education might make a man more likely to take advantage of support and education related to prostate cancer and to seek it out. He raised the question of how best to deliver support to people less able to negotiate the medical system.

“It’s very easy to look after people who are intellectually OK, who are reasonably informed themselves but it gets very difficult with people who can’t articulate what’s going on. ...people who take advantage of these things are the people who know about the benefits and understand. It can be cultural, or individual preference not to know too much or even being intimidated by the health professionals and not able to question.” [ID 1, age 62]

Some men commented about what they saw as the importance of raising awareness of prostate cancer in the community, which may contribute to earlier diagnosis.

“I want to do something locally so that if I can talk to someone who’s about to have the experience and I’ve done that on the telephone thing too and basically raise awareness because it’s with men, it’s a taboo subject.” [ID 18, age 53]
THEME 3: ADJUSTMENT PROCESS

The Adjustment Process after prostate cancer was the third major theme which emerged in the discourses, reflected in the sub-themes of Lifestyle Changes, Coping Strategies and Striving for Acceptance and Integration in what has become a “new normal” life for them.

a) Lifestyle changes

The post-treatment lifestyle changes reported by men varied. Some described lifestyle changes in terms of improvements they had made in their approach to their general health, particularly with regard to exercise and diet. For some men lifestyle changes included taking medication to obtain an erection and one man reported he had adjusted his meal times around medications to ensure the drug’s efficacy. Others reported changes in their daily activities, changes in sleep requirements because on ADT they always feel tired and men with continuing continence problems reported they now make it a point to know where public facilities are when away from home or the workplace.

Men on hormone therapy describe some weight gain since commencing it. Although one of those men related it to occurring since his operation this coincided with the commencement of ADT. A number of men reported an improvement in their overall attitude to their general health since diagnosis and now watch their diet and exercise more with one man being more particular about using organic products including soaps.

“I try to look after myself ... since I’ve had the operation I’ve got like a big beer sack in my abdomen and I can’t get rid of it. I’ve cut my meals down a little bit, instead of eating big plates of stuff ... and I’ve started eating fruit.” [ID 7, age 61]

“One of the big benefits that’s come out of it that I really do now look after myself. I don’t eat junk food or anything like that and we order online and certified organic – vegetables, fruit and all this. Same with skin and hair products. I really watch myself and hope to pass it on to our kids. My wife is starting to do it.” [ID 4, age 63]

“I guess I’ve always been encouraged to eat the right foods and I still do although I’m single and I just cook for myself. I still eat my green vegetables and that sort of thing. I think diet is important. When I’m by myself I cook the vegetables but I think you’ve got to help yourself a bit – look after your diet and that sort of thing. I think the diet is pretty important now.”[ID 8, age 69]

“I’m always moving, walking somewhere, and I swim. I’ve given up smoking. I mainly have vegetables – I throw it all in a big juicer – that’s how I keep healthy because I’m not much of a cook.” [ID 11, age 67]

Most of the men who had urinary continence problems post treatment reported that, in order to reduce the impact of that problem or improve it, they had undertaken lifestyle changes such as doing specific exercises (pelvic floor), reducing general fluid and alcohol intake, and forward
planning their activities and travel by investigating the availability of toilets. Participants who required medication to achieve erections reported they had to make changes relating to meal times to get the best results from certain products.

“I do those pelvic floor exercises ... I try anyway”. [ID 6, age 58]

“I’ve cut my beer consumption down.” [ID 7, age 61]

“But I work and everything like that, it doesn’t stop me. But I do go look for toilets – when I go somewhere I like to know where the toilets are just in case.” [ID 3, age 60]

“If I’ve had a meal before I go to bed and have the Viagra I don’t seem to have much interest ...but I wake up in the morning and I’ve got an erection. I’ve found if I have afternoon tea at 4pm (and skip dinner) then at 7.30pm I take the Viagra and by 8.15pm I’m fully erect...now I’m aware of what sort of limitations (food) may create so I’ve made adjustments ...If I don’t make adjustments with the food ...it may not happen that particular evening but 6.30 or 5.30 the next morning.” [ID 18, age 53]

As a consequence of the effects of their treatment some men have experienced a decrease in their physicality and no longer participate in sporting or other activities. These changes meant that some men now undertook quite different domestic tasks like shopping or house-cleaning which in the past they had not done.

“It was terrible...embarrassing and limiting...before I used to do a lot of walking...one of the things it really inhibited was going for a swim”. [ID 1, age 62]

“I go shopping with her now; I don’t mind doing the grocery shopping. I’m also vacuuming. I’m a house-dad.” [ID 7, age 61]

b) Coping strategies

Men described various coping strategies from the time of diagnosis to the stage where they were living with side-effects.

A few men reported denial behaviour in that they chose not to read the information given, and one man reported that right up to the time of having the surgery he did not believe he had the disease. Another man described his avoidance behaviour when he left the room while a doctor was trying to provide him with information regarding what would happen during his surgery. Some men felt there was nothing they could do but trust in their doctor and did not want to be bothered by the details of the disease or its treatment.

“When I originally got diagnosed, I didn’t believe I had it so I didn’t think it would affect my life at all. Even when I had the operation I still believed that when they opened me up there would be nothing there. I didn’t think I’d have any change at all in the actual way I lived.” [ID 5, age 60]
“The anaesthetist started telling me all the things that could possibly go wrong as I’m being rolled in and I started feeling sick again. And I said “please don’t tell me anymore” and he said “I’ve got to”. I saw one somewhere before that and he started telling me the same things...“they’re going to do this, this and this” and I had to leave the room and he followed me out to tell me all these things. I would have rather not known. I said “tell my wife, don’t tell me” and I left!” [ID 6, age 58]

Other men reported they did not discuss with their partner how they would manage any sexual difficulties that might arise from the treatment because they didn’t think that would be necessary. Some men reported they chose not to think about what the consequences of treatment might be because they thought they would not suffer any side-effects, or they would not be significant and they would be able to adjust.

“Prior to treatment we didn’t talk about how we would manage any sexual difficulties that might arise as a result of treatment because I didn’t think there would be any.” [ID 5, age 60]

“I really didn’t think about it then. I thought I was very strong and fit, would get through it and it wouldn’t really affect me. I was very positive that “well I’ll get over it and there won’t be any problems with me and if they’re minor, I’ll adjust to them.” [ID 6, age 58]

Some men reported that the crisis of diagnosis, treatment and coping with side effects seemed to act as a catalyst for psychological distress around issues not specifically related to the prostate cancer, and some men reported undergoing therapy with a psychologist or psychiatrist. One man who reported long-term avoidance behaviour to manage sexual issues in his relationship underwent treatment for depression associated with post treatment continence and sexual function issues with resulting changes in his attitude to the sexual issues in his relationship. More than one man reported the benefits of receiving psychosocial support.

“My GP (referred) me to a psychiatrist ...and I was started on Sertreline and it was marvellous. The effect was dramatic ... there was relief of all the distress... I began to start to get some sort of realisation of self which I’d never ever had before... I am (now) of the view that I am entitled to have a sex life but I can’t have it with my wife”. [ID 10, age 66]

“The sessions (with a psychologist) were wonderful and basically picking out those things that were important enough and the rest of it was rubbish. It’s like wheat – you’re just picking out the good stuff.” [ID 18, age 53]

Others also reported improved coping skills as a consequence of professional treatment of the depression they experienced following a prostate cancer diagnosis.

“The psychologist and medication brought me up out of the depression and having a goal that I didn’t know if I’d be able to achieve but I have achieved it.” [ID 10, age 66]

“Post treatment I was going to see a psychologist ... (and I learned to look at issues as) ‘what’s the worst possible thing that could happen here’ and I use that as a mantra...not just with me but in meetings and crises at work.” [ID 18, age 53]
Now that they were experiencing the ongoing effects of prostate cancer treatment, some men reported that they were coping by allowing the time for improvement and filling their lives with other interests. Related to reduced or no erectile function one man reported he had changed the way he mentally approached occasions of sexual intimacy by being more mindful of what he was experiencing rather than what he wasn’t.

“It’ll take time, like everything takes time.” [ID 6, age 58]

“Not letting it consume me and ensuring that there are lots of other things happening around me in my life. I’ve got a number of compartments – part-time work, counselling, hobbies and golf, church – it’s a balanced life and while one of it might not be quite working as it used to be, all this other stuff helps me. It’s a matter of normalising the whole process.” [ID 16, age 66]

“We’ve sort of changed our lives round for our grandchildren more than anything else and we’ve changed our lives to make sure that we’re secure in what we do and how we’re going to spend the rest of our lives together.” [ID 7, age 61]

“That’s why I’m thinking the more I physically think about this the more I’m holding myself back. You have to be with the moment. While I complicate it (getting an erection) in my head it doesn’t (happen)...sometimes it might take less time and sometimes more but it’s that time without pressure, to take the pressure away.” [ID 18, age 53]

A number of men reported that their positive attitude in general had helped them through the difficulties they had experienced following a diagnosis of prostate cancer. For some this meant not entertaining the possibility of disease recurrence and some men had accepted their diagnosis and recognised that they had to deal with whatever happened as a consequence of the disease, and that this might take time.

“You’ve still got to live. I’ve tried to continue, realising I can’t live the life I was living but I can’t because of my age. I’m getting older. You’ve got to think positively.” [ID 8, age 69]

“The urologist said, ‘we’re going to give you quality of life’ and I went ‘yeah, mate, I want to see my granddaughters grow up’. That’s what keeps me going”. [ID 7, age 61]

“I guess it’s a mindset that says ‘today is going to be a new day’. I’m better than what I was before... I have a positive aspiration.” [ID 18, age 53]

“You might think I’m a bit negative in some respects but you’re still positive over all. There’s negatives there but you take it in your stride.” [ID 8, age 69]

c) Striving for Acceptance & Integration

Not all the men felt they had successfully accepted the changes in their life which occurred as a consequence of prostate cancer treatment, although many were endeavouring to do so. Some reported that talking to other men who have been through treatment, and health professionals
experienced in prostate cancer, provided a good way to start accepting the post treatment changes and integrate them into their life after cancer. Some men recognised that they were “getting on” with life even though they had not completely accepted their current condition, but were continuing to try and adjust.

“Adjustment is just happening now, I could have been adjusting a year ago and I’ve sort of wasted a whole year and I’m starting to realise it now when I’m adjusting my life. I’ve gained so much from the comment (in the patient information sheet) “a process of acceptance and adjustment”. So I’ve got to do that now. Accept it and then adjust to it. I’m still sort of living in the past a little bit saying ‘well, why I can’t do these things anymore.’” [ID 6, age 58]

“The most difficult thing I guess is getting to the degree of acceptance... I don’t know if I’ll ever get to that stage but anyway... maybe that’s good, maybe it’s not.” [ID 9, age 62]

“Even though I was ready for it, it was still difficult to accept when it did come as bad as it has... I just think it was being mentally ready for the best and the worst and being able to accept it once you got the card dealt to you.” [ID 19, age 64]

“It is never going to be the same and if you know that, in my case I accept it ... you just accept my condition, my situation for what it is and I’m happy that my wife understands the situation the same way.” [ID 13, age 64]

Some men reported they had re-evaluated aspects of their life and this had helped them adjust to their “new normal” – one man spoke of reassessing his previously high interest in sex to help accommodate the changes he had experienced in sexual function and the impact that had on his life.

“I thought ‘OK, what would be the worst that could occur’ and the worst that could occur is that I’d be walking around in pads for a long period of time.” [ID 18, age 53]

“Interest in sex prior to treatment was very high, now it’s very low. Apart from 3 occasions where things actually worked properly I guess I’m very hesitant when it comes to the sex side of things because I get a little bit of pain...I hold back a bit on it. I’ve also come to the idea now that sex isn’t all that important so ... it is really but...” [ID 12, age 51]

“It’s about my life, not just my sexual performance.” [ID 19, age 64]

Some men could see some progress in their adjustment and acceptance. A few men commented that they had been unable to fully understand the potential consequences of treatment prior to having it and it was only now that they were actually having the experience that they really understood.

“It’s just the experiencing of (impotency) is terrible. I thought the impact would be terrible and it is, but the experience is something that you have to deal with on a day by day basis...the difference is that you are dealing with it rather than thinking about dealing with it... you’re actually sort of stuck right in the middle of it and you’re actually dealing with it all the time and you can’t walk away from it.” [ID 9, age 62]
“It’s like bringing a new baby home, you don’t, you know you’ve got a lot of stuff there in theory but you don’t quite know, it doesn’t quite hit the reality until it’s there. I think you’ve just got to live through that.” [ID 1, age 62]

Men also reported that integrating side effects of treatment and their impact was clearly an ongoing process, and some commented that, as they could not escape their current situation, they felt they had no choice but to adjust and were endeavouring to do so.

“.... that process of adjusting to it and accepting it and I’m only doing that now because I thought I would get better and I didn’t have to worry about that. But now I’m adjusting to it.” [ID 6, age 58]

“...to accept the limitations, that was the hardest thing to start with but now realising that ‘ok it didn’t work tonight, and not having any expectations that it will be alright the next morning but waking up the next morning and all the little surprises...when you’re not expecting it. And that goes with the head stuff’” [ID 18, age 53]

“I guess it made me think ‘I need to make the most of my life’ rather than sometimes good and sometimes not so good. I’ve been thinking I have to make it all good because life is limited. I had a close call and I came through it ok. I re-evaluated.” [ID 20, age 59]

“When things finally settle down and you think ‘this is what it’s going to be like forever’ then you accept it. I came across that on one of those health shows on TV, talking about people having to accept “the new normal” and I thought that’s a lovely phrase. I could relate it to me.” [ID 6, age 58]
CHAPTER 4

DISCUSSION

The aim of the current research was to explore men’s experiences of prostate cancer and the impact of treatment-induced changes on men’s sense of masculinity and self perception, as well as their intimate relationships and overall quality of life. It was expected that the obtained findings will add to the existing but limited body of knowledge related to the psychosocial impact of prostate cancer treatment and improve understanding of the adjustment process and the “new sexual self” that men develop following treatment. The ultimate goal of the current research was to inform the development of tailored psycho-educational tools / interventions to improve the psychosocial care of men affected by prostate cancer.

The quantitative data revealed that the current sample of men reported levels quality of life (as measured by the FACT-P scale) comparable to the norms for prostate cancer population, however scores on the subscales for Urinary Incontinence, Sexual and Hormonal functioning were comparably lower than the norms within the EPIC scale. On the Male Sexual Health Questionnaire (MSHQ) measure the majority of men reported they were unable to ejaculate (85%) and that pleasure when ejaculating had decreased (90%). Overall satisfaction with their sexual relationship, quality of their sex life and communication with their partner about sex was reported as “quite a bit/very much” by about one third of the men, although slightly more than 50% reported their satisfaction with affection during sex as “quite a bit/very much”. Participants’ scores on the Men’s Sexual Self-Schema (MSS) were comparably higher than the normal population on the domains of Passionate – Loving and Open-minded – Liberal domains but comparably lower on the Powerful – Aggressive domain. While they rated themselves overall as being more Passionate-Loving and Open-minded-Liberal than the normative population, the degree to which the current study population considered themselves to be Powerful-Aggressive was in fact quite the opposite and less than the normative population, and may be a reflection of the detrimental impact of treatment side-effects on the masculinity and self-perception of this group overall. On the Self Esteem and Relationship (SEAR) scale, current study participants scored lower than the validation study population in their perception of their sexual relationship and confidence, particularly in the subscale measuring self-esteem. The majority of participants (n=18; 75%) reported (sub) clinical levels of anxiety whilst only 4 participants reported (sub)clinical levels of depression (17%). The current sample reported a high number of unmet needs in the Sexuality and Psychological domains.

The qualitative analysis of the participants’ interviews revealed 3 themes which contributed to the understanding of the men’s psychosexual adjustment following their treatment for prostate cancer.
The 3 themes (see Figure 4, page 78), Changes In Self-Identity, Communication And Support and Adjustment Process, were each comprised of a number of sub-themes.

In this section, the current qualitative and quantitative findings will be discussed in the light of existing literature, followed by recommendations for future research and clinical implications.

**CHANGES IN SELF-IDENTITY**

Within this theme, there were five sub-themes: Physical Changes, Changes in Self-Perception, Psychological Adjustment, Existential Issues and Changes in Relationships (see Figure 4, page 78).

**The impact of physical changes on sexual identity**

Participants reported that as a result of their prostate cancer treatments they had experienced physical changes such as erectile dysfunction, urinary incontinence, urine leakage (during arousal or at orgasm), reduced genitalia size, lack of or decreased ejaculate, orgasmic changes, diminished desire, and pain. Analysis of the qualitative data identified changes in men’s self-identity which emerged as a consequence of these treatments related changes.

The onset of erectile dysfunction occurs immediately following surgical treatment and more gradually with radiotherapy. [106] In the current study, 22 of the 24 participants underwent radical prostatectomy with immediate loss of erectile function. Two men underwent radiotherapy in the form of high dose brachytherapy and received adjuvant androgen deprivation therapy, resulting in a reasonably quick decline in erectile function. In this study population, the timing of the onset of erectile dysfunction did not appear to change its impact on men’s quality of life.

Some men, whose previous expectation was that sexual activity should end in penetrative intercourse, reported they now refrained from any physical intimacy with their partner, since they perceived proceeding to penetrative intercourse was not an option. Sexual activity, previously spontaneous, was now a much more conscious activity as men monitored their body’s response to sexual stimulation.

The effect of erectile dysfunction following prostate cancer is not limited to an inability to participate in penetrative intercourse. It can be compounded by pre-existing and ongoing couple communication issues further impacting men’s desire and their overall sense of masculinity. Some men described a discrepancy between their motivation for sexual rehabilitation and that of their partner, particularly where a lack of communication on such matters existed. Some men saw this attempt at trying to re-establish ‘normal’ sexual activity as being thwarted by their partner. This in
turn had a negative effect on the man’s perception of himself as the instigator of sexual activity often finding himself waiting for sexual activity at the discretion of his partner, having lost some control of the whole process.

Responses to questionnaire items related to side-effects showed the majority of men were unable to have and maintain erections, had to limit their sexual activity in some way because of side effects, had no or very poor ability to have an erection and were unable to achieve erections firm enough for intercourse. Just over half of men (58%) reported they were “not at all” bothered or inconvenienced by treatment side effects when measured by quantitative scales. In qualitative interviews, the majority of men reported being psychologically affected by these treatment related side-effects. Such discrepancy in findings supports the value of mixed method research, where qualitative responses can illuminate coping mechanisms of adjustment to post-treatment changes which are potentially underlying the reported quantitative responses. It may also reflect previous research which found men may under report distress and anxiety associated with physical side-effects of treatment which impact on their feelings of sexuality [19, 20] quality of life, self-esteem and intimate relationships [36]. It has been argued that rather than quality of life being unaffected, quality of life measures may be insensitive to patients’ actual experience [27]

Studies suggest that function and inconvenience may not be perceived in the same way and that men’s perception of the impact of treatment side-effects may be markedly individual. That is, the degree of sexual dysfunction experienced may not correspond to the reported degree of associated inconvenience. [49] Smith et al (2009) also reported a similar discrepancy between men’s reported experience of side-effects and associated inconvenience. Three years after treatment for prostate cancer men in Smith et al’s (2009) study reported impotence rates as 68% (nerve sparing radical prostatectomy), 87% (non-nerve-sparing radical prostatectomy), 68% (external beam radiotherapy) and 36% (low dose brachytherapy) however impotence related inconvenience was reported at the same time as only a “small” problem. [21]

The variation in reporting of function and inconvenience may also be explained by a phenomenon called a response shift. When patients are confronted with a threat to their lives, it is likely that their internal standards of quality of life, and sexual functioning in particular, undergo an alteration. This process, termed “response shift”, has been recently recognised within clinical and scientific settings. Response shifts involve informative shifts in an individual’s internal standards, values and priorities, and/or in the conceptualisation of quality of life, concurrent with changes in actual health status. [107] Men may minimise dysfunction associated inconvenience by re-evaluating the importance of sexual function in their life. [21, 42, 47, 82] They may view lost sexual function as
Men and their partners may normalise diminished sexual function by inferring it is a common feature of aging or other health issues and therefore not related to masculine identity. [74, 85] Men may also concentrate on other areas of their life, such as hobbies or work, to distract them from their altered sexual function. [35, 42, 86, 87] This was true for the current study population, many of whom mentioned a greater focus on other activities and interests they were involved in as being more important.

Urine leakage impacted on lifestyle and the majority of men seemed to adapt to incontinence the longer it persisted. Urine leakage ranging from about once a week to more than once a day was reported by 48% of participants, with more than half reporting they had no control of their urine or suffered frequent dribbling, half described feeling embarrassed and more than one third of men reported they did not like to be too far from a toilet.

The literature suggests that men respond differently to the changes in urinary (and sexual function) which occur after prostate cancer treatment. [35] This can vary between trying to maintain a sense of control over one’s life and actively trying to limit the problems associated with dysfunction, such as doing pelvic floor exercises or limiting alcohol intake, or a more passive acceptance of the changed function. In the current study, men reported trying to get on with their daily activities, however a few did not wear continence pads despite urinary leakage and reported feeling embarrassed if leakage occurred. One man who refused to wear continence pads reported he now always wore darker trousers in an endeavour to hide any tell-tale dampness. A few of the men commented they did not do pelvic floor exercises although they knew how to do them and were aware of the benefits of such exercise. One man, whilst admitting he was aware of the benefits of limiting alcohol intake to minimise risk of embarrassment due to urinary leakage, continued to drink heavily a few times a week.

Wootten et al (2007) described men’s different management approaches to dysfunction and reported men were more problem-focused in dealing with urinary side-effects and more emotion-focused in their approach to sexual side-effects. [11] It is thought that lack of practical information may be associated more with the sexual dysfunction and may prevent men taking a more problem-focused approach to the condition. In this study, however, a few men stated that, despite knowing the benefits of wearing continence pads, doing pelvic floor exercises and limiting alcohol, they chose not to use those strategies to minimise urinary leakage and embarrassment. One man, despite appreciating the benefit of wearing continence pads, reported his choice not to wear pads was based on his feeling that women, not men, wore pads. The provision of appropriate and timely practical
information as part of men’s ongoing care may better inform men’s approach to living with side effects and provide them with practical strategies for dealing with dysfunctions.

Men in the current study reported urinary loss occurring during sexual activity and/or at orgasm. This occurred in men who reported ongoing problems with incontinence and in others who had no difficulty with urinary leakage at other times. Urine loss during sexual activity was described as embarrassing, difficult for both the man and his partner to ignore and, when it did occur, it tended to stop the sexual activity which had precipitated it. Single men reported that the potential for urine loss during sexual activity interfered with them pursuing sexual relationships. One man reported that he understood his wife’s negative response when he experienced urine loss during sexual activity (she immediately had a shower and has refused to talk about sex since the occasion). However, whilst he appreciated that it was beyond his control, he nonetheless was distressed as a result of the episode, and his wife’s reaction. Urinary loss occurring during sexual activity or at orgasm is clearly a very sensitive issue for men and their partners and one that is difficult for many couples to discuss. The research into urine loss during sexual activity is limited, however Guay & Seftel (2008) reported 38% of 24 men in their study suffered urinary incontinence during foreplay however urine loss at orgasm was not investigated. [51] Koeman et al (1996) reported 9 of 14 participants experienced urine loss during sexual activity and 5 of those men reported they did not engage in sexual contact as a consequence. [20] While there were no items included in the questionnaire which measured urine loss during sexual activity it is clear from the men’s interviews that this is an area which warrants further investigation in order that men may receive appropriate information prior to treatment, as well as receive appropriate information, support and counselling after treatment.

Some men in the current study reported changes in genitalia associated with surgery or androgen deprivation therapy, however no items assessed perceived changes in genital size were included in the questionnaires. Men who described diminished genital size reported associated practical difficulties such as problems urinating and, using penile injections or erectile devices and some reported embarrassment and feeling less masculine as a consequence of the changed size. This is in line with existing research which shows that men experience a decrease in their sense of masculinity after prostate cancer treatment due to decreased genital size and/or erectile dysfunction [11-13]. Only one study reported no such relationship [14], however this particular study was based on a sample of only 6 men. It has been suggested that men adjust their individual concept of masculinity to incorporate the change in genital size and therefore maintain their masculine identity. [5, 15]
Five participants in the current research were being treated with androgen deprivation therapy as a consequence of their disease being locally advanced or had received adjuvant androgen deprivation therapy while undergoing other treatment. These men all described common side effects which were difficult to accept and included diminished or non-existent libido and erectile function, decreased size of genitalia and depression. The literature supports this finding [11, 12] and confirms that men tend to stop sexual activity as a consequence of androgen deprivation therapy induced side-effects. [13]

While previously men had been used to ejaculating at orgasm, treatment for prostate cancer had resulted in the loss of ejaculate in the men who had undergone radical prostatectomy. Participants reported reduced intensity or even lack of orgasm as well as physical and emotional changes in orgasm as a consequence of treatment for prostate cancer. One participant described the sensation of orgasm as being more intense than previously. In this study, 22% of participants reported their ability to orgasm as “none/very poor” with a further 43% describing it as “poor/fair” and over half the participants described the inability to orgasm as a “very small” to “big” problem however questionnaire items related to ejaculation and orgasm were reported as confusing by some men (noted by them on returned questionnaires) as they regarded them as the same entity.

These findings are similar other studies, as it was found that 37% of 239 men reported complete absence of orgasm with a further 37% reporting a decrease in orgasmic sensation with only a few men reporting a more intense sensation. [11] In the current study, the one participant who reported more intense sensation at orgasm explained that for him it now took much longer to become aroused to the point of orgasm and arousal now no longer peaked and waned in wave-like sensation as excitement increased overall. Sexual arousal may be impacted by the fact that men may be experiencing reduced sensation or, lack of spontaneous erections may result in distraction thus hindering their ability to enjoy the sensations which are occurring and inhibiting the arousal process. Further research is required to provide an insight into men’s understanding and experience of orgasm and decreased or total loss of ejaculatory fluid following prostate cancer treatment.

In the current research pain or burning on urination was described by 3 men and pain when ejaculating was described by five. Pain on ejaculation was reported by 19% of participants and the majority reported it took too long to ejaculate and physical pleasure when ejaculating had decreased. Men who experienced pain associated with sexual activity stated it reduced libido. Perineal or penile pain was described by a few men who had undergone either radical prostatectomy or brachytherapy however this had resolved for one man. One participant with confirmed extraprostatic disease described ongoing pain for which he had been investigated with no apparent cause found.
Men in this study also reported feeling that sexual changes such as lack of erections (66%), and the associated effort required to now get and keep an erection, as well as diminished orgasmic sensation (91%) and possible loss of urine, resulted in diminished self-esteem (50%) and sexual desire 48%). This finding is supported by the literature which reports that men with erectile problems are more likely to experienced less sexual desire, sexual pleasure and intimacy, which has adverse effects on their levels of sexual confidence, feelings of masculinity, self-esteem and body image. [11-13]

Koeman et al (1996) reported more than half of their study population described reduced sexual desire. [20] Changes in sexual function may result in anxiety related to sexual intimacy and performance which can result in diminished desire. Such diminished desire and orgasmic pleasure is reported by men equally dissatisfying as erectile dysfunction. [12]

The overall impact of altered function and an uncertain sense of sexuality has been reported to impact on men’s day to day interactions with women in general and may be more significant a problem for men who are currently not in a relationship. Men in this study reported the loss of sexual fantasies, which represented previously a pleasant, but not acted upon, part of every day. Fergus et al (2002) reported similar a finding, when sexual fantasy is interrupted by the realisation that the individual lacks the sexual capacity required in his fantasy, described by a participant of that study “imaginal interruptus”, [42]

Men’s level of sexual desire can be a moderating factor regarding the impact of treatment induced sexual dysfunction on quality of life. Namely, men who report low sexual function but higher desire also report lower quality of life whilst men with low sexual function and low desire report higher scores. [39] This was true for a small number of the men interviewed in the current study who reported low sexual desire, good quality of life and adjustment to their changed sexual function. In other words, frustration, embarrassment, disappointment and possible relationship stress associated with higher desire but diminished sexual function is likely to impact on overall quality of life. [39] Since to date, the research into sexual changes after prostate cancer treatment has predominantly focused on erectile dysfunction rather than changes in orgasm and desire, a greater research focus on these areas is warranted, to assist men in understanding and adjusting to the post-treatment changes.

Although there was no opportunity to report use of erectile aids and their side effects in the questionnaire, men’s qualitative responses showed that the current sample used various erectile aids but mostly oral and injectable medications. Participants commented on the expense related to the use of such aid and the lack of spontaneity associated with requiring an aid to obtain an erection. In this sample, the side effects associated with erectile medications (oral and injectable) resulted in
some men not continuing with their use. In line with these findings, literature suggests that the majority of men using aids when seeking a treatment for erectile dysfunction following prostate cancer tend not to persevere with long term use. For example, although Schover et al (2002) reported 59% of 1236 men with prostate cancer-induced erectile dysfunction had tried treatments for their condition, only 30% were still using them 4.5 years later. However, men who had tried 2 or more treatments were more likely to respond to a therapy.

The most invasive erectile therapies, penile implant and penile injections, are reported to be the most effective although oral therapies for erectile dysfunction are the most commonly used. However, the latter are not helpful to men who have had non-nerve sparing surgery or in whom erectile nerves have been damaged by treatment. Further, men with disease progression or on androgen deprivation therapy are generally less likely to try erectile aids and more likely to not persevere if they did use them.

Studies show that men who seek treatment for erectile dysfunction after prostate cancer treatment are likely to be younger, have a willing partner, be in good physical and mental health, have had nerve sparing radical prostatectomy, be better educated and financially comfortable. Men have also been found to be more motivated to regain erectile function if they are in newer relationships or had a much younger partner. A willing partner is important when men pursue treatment for erectile dysfunction. Female partners of men affected by prostate cancer may be at the stage when they themselves experience menopausal or other health related sexual difficulties, including diminished libido and discomfort or pain during intercourse. Such women may be accepting of their partner’s erectile dysfunction or may show little interest in men’s sexual rehabilitation. Some women may engage in intercourse in the interest of increasing their partner’s confidence and self esteem but may not be enthusiastic about the restoration of erectile function and in fact may welcome the opportunity to engage in physical intimacy which does not include penetration. Further research into women’s experiences of partner’s treatment induced erectile dysfunction is needed, with a view to informing couples interventions which encourages the negotiation of a new sexual repertoire after prostate cancer treatment.

When compared to the general population, men who are treated for prostate cancer by surgery or radiotherapy tend to report lower levels of sexual intimacy. Also contributing to reduced sexual intimacy may be other components of sexuality affected by side-effects of prostate cancer treatment including decreased sexual desire and sexual confidence, impaired feelings of masculinity, self-esteem and body image.

Men who report bowel related symptoms following radiotherapy for prostate cancer are more likely to report reduced sexual intimacy and marital affection, however in the current study almost all
participants reported overall bowel function as “small to no problem”, suggesting for this population at least, reduced sexual intimacy was more likely a consequence of urinary and/or sexual dysfunction.

Considering the scarcity of information available about men’s recovery of function or adjustment to ongoing dysfunctions and the effects of sexual dysfunction on couples [14], the current study provides a valuable insight the impact of changes in urinary, bowel and sexual function following prostate cancer treatment, and the subsequent impact of these effects on men’s relationships and quality of life. Of particular importance are the novel data from this study, exploring men’s understanding and experience of orgasm and decreased or total loss of ejaculatory fluid following treatment. Currently, information provided to men regarding changed sexual function is generally in the narrow context of erections and men would be better served if they were provided with more information about changes in overall sexual function after treatment as well as practical suggestions to manage their changed sexual function. These strategies could include changing mental concepts to reduce stress and increase satisfaction levels such as relaxation and meditation, as well as practical problem-focused fact sheets. The current data will inform the development of intervention programmes for men and partners which could be introduced at diagnosis and be ongoing through decision making, treatment and post–treatment recovery.

Changes in self-esteem/self-perception and its impact on self-identity

The current quantitative and qualitative data indicated that the reported treatment side-effects greatly impacted on men’s self-perception/self-esteem. A number of participants reported they now perceived themselves differently as a consequence of the physical changes (urinary leakage, sexual dysfunction and decreased genital size) resulting from prostate cancer treatment. Many of the men expressed their feelings related to these changes but were unable to define their responses to the changes they experienced as a tangible concept.

On the Self-esteem and Relationship (SEAR) questionnaire, only half of the participants reported they had good self esteem (50%) and at the same time when responding to individual items, 54% indicated that they “never” felt like a whole man and 59% were inclined to feel like a failure “a few times/sometimes”. Some men reported that the physical changes they faced had a negative effect on how they saw themselves, identifying self-esteem in particular. Men reported a decrease in their sexual confidence and many, single men specifically, felt less confident about engaging in sexual activity. Some men, both single and partnered, reported avoiding interactions which might lead to intimacy and described some discomfort with general social interactions with women. Men with
partners described experiencing difficulties with their self-esteem as a consequence of their changed sexual function. Some participants reported their sense of themself as a male in the world was now compromised and one man was still affected by his feelings of helplessness and inadequacy experienced some 2 years previously whilst a patient in hospital.

Reduced genital size complicated the use of some erectile aids on a practical level but men described a further assault on their self-esteem as the models featured in instruction materials for such aids had above average size genitalia. On the other hand, men who used erectile aids with success identified the additional benefit of restoring their confidence as a male.

The literature provides evidence that undesirable changes in sexual or urinary function may be associated with lower masculine self-esteem, [36, 42] as they are “intimately tied to dominant notions of masculinity” and challenge men’s sense of masculinity and self-esteem. [42, 82] Men who experience diminished masculinity as a consequence of functional changes following prostate cancer treatment describe reduced self-esteem and report feeling changed and no longer a “whole” man. [35] Men for whom urinary leakage limits more physical work may take on less physical roles, perhaps viewed by them as “woman’s work” which may also contribute to reduced self-esteem. [66] Clark et al (2003) report that men living with treatment side-effects are likely to suffer decreased self confidence and self-perception. [36] Men being treated for cancer may feel a lack of control over themselves and their illness which can further impact on self-esteem. Yet, Bokhour (2007) suggests men may re-configure their self-identity by augmenting other aspects of their life such role as a partner or worker. [82]

Not all participants were concerned about the physical changes. A few had experienced sexual difficulties prior to prostate cancer treatment due to pre-existing erectile dysfunction or partner-related sexual issues, and reported they were accepting of the changes in sexual function. A few participants reported they were adapting to the changes or felt they had already done so as a consequence of what they described as an improved self-awareness since treatment.

It has been suggested in the literature that each man may have a “unique and highly personal” reaction to the functional consequences of prostate cancer treatment [39], with Perez et al (2002) suggesting that the individual’s underlying disposition should be factored in when measuring men’s post-treatment adjustment.

Men who suffer bowel symptoms following radiation therapy are more likely to report reduced lower self esteem and reduced quality of life. [36] In this project bowel symptoms were not reported by participants to any degree, however Clark et al suggest that low reporting may be a
reflection of low incidence of symptoms or a consequence of men feeling embarrassed about reporting such issues. [36]

While some men were eager to pursue sexual rehabilitation, their otherwise supportive partners were markedly less interested. Those men reported the combination of sexual dysfunction and partner disinterest had in some way diminished their self-esteem and self-confidence.

Finally, a few men in the current project reported that the functional changes they had experienced as a consequence of prostate cancer treatment had led to a level of self awareness not previously experienced. They described an acceptance of both the changes and the impacts of those changes which had allowed them to “move on” to a new “normal”. This finding in particular would suggest future research is warranted into the contributing factors to men’s adjustment following prostate cancer and whether there are external factors which can be applied to improve the outcomes for all men.

Functional changes resulting from prostate cancer treatment can impact on the physical and psychological aspects of men’s quality of life, which for some can result in diminished self-esteem or self perception and negatively impact self-esteem, thus further contributing to reduced quality of life. Men should receive early and ongoing educational and supportive care to enable them to understand the multifaceted impacts of prostate cancer treatment to mitigate what, for a number of men, can be distressing consequence of treatment.

**Psychological adjustment and its impact on self-identity**

Surgical and radiation treatment side-effects include a number of physical symptoms which can increase anxiety and depression in men [4, 21, 26] and in turn may further impact on an already reduced sexual function. [75, 77] Androgen deprivation therapy may result in depression, mood swings, and reduced cognitive function with an associated decline in quality of life. [29]

The majority of men participating in the current study were symptom-free at diagnosis and reported feelings of shock when they received the diagnosis of prostate cancer. A number of men reported it was difficult living with the ongoing nature of treatment consequences and reported emotions such as anger, depression, disappointment, and a sense of loss. These feelings were predominantly associated with the side effects of urine leakage, changed sexual function, penile shortening and loss of libido. One man described substantial distress at ongoing pain (“burning”) on urination and intermittent urinary obstruction 2 years after treatment, exacerbated by evidence of disease progression. Some men also reported periodic anxiety at routine follow-up related to possible
disease recurrence. Men currently or formerly treated with androgen deprivation therapy noted its potential for exacerbating emotions, particularly those that were negative.

Although most participants appeared to be coping well despite the challenges they faced in adapting to their changed lives, some men reported feelings of disappointment and even depression at the way life was for them since treatment. They described feelings of sadness or sorrow and a sense of loss related to their changed sexual function. Men for whom initial treatment did not result in a cure and who were now faced with progressing disease, reported a sense of lost expectations of their future. Men who were diagnosed just prior to, or just after, retirement described a similar sense of lost expectations for the future, since life had turned out differently to what they had been planning. Although challenged by a number of issues since diagnosis, one man was able to see how supportive his daughter had been and was appreciative of the deepened relationship he now had with her and how beneficial that was to him, highlighting the importance of family support to help adjustment to distressing side effects and altered quality of life.

In the current study, 21% of participants were found to have clinical levels of anxiety and 6 men were in the sub-clinical range. There were no cases of clinical depression elicited in the study population, although 4 men reported sub-clinical levels of depression and 5 participants reported they were currently taking antidepressant medication. At the time of this study, all participants had either responded well to initial curative treatment or were being treated for locally advanced disease, however no participants had known distant metastatic spread. Similarly to the current findings, Cliff and MacDonagh (2000) and Wootten et al (2007) found reports of some level of psychological distress after prostate cancer treatment (21% and 14% respectively). The variation in their findings can be attributed to the inclusion of men with advanced disease in Cliff and MacDonagh’s work while all patients in Wootten et al had localised disease. [76, 78]

Functional changes after prostate cancer treatment affecting sexuality may cause psychological distress which in turn can cause a further decrease in function. [75, 77] Men may experience feelings of loss and grief related to their diminished physical strength and altered sexual function and the associated impact on their quality of life. [35] Men not sexually active prior to treatment have been reported to experience the same levels of distress as more sexually active men, that is their grief is for lost sexual capacity rather than sexual activity. [42, 43] Further, Couper et al (2006) found that partners of men diagnosed with prostate cancer had increased distress from diagnosis to assessment at 6 months whilst men had the opposite response. [79] Gender differences have been shown to exist in the reporting of symptoms of anxiety and depression, with women being more likely to report symptoms of anxiety and depression than men. [79] It may be then that men are experiencing anxiety and depression but not reporting it although some research suggests that men
with prostate cancer report clinically significant psychological distress at a rate of 20-38% more than the normal population [108] and this was true for the current study where 21% of men were found to be clinically anxious.

A generally optimistic outlook on life may be innate as well as a protective factor in men’s attitudes to the changes in function after prostate cancer treatment, as it provides a relatively stable view of himself in the world. Therefore, individual’s underlying dispositions, such as a generally optimistic attitude, should be accounted for when assessing adjustment following prostate cancer. [80] Further research would be worthwhile in developing models of adjustment dependent on individual factors, including disposition, to allow psychosocial interventions to be tailored to the individual as much as possible.

**Existential issues and their impact on self-identity**

Not surprisingly, since the majority of participants were diagnosed with localised prostate cancer and responding well to treatment, issues relating to treatment side-effects seemed to be of more concern to them than the possibility of dying from the disease. However, men with progressive disease reported they were more cognisant of their limited life expectancy, with one man feeling time was slipping away leaving him a somewhat resentful of the time his partner spent caring for others. Conversely, another participant reported he sometimes wanted to choose how he used his time on a daily basis rather than be cajoled by a caring partner into “doing” things to make the most of their “limited” time together. One man described the difficulty he faced comprehending and adjusting to the fact that his potentially curable disease had progressed.

After the initial shock of diagnosis and owing to the slow growing nature of prostate cancer, for most men treated for localized or locally advanced disease, prostate cancer may be more comparable to a chronic illness than an immediately life-threatening illness. It may be for this reason that only a small number of men’s narratives included existential issues and not surprisingly this was a recurring theme specifically within the interviews of men who had locally advanced disease. While death from prostate cancer may not have been imminent it seems this small subgroup of men perceived it as a more likely prospect than other participants, and their awareness of a limited life-span permeated their narratives. When men are diagnosed with prostate cancer, particularly localised disease, the risk of their dying from the disease if left untreated should be included in the information they receive. For men diagnosed with, or progressing to, advanced disease, end of life issues should be addressed in a timely and sensitive manner.
Changes in an intimate relationship and its impact on self-identity

Treatment side effects can have an impact not only on the man but also on his partner. Most of the married participants in the current research identified that prostate cancer had affected their relationship with their wife. Some participants reported reappraising their relationship and reported that their relationships had been strengthened despite the impact of changed sexual function, and in some instances with ongoing and unresolved issues regarding sexual life.

Sexual function was reported by 26% participants in the current research as “none” or “very poor”, with a further 57% describing it as “poor” to “fair” and sexual function (or lack of it) was seen as a “moderate” to “big” problem by 77% of the men. It was not unexpected then that 61% of men reported the frequency of sexual activity as “not at all”. The design of this study did not provide for collection of data from partners, however men were asked in the questionnaire to report what they felt partner response would be to 2 items related to their sexual relationship. The majority of men (59%) reported that partners were “never” unhappy with the quality of their sexual relationship and the majority (68%) reported that partners were satisfied with the relationship in general “most times/always”. Since only 2 items were used to derive the information and importantly, these responses were men’s perceptions of partners’ responses, such data need to be interpreted with caution due to response bias. This may indicate that partners may not view problems reported by men with the same concern. This discrepancy may be due to actual differences in sexual needs where partners may not feel the same level of loss as men, perhaps due to their own health problems, menopausal issues etc. Further, partners may value the overall relationship more than the sexual relationship or may have adapted to the changed sexual ability of men, perhaps in an endeavour to reduce men’s concerns relating to sexual dysfunction. There was no opportunity to explore the differences in men’s and partners’ satisfaction levels however further research would be worthwhile to identify factors which contribute to these differences.

Long-term communication difficulties related to sexual issues or feelings tended to be exacerbated for some couples following prostate cancer treatment. Despite some side-effect related problems in some relationships, men described their partners as being very supportive in terms of diagnosis and treatments. Men also reported relationship difficulties when partners’ enthusiasm for sexual rehabilitation did not match their own. One participant who had been proactive in choosing treatment with the best chance of retaining sexual function, was in the process of leaving his wife, since her lack of support for his sexual rehabilitation highlighted the continuing difficulties in their relationship.
Single men reported that treatment side effects were an impediment to them seeking a relationship and commented that the absence of a partner was felt more acutely in difficult life situations such as a prostate cancer diagnosis and treatment.

Changed sexual function can result in men doubting their sexual performance and their ability to sexually satisfy their partner and be sexually satisfied themselves. Changed function can inhibit relationships with women and men may feel uncertain about instigating sexual intimacy. [36] Men who are in newer relationships or who have younger partners are more likely to try and restore sexual function. [64]

Not all women are supportive of their partners’ attempts at sexual rehabilitation although this may be a consequence of poor sexual communication in the relationship. Women may not always be included in the decision to use erectile aids and in Potts et al (2003) female participants reported instances of partners using aids to achieve an erection before discussing the possibility of intercourse with their partner. The cost of some medications made some women think they could not “waste” the erection. [65]. It may be that penetrative intercourse is problematic for women due to menopause or other health problems, or just plain personal preference, although they may still desire sexual intimacy such as touching and kissing. [65] Longstanding unresolved relationship issues related to sexual communication are likely to be exacerbated at this time. Indeed, altered sexual function has been found to have an impact on the couple’s overall and intimate relationship and subsequently on overall quality of life. [36, 39] Further research is required relating to the benefits and timing of marital counselling as well as practical advice to broaden a couples’ sexual repertoire as an element of supportive care for couples facing prostate cancer treatment or recovery. As with any counselling, willing cooperation of both partners is crucial for effective resolution of problems.

COMMUNICATION AND SUPPORT

Communication and Support was an overarching theme throughout the participants’ interviews, supported by the unmet needs quantitative responses from the Supportive Care Needs Survey (SCNS-SF34). Within this theme, there were six sub-themes: communication and support between men and their Doctor, Partner, Other Health Professionals, Other Men with Prostate Cancer and Support Groups, as well as Information Provision and Recommendations for the Future.
In general, the data indicated that men in the current research who felt they communicated well with their partner, doctor and other health professionals and those who felt well-informed, reported better acceptance and adjustment to their post-treatment altered functions.

**Doctor-Patient Communication**

Despite wide use of the Internet, doctors continue to be the main source of information for patients. [91] In hindsight, some of the participants reported that at the time of diagnosis they did not know what questions to ask and they felt their doctors had not provided adequate information, explanation or time to understand the information given. Some men reported seeing the Urologists as someone who explained the different treatment options rather than referring men to a specialist for information regarding radiation treatments. Now living with chronic side-effects, some men reported that during consultations with oncologists, they felt the risk of side-effects was somewhat minimised and many participants commented they now thought they ought to have received information detailing possible side effects, the likely risk of them occurring and management options if they did occur. Despite being aware of a gap in the information originally provided, participants reported trust and faith in their doctor. Men who felt their doctor had provided both good information and the opportunity to ask questions also reported a trust in their doctor.

However, it is also important to consider that stressful situations impact negatively on the ability to hear, understand, process, remember and recall information, particularly during diagnosis. [98] At this time, the patient and their family are likely to be anxious and distressed, and need to absorb a lot of information about the disease, treatment options, side effects and prognosis. Therefore the current responses may reflect recall bias, however the degree to which this is the case cannot be determined.

On the other hand, men described clear instances where they felt they had experienced inadequate provision of care. For example, one participant reported that while in the anaesthetic bay outside the operating theatres he requested to see his Urologist while being prepared for anaesthetic since he was having second thoughts about having the operation. The next thing he remembered was waking up, the surgery having been completed, without having spoken to his urologist. A number of men reported they were unaware at the time of diagnosis of available psychosocial support, and it had not been offered by their doctors. A few men reported their doctors did not address psychological issues and failed to respond to cues men had given regarding emotional distress.

Prostate cancer research has shown that men who feel they were given the information necessary for them to make an informed treatment decision were less likely to feel frustrated with their doctor or angry about side-effects [89, 97] In this study, however, despite the fact that in hindsight
participants suggested they did not receive enough information prior to treatment, many of them were accepting of their situation and reported trust in their doctor. This suggests perhaps that the ongoing relationship with one doctor may mitigate negative feelings surrounding perceived insufficient information. It may be that men believe that, despite incomplete information and side-effects of treatment, they chose the right treatment, particularly if they are disease free, and perhaps credit their doctor’s clinical skills with the result. Further research in needed to clarify this further.

Psychosocial clinical practice guidelines are now available in Australia to inform the care of cancer patients [66], however integrating these guidelines into standard care remains a challenge. [109] This may be due to the traditional disease-focused health system within which health professionals function, or perhaps a lack of appropriately skilled health professionals to detect and address emotional cues and refer patients to psychological services. By the same token, patients may be unwilling to undertake psychosocial care/services for a variety of reasons such as limited time, financial concerns or lack of knowledge of its benefits. [66] Further research is required into the barriers to: i) the use of psychosocial clinical practice guidelines, ii) the availability of and access to health professional and iii) patients undertaking psychosocial care, particular in the prostate cancer setting.

Some men found it difficult to discuss sexual issues with their doctor and were dependent on the doctor to raise the topic, which sometimes did not happen. Other men, similarly uncomfortable discussing sexual functioning, expressed appreciation that their doctor did introduce the topic on multiple occasions. A few participants commented on language used by some doctors to describe sexual changes. The information provided on sexual changes was included euphemisms and men did not understand the full impact of what they were being told. For example, one man did not understand before treatment that “you’ve finished having any more family” meant that he was to experience sexual changes, including erectile dysfunction. Men also reported that after treatment, doctors seemed more focused on monitoring the cancer, whilst side effects such as erectile dysfunction, and incontinence were not regarded with the same importance. Some men appeared dissatisfied with this emphasis. Whether this can be interpreted as doctors’ not being concerned with those side effects or lacking skills to adequately communicate these is unclear.

Considering the serious physical and psychological consequences of prostate cancer it is important that all the treatment options, including watchful waiting if applicable, are provided to patients including the consequences of each option. Yet, it is important to also acknowledge that treating cancer patients is a difficult and challenging task for doctors who must provide information that is difficult for them to impart as well as for patients to hear.
There is a significant need to address the discordance in doctor-patient communications with regard to delivery and understanding of difficult topics [21, 33, 34]. Training should be implemented for doctors to acquire skills related to communicating sensitive information which should include their eliciting responses from patients to gauge their level of understanding. Care plans for patients should also be made available which include written information and opportunities for patient to explore that information with health professionals.

**Partner-patient communication**

Some participants stated how they had faced previous challenges together in the past had influenced how they now worked through the issues associated with a prostate cancer diagnosis and subsequent treatment side-effects. For some couples communication strategies which had been satisfactory in the past proved problematic in the face of altered sexual function. Struggling with recent and difficult sexual dysfunction, embedded in longstanding communication difficulties, sexual activity became a bartering tool for one discontented couple. Other men, who had enjoyed good communication with their partner in difficult times in the past, reported continued good communication as they dealt with prostate cancer related difficulties.

One of the participants described the final breakdown of his marriage approximately 2 years after treatment and which he described as ‘faltering’ prior to his treatment for prostate cancer diagnosis. Living with side effects of prostate cancer treatment imposes an additional stress on a relationship and can contribute to the breakdown of an already impaired relationship. [35] Research has shown the impacts of prostate cancer treatments on men’s quality of life as well as their personal and intimate relationships. [39]

Some men reported that they and their partners found it difficult to discuss the functional changes resulting from treatment, whilst others reported they would not consider using some or any erectile aids and for some participants this meant no sexual activity, as they defined it in terms of penetrative intercourse only.[43] Shared affection was limited, in order to prevent sexual arousal which could not be acted upon under those constraints, adding further stress to the relationship [91]

Many couples affected by prostate cancer had been together for many years. Any threat to such a relationship may compromise recovery and adjustment to an irrevocable change in lifestyle. Couples facing more intractable problems could be offered a referral for professional counseling to address their most pressing concerns. Not all patients or couples, however, felt negatively affected in their adjustment to life-threatening illness and a proportion describer its impact in positive terms.
For some it prompted self-examination and personal growth, and repair or strengthening of relationships. [110, 111] It is clear that couples facing life-threatening illness will benefit from interventions that would assist them in this difficult but important phase in their relationship. Research in the future could focus on the benefits of simple skills training, to assist couple communication throughout the course of prostate cancer treatment and recovery.

**Communication with /support from Other Health Professionals**

Throughout the interviews, men commented on the help and ongoing support they had received from health professionals other than their treating doctors. The opportunity to speak at length, frankly and informally, with a prostate nurse was reported as being very helpful for men in understanding the issues they faced after diagnosis of prostate cancer. Men who had received psychological support from a resident psychologist were equally appreciative; particularly men who had been struggling to come to terms with the impact of ongoing treatment side effects and progressive disease.

Although the hospital where the participants were receiving treatment provided interventions such as prostate nurse-led educational sessions and psychological services provided by a clinical psychologist, the interviewed men reported having varied access to both of these interventions. Namely, of the 24 men participating in the current study 10 men reported that their clinicians referred them at the time of diagnosis and 2 when disease progression was diagnosed, whilst 8 men had been referred or sought support themselves at a time of crisis, other than disease progression. Four participants only became aware of the service some time after treatment and had not accessed the nurse-led service. Men in the current study who experienced these interventions commented on their usefulness and importance. Patients have been found to report moderate to high need in the domains of information related to disease, treatment options, side effects and their management, and supportive care.[84]

Two participants described a doctor-initiated referral for management of erectile dysfunction “lost in the system”. The men reported as time passed, embarrassment prevented them from calling their doctor’s secretary to enquire about the delay. A nurse-led care coordination role would be beneficial in assisting men negotiate the complex health system they are now involved in as well as providing information and support. Further research is warranted into the benefits of such a role in
reducing anxiety and distress in men living with the consequences of prostate cancer, including the overall impact on their quality of life, self esteem and relationships.

Following diagnosis, patients often feel “lost in the health care system” as they dealt with multiple health care providers, across multiple health care facilities, over prolonged periods of time [112]. The prostate nurse coordinator represents an ongoing point of contact for patients whenever they have concerns related to diagnosis or treatment, thus promoting the continuation of care. The prostate nurse coordinator role involves supporting patients and their families in treatment decision-making, providing information on treatment procedures, side-effects and evidence-based self-care strategies, addressing psychosexual needs, and facilitating access to resources, services (e.g. support groups), and multidisciplinary care [113].

Research into the barriers to men accessing information and support other than that provided by clinicians is warranted. The opportunity to access different sources of support such as specialist prostate nurse, clinical psychologist, support group (including a telephone-based support group for men 55 and under) was credited as particularly beneficial, helping men work through a very stressful time.

**Communication with other men with prostate cancer and support groups**

The participants in the current study were all recruited via a hospital based prostate cancer support group newsletter although, while not all the participants had attended group meetings, they reported that receiving the monthly newsletter was a good source of information. Men who did attend meetings described them as a reliable information resource, providing an opportunity to speak openly and safely with others who understood their situation. Men who chose not to attend the meetings reported that they found the existence of the support group reassuring in case they had a future need.

Gregoire et al (1997) found that men with prostate cancer believed attending support group meetings had improved their understanding of their illness and felt more in control of their illness and treatment [114]. These findings are supported by other research which describes the benefits men experience when they exchange information and their experiences of living with prostate cancer with other men similarly afflicted, namely reduced anxiety and a more positive outlook. [66] Therefore, this study verifies the value of support groups in improving men’s adjustment to prostate cancer treatment.
Information provision and recommendations for future

From their experience of prostate cancer, men in this study reported that men’s information needs vary from minimal to as much as possible and the information provided by doctors varies similarly but patient needs do not always fit with what is provided by the doctor.

In the current study, a few men commented on a scarcity of information related to the prostate biopsy which preceded diagnosis and in an effort to reduce patient anxiety, they urged health professionals to give clear explanations of what to expect. Men described an inability to comprehend much information once the word “cancer was used” and advised men in the future to take a relative or friend to consultations where test or biopsy results are to be provided. Participants in the current study also reported that they understood that detailed information given too early may be frightening. However, as time has passed since the diagnosis, participants reported they now believed that detailed information provided early and at appropriate intervals may have facilitated their earlier adjustment to the functional and emotional changes that followed prostate cancer treatment.

Early and well coordinated interventions for side-effects, particularly those affecting sexual functioning, were regarded as important to the participants. On a validated measure, the participants reported unmet informational needs related to changes in sexual feelings (48%), changes in sexual relationships (43%) and information about sexual relationships (29%). Steginga et al (2001) found that 25% of 206 men in their study who had been treated for prostate cancer continued to report moderate to high unmet need for information related to prostate cancer, investigations, treatment options, side-effects and their management. [84] It is important that men are well-informed about treatments for erectile dysfunction and offered sexual counselling. [39] It would be particularly helpful if men received practical advice for couples about exploring sexual activities other than penetrative intercourse, such as oral sex.

Unrealistically low impotency and incontinence rates provided to men are often based on varying definitions of potency and continence and data from tertiary specialist centres which are unlikely to be replicated in the wider community. [36] In the current study, only one man referred to the statistical risk his doctor had given him regarding the likelihood of developing urinary or sexual side-effects. Now living with distressing urinary and sexual dysfunction, he recalled being told the likely risk of side effects was 2% for either incontinence or impotence. This is a very low estimate, considering that Smith et al (2009) found incontinence highest in men following radical prostatectomy (12%) of men and 87% were impotent following non-nerve sparing radical prostatectomy at 3 years. [2] While the patients’ response may have been inaccurate due to recall
bias, it does highlight the importance of men receiving data relevant to their treating surgeon or radiation oncologist rather than data from other practitioners in other facilities, and in the format that facilitates comprehension of the tailored risk information. Inconsistency in the definitions of continence and potency contribute to the variability of reported rates of side-effects and patients’ confusion. [21] Health professionals should clarify whether the potency data presented are based on the use of erectile aids or spontaneous erections. Further, if both men and their treating doctors are uncomfortable discussing sexual function in any detail, men may be deprived of the opportunity to better understand and better manage their erectile dysfunction. [24]

A few men reported only a short interval between diagnosis and treatment which did not allow time for investigating and processing information about the disease, treatment options and potential side effects. At the time, these men did not recognise the significance of the lack of time from diagnosis to treatment. Other men reported they had been given ample time to consider the information provided, allowing them to comprehend the condition, potential treatments and associated side-effects. A number of men reported that as well as discussions with their specialist and partner they had opportunities to discuss issues related to their prostate cancer diagnosis with their general practitioner, specialist prostate nurses, partners and/or men previously treated with the disease. One man commented that he reduced his cancer related anxiety by taking time to be better informed and discuss concerns related to treatment and side effects. Another man reported receiving information about side effects only after treatment and another admitted he and his partner did not discuss functional changes until after treatment, with both men commenting on associated increased anxiety levels. Finally, participants who experienced disease progression, wanted as much information as possible and, while they may have understood there was no immediate hurry to proceed to treatment, they wanted the information and an opportunity for discussion as soon as they were aware of the change in their condition. Therefore, health professionals need to be cognisant of patient’ limited knowledge and the high level of anxiety that can be associated with cancer diagnosis and treatment. Research shows that men with prostate cancer are less likely to feel dissatisfied with their doctor and more able to cope with the side effects if they believe they were provided with sufficient information prior to choosing a treatment. [91]

Wootten et al (2007) found that men employ a more emotion-focused approach to the management of sexual dysfunction while they use a more problem-focused approach to management of incontinence. More importantly, they suggests this variation in management approaches may be a result of men receiving inadequate practical information to assist in the management of their sexual dysfunction. [76] There may be many reasons for lack of communication about practical strategies for sexual problems. In this study, a few men commented that, when there was a lack of any
disease-related problems, the intervals between specialist appointments lengthened, and it was commonly during these periods that men experience concerns regarding management of sexual side-effects. For example, if men were prescribed oral medication to enhance erectile function which was not effective, they waited 3 to 6 months before seeing their specialist during which their sexual problems affected their relationship and self esteem. Some men were embarrassed to see their GP about erectile treatment and waited until their next specialist appointment to pursue the problem. These experiences exemplify how a familiar and trusted prostate nurse may assist in ongoing management and expedite follow-up for erectile dysfunction.

In this study, men believed that more information and psychosocial support should be provided at the time of diagnosis, through treatment and when managing side-effects, however less than half the participants were referred by their treating doctors for additional support and information from other (nursing/allied) health professionals. They particularly commented on the value of talking to other men who were previously in a similar situation. In an effort to help other men avoid experiencing the problems such as they had, some men expressed eagerness to support other newly diagnosed men in the future. Models of psychosocial cancer care have identified a pivotal role for peer support programs. [115] The unique perspective of a peer lends authenticity to support that facilitates sharing, and practical, social and emotional coping. [116, 117] A systematic review indicated high satisfaction and perceived psychosocial benefits amongst participants of cancer peer support programs. [116] Some patients even prefer peer-delivered over professionally-delivered support. [118]

However, there is an argument that men, who are providing other men with more detailed and one-on-one information and support, should receive a minimum level of appropriate counselling training. [119] The NSW and other Cancer Councils provide training as well as ongoing education and support for men to enable them to be volunteers in a peer support network. These volunteers, who are at least two years post treatment, are a good source of support for other men newly diagnosed with prostate cancer. They provide practical information from their own experience, but do not give medical advice. With high quality training and supervision, volunteer phone intervention programs to address unmet needs are known to be feasible and successful in accessing sick and remote patients [120] Despite widespread use and positive participant perceptions, only two RCTs testing one-to-one telephone peer support were identified. Houts et al. [49] reported no significant difference in emotional distress, however the sample size was small (n=32), whilst Rudy et al. found perceived social support was higher amongst those receiving telephone peer support (Rudy et al, 2001 in Hoey et al [116].
In this study, one participant commented that men with a higher level of education may be more likely to seek out support and education related to prostate cancer. He expressed concern that access to good information and support may be more difficult for men who are not educated or men with language and cultural differences. Studies have shown that people with low literacy are less likely to comply with prescribed treatment or self-care plans. [121] By improving access to effective information and improving communication the uptake of and adherence with planned treatment will be maximized.

Further research is required into the most beneficial modes and timing of information provision for men with prostate cancer. Interventions aimed at facilitating patient involvement in decision-making, such as question prompt sheets, access to audio-recordings of consultations and patient decision aids, have been shown to facilitate patient understanding of their options and involvement in decision-making.[122] A multi-tiered approach, where clinicians, nurses and allied health professionals, as well as peers work together to provide appropriate information and support over time is likely to be the most effective model of care. The nursing and peer based supports may be particularly beneficial for rural and regional patients to access better information and support.

ADJUSTMENT PROCESS

The slow natural history of prostate cancer, high incidence of diagnosis, high localised disease survival rates and the findings related to the impacts of treatment on men’s quality of life, self-esteem and intimate relationships [36], indicates a need for better support of men who undergo treatment for the disease. Men commonly experience, but may under report, distress and anxiety related to physical side effects of treatment and possible disease progression which impacts on their feelings of sexuality, [19, 20] quality of life, self-esteem and intimate relationships [36]. Self-reports of function and bother do not always correlate, suggesting men respond to prostate cancer in their own unique fashion. [11]

Although Wei et al (2002) reported comparably higher scores to the validation study (mean 34.4) on the Prostate Cancer Subscale for surgery (mean=36.9), radiotherapy (mean=36.4) and brachytherapy (mean=32.4), the current study population of whom 22 of 24 participants had undergone radical prostatectomy, scored comparably lower (mean 33.25) on the Prostate Cancer Subscale. However, 51% of the men in the current study reported trouble controlling their urine which would suggest that men in this group may be under reporting their symptoms on inventory.
**Lifestyle changes**

In this study, side effects of treatment caused some of the participants to make lifestyle changes to manage their symptoms. Urinary symptoms resulted in just over half the men reporting they needed to urinate frequently to avoid leakage, one third had to wear continence pads for urine leaks and 42% reported being afraid to be far from a toilet. Some men reported they no longer participated in sport or other physical activities because of urine leakage or fatigue, the latter being mostly associated with androgen deprivation therapy. Continence pads were not compatible with swimming so one participant had to cease his lifetime regular activity. The change in physicality meant that men were participating in tasks/activities not previously engaged such as shopping and vacuuming. Other research found that when men take on less physical work, generally perceived to be “woman’s work”, their self-esteem may be further reduced. [74] However, the men in the current study did not seem concerned regarding their changed activities. In their quantitative responses participants indicated that they continued to enjoy the usual fun things (88%), were able to work (92%) and were able to enjoy life (96%) “a little bit” to “very much”.

Men reported doing pelvic floor exercises to improve their continence, reducing fluid and alcohol intake, and some men planned trips according to availability of toilets. Some participants taking oral medication to achieve erections had made changes to their dining schedules to ensure the efficacy of the drug.

On the positive side, participants in the current study reported adopting a healthier lifestyle since treatment and reported making dietary and exercise changes. One man reported he and his wife now used organic foods and products such as shampoo and were encouraging their adult children to do similarly. These health related strategies may contribute to men feeling they had some control over their disease and related side effects and possibly reducing the impact of side effects on their self esteem and quality of life.

**Coping strategies**

According to Hervouet et al (2005), men may use disclosure as a coping strategy, advising other of their prostate cancer diagnosis and related anxiety. Men also cope by continuing to plan their future, albeit an altered future to what they may have perceived it to be prior to diagnosis. [86] One participant in the current research reported that psychological intervention, in which he was able to identify the concept of “future loss”, allowed him to reframe his view of the future and integrate an altered future into his life plans. Conversely, other men find it more useful not to reveal their
prostate cancer diagnosis or associated difficulties to others [35, 82, 86], however this approach is likely to increase anxiety in these men.

The degree of bother related to sexual dysfunction has been found to significantly inhibit men’s ability to adjust to their changed life after prostate cancer treatment [76] and men have been found to use different coping mechanisms to manage sexual dysfunction and urinary dysfunction. [76] Wootten et al (2007) looked at the use of coping strategies to ameliorate stress in men with prostate cancer. They found that emotion-focused coping, using methods such as distancing, self-control, escape-avoidance and positive reappraisal, was mostly used by men living with sexual dysfunction.

Fergus et al (2002) suggest many men use coping strategies early in the course of prostate cancer diagnosis to prevent/minimise sexual dysfunction, (by endeavouring to find treatments that are likely to have the least impact on function) and after treatment to adapt to the resulting side-effects. Men may use humour to “contain the loss” of sexual function, reprioritise the importance of the changed function and/or change sexual practices such as non-penetrative sexual activity. [42] Some men coped with treatment side-effects by perceiving the lost (sexual) function as no longer necessary, for example, in terms of fathering children. Men may also perceive the lost function as an unfortunate consequence of beating cancer, with survival being more important than retained sexual function [42, 74], however maintaining such stance in the event of recurrent cancer diagnosis would be challenging.

Involvement in work, leisurely pursuits or similar diversions, have been found to provide distraction from side-effects or provide other focus for men coping with an altered life. [35] Men in the current study reported they coped by accepting the fact that it may take time for side-effects to improve. They also ensured they kept themselves busy with other activities such as hobbies, work and caring for grandchildren.

As a result of their attitude, men with a more optimistic outlook on life tend to view their quality of life more positively [80, 123] and men with better scores on quality of life measures tend to minimise illness-related stress compared to men with poorer quality of life. [77]. A number of men in the current study reported the influence of their overall positive attitude in helping them cope with difficulties after prostate cancer treatment, supporting the findings of the literature.

Individuals differ in their response to altered urinary and sexual function following prostate cancer treatment. This can range from tolerance to striving for a sense of control by trying to manage the dysfunction [35] and keeping their daily activities as normal as possible. Feeling a sense of control over one’s life is important for many men after prostate cancer treatment. [89] While most of the men in this study reported problems associated with side-effects impacting on their quality of life
and many described difficulties adjusting, they all coped by continuing to work either in paid employment, voluntary work or on projects around the home, fill their days with varied activities, plan holiday trips and generally continuing in their life roles, despite the effects of their treatment.

**Striving for acceptance and integration**

While the men in the current research project endeavoured to accept the changes in their life resulting from prostate cancer treatment, many reported they had not been completely successful but continued their efforts to adjust and get on with life as it now was. This was supported by a wide range of participants’ quantitative responses with 21% of men indicating that they had accepted their illness “a little bit/somewhat” and 71% reported they had accepted their illness “quite a bit/very much”.

Sensitive and effective communication with health professionals that was tailored to the needs of patients was highly valued by men and was consistently reported to be the most important determinant of positive adjustment. Some men also reported the benefit of meeting with other men in a similar situation and talking with health professionals involved in the care of men with prostate cancer. These men reported such interactions were helpful in their acceptance of the changes they experienced and integration of them into their altered life.

Hedestig et al (2005) identified 3 adjustment strategies men used after prostate cancer treatment. One of the strategies, living in the present was exemplified by one participant in this study who now understands he can complicate sexual activity by worrying about whether an erection is occurring or just “be with the moment” and enjoy the pleasure he is experiencing. The second strategy, focusing on the curative intent of treatment, was mirrored in some participants in the current study comments that sexual function was not as important as surviving cancer. Many of the participants gave examples of the third adjustment strategy, reappraising the importance of aspects of their life which would improve their quality of life, such as reappraisal of their relationship which many described as stronger than prior to diagnosis.

The physical and psychological impact of prostate cancer is considerable, and ramifications follow for partners and for the couple relationship itself. Post-treatment adjustment requires for the couple to reevaluate their life and cope with any losses incurred. Manne et al (2008) comment that relationship changes as a consequence of prostate cancer treatment are more affected by the dyad’s coping with cancer in their lives rather than the disease itself. Clark et al (2003) found similar marital affection scores in men treated for prostate cancer by surgery or radiotherapy and men
without cancer [24] and men who reported good social support and self esteem were more likely to report better quality of life. [6, 9]. This supports the findings in the present research where the majority of men in relationships reported being satisfied with their relationship, despite the majority reporting sex function related concerns, and many commented on the support their partners had provided. Couple therapy can provide a forum for couples to better understand the ramifications of the threat of loss for their relationship, and help couples develop resilience in order that they can effectively support each other. [124]

The participants in the current study spoke frankly about their experiences of life after prostate cancer which for some was more distressing than others. While the men acknowledge the difficulties they have encountered and continue to encounter in a number of cases, they are trying to adjust to what is for them a “new sexual self” that emerged after the treatment for prostate cancer. The detrimental effect that changed sexual function has had on some of the men’s masculine identity and self perception impedes that adjustment in varying degrees, however the men seemed to have achieved various levels of adjustment and continue to work towards further adjustment.
CHAPTER 5

Limitations And Strengths Of The Study

It is acknowledged that there are some limitations of the current study and inferences from the results should be made bearing these limitations in mind.

Firstly, the study sample is relatively small: 24 men of whom 22 were treated with radical prostatectomy, a common prostate cancer treatment. The primary aim of the current study was to qualitatively explore responses of men affected by prostate cancer, with the quantitative measures serving to characterise the sample and check their acceptability for this population. Considering that the current sample size allowed for data saturation within the qualitative analysis (i.e. a point at which no new themes emerge from the data), the current sample size seems justified.

Secondly, the study population was self-selected from a group of more than 400 men on a newsletter mailing list of a Prostate Cancer Support Group, coordinated by the researcher. This may, therefore, affect the generalisability of the results, since men who volunteered to participate may differ from those who did not volunteer to participate. For example, this type of research may have appealed to men who were experiencing substantial side effects of their treatment, or those who were unhappy with residual side effects no matter what the degree, or men who were more willing to discuss their personal lives and sensitive topics, or those who had a personal bias or message to share. However, when asked during the interview what motivated them to take part in the study, most participants mentioned they hoped their experience would be helpful to other men in the future, indicating altruistic motivation. Further, both quantitative and qualitative results reflect existing research findings regarding men’s quality of life after prostate cancer, suggesting that the current population experienced similar levels of quality of life.

Thirdly, the cohort consisted of mainly married heterosexual men who would have a unique set of experiences that may not generalise as easily to single men or homosexual men (although this group did have one homosexual man, 2 unmarried men and 2 divorced men, none of whom were in a relationship). Future studies would benefit from employing purposive sampling to target specific subgroups of men, in order to increase the generalisability of findings.

Another limitation is that the current study attracted men whose experiences related to side effects of treatment for localised or locally advanced prostate cancer, and therefore, although useful in this population, the results are not generalisable beyond this specific clinical population. Men diagnosed with advanced prostate cancer or at palliative stage may view and cope with side effects
of treatment differently to men with a favourable prognosis. Similarly, men initially diagnosed as having localised or locally advanced disease but who now experience symptoms related to distant spread of the prostate cancer may also have a different perspective of symptoms and initial information associated with their initial treatment.

An additional issue to consider is whether the female gender of the interviewer potentially influenced the nature of the participants’ responses, especially since the interviews involved discussion of private issues such as loss of urinary control, sexual dysfunction, reduced self image and problems in intimate relationships. Namely, men being interviewed by a female researcher may not be as open as they might be if interviewed by another man, especially when discussing the very personal nature of the side effects of prostate cancer treatments. However, during the interviews, participants appeared to be very open and willing to discuss their experiences of side effects candidly, including their impact on their quality of life and their relationships. It is possible that some information may have been tailored to impress the female interviewer and may have been presented differently were the interviewer a male. At the conclusion of each interview men were asked “What, if anything, would have made you feel more comfortable during this interview?” All the participants responded that they were comfortable in the interview, and some voluntarily mentioned they preferred to be interviewed by the researcher whom they knew (the interviewer being a facilitator of their support group) rather than a stranger, and a couple of men commented they found it beneficial to tell their prostate cancer history.

Finally, we recognise the importance of comments from partners of patients with prostate cancer. There is a paucity of studies addressing the concerns of partners are available. Although the current study aimed to deal with relationship issues, information regarding partner’s responses thoughts and feelings were sought only from the perception of the male patient. These responses need to be interpreted with caution due to potential bias. A direct approach to partners may have revealed different responses.

These limitations notwithstanding, the current study has distinct strengths. The majority of literature available in the field of prostate cancer treatment side effects is quantitative and describes the incidence of treatment side-effects rather than investigating the experiential impact of those effects on men, particularly with regard to their sexual adjustment, self-perception and relationships. Qualitative methods can provide comprehensive information about individuals’ reactions, thoughts and feelings relating to specific proceedings which quantitative measures may not capture, and allows meaning to emerge from the data. [125] Using both quantitative and qualitative methods allowed the emergence of a broader picture of the impact of side-effects, particularly sexual function, on the participants than might otherwise have occurred.
Further, the current study provides a comprehensive picture of post-treatment adjustment, via the use of a wide range of standardised measures targeting physical, emotional, functional, sexual, relationship and self-esteem domains of functioning and wellbeing. The selected scales appeared relevant and acceptable to the current population, pointing to their usefulness in future descriptive and interventional studies.

Finally, the current study was a clinician-initiated project, initiated by the researcher (NH) who has been a Clinical Nurse Consultant caring for men with prostate cancer in an outpatient setting for over 10 years. The researcher recognized there was a need for better understanding of, and development of tailored interventions, for changes in sexual activities and self-identity post-treatment, which has not been targeted in the existing research and its importance, has been confirmed by the current study.

**Implications For Practice And Future Research**

Based on the obtained findings, a number of implications for clinical practice and research can be made.

A diagnosis of prostate cancer can be a very anxious and confusing time for men and their partners and families. There is much information about the diagnosis, prognosis, various treatment choices and potential side effects for men to absorb and apply to his specific circumstances. The post-treatment adjustment is an equally challenging, which is not only complex but also prolonged. The current data indicate that:

*Doctors* need to be cognisant of the potential for patients to be overwhelmed by information and provide clear, easy to understand information, involve men in treatment decision-making and facilitate access to multiple sources of information and support. Question prompt sheets which list commonly asked questions or decision aids which objectively present pros and cons of each option, may serve as valuable supplementary resources for facilitating doctor-patients communication and informed treatment decision making. There is a need for communication skills training for health professional to improve their confidence and skills in discussing sexual issues.

*Men and their partners* need to be informed of the broader nature of post-treatment sexual dysfunction, namely changes in desire and orgasm as well as erectile function and the potential
impact on self-esteem and quality of life. Such discussions need to take place prior to the treatment and continue throughout the actual treatment and recovery. In the lead up to making a treatment decision, an honest assessment of the importance of sexual function to both members of the couple should be made with a view to tailoring a plan prior to treatment for sexual rehabilitation after treatment.

*Partners* should be involved in sexual rehabilitation and appropriate information whenever possible and timely referrals for sexual counselling provided if appropriate.

*Other health professionals:* During the course of the interviews men reported their perceived benefit of receiving additional information and support from sources other than their doctor. Current and existing data indicate that there are a number of men living with the consequences of prostate cancer treatment and a number of these men would benefit from ongoing psychosocial support. Early psychosocial supportive interventions may prevent or reduce the long-term concerns of men. Such psychosocial interventions seem to be best provided by specialist nurses. Prostate cancer nurses’ role is to educate and support men and their families from diagnosis, through and post-treatment and to refer men and their partners as appropriate for further clinical or supportive care. Therefore, the employment of prostate cancer nurses has the potential to facilitated streamlined and efficient health service delivery, and improved patient experiences of care, satisfaction, and quality of life.

*Future research* is recommended to examine a nurse-led information and psychosocial support role and to confirm the benefits reported by participants in this study and identify other potential benefits or otherwise. This research should also include the identification of appropriate content, optimum timing and duration of a nurse led information and psychosocial intervention to develop a best practice model of care for men with prostate cancer. Although the scope of this research did not include the referral pattern or patient take-up of the service, research is warranted into the impediments to clinician referrals of newly diagnosed men and patient take-up of the service.

The majority of research regarding post treatment changes in sexual dysfunction has focused on erectile dysfunction; however sexual function also includes changes in desire, orgasm and men’s sexual self confidence and may be affected by changes in urinary or bowel function. Further research is required to determine tailored interventions which would provide long-term benefits to men and their partners adjusting to changed sexual function after treatment.

Further, access to information and support for sexual dysfunction appropriate to their needs may be a challenge for men and their partners following prostate cancer treatment. Providing practical information and support for these men may also be a challenge for health professionals to deliver.
Health professionals should be well informed and comfortable discussing the sensitive issues surrounding changed sexual capabilities and be able to provide practical advice. Further research is required to determine and improve education needs of health professionals dealing with men with prostate cancer.

Further research is also required into the most beneficial modes and timing of information, and should perhaps look at a multi-tiered approach where clinicians, nurses and allied health professionals, as well as peers work together to provide appropriate information and support over time.

**Conclusion**

With the increase in survival rates in patients diagnosed with and treated for prostate cancer comes the necessity to expand current understanding of adjustment and quality of life following treatment regimes.

The current study provided insight into the adjustment process men undergo, focusing on the area of sexual functioning following their prostate cancer treatment. Such findings contribute to improving understanding of the “new normal” sexual self that emerges at the end of prostate cancer treatment which can be used to inform and improve care for men with prostate cancer who are experiencing sexual difficulties. Areas of deficit and suggestions for improvement for clinical practice and future research have been highlighted.

It is anticipated that a timely provision of information and support to newly diagnosed men will endow them with a better understanding of the potential impact of side effects, particularly relating to sexual function, on their personal and social relationships, their body image, self esteem and sexuality. By identifying potential issues early, and providing relevant information and support, men in a similar situation in the future will be better equipped to accept and adjust to the post-treatment changes in their sexual function. The obtained data can be used to inform future research into the development of specific psycho-educational and decision-making interventions to facilitate post-treatment sexual adjustment and rehabilitation for men and couples affected by prostate cancer.
REFERENCES

58. www.medscape.com/viewarticle/542736_4, Phosphodiesterase Type 5 (PDE5) Inhibitors in Erectile Dysfunction: PDE5 Inhibitors
60. www.cialis.com/Pages/36-hour-cialis.aspx, Cialis.


Appendix 1

The University of Sydney

NSW 2006 Australia

Human Research Ethics Committee
www.usyd.edu.au/ethics/human

Senior Ethics Officer:
Gail Briedy
Telephone: (02) 9351 4811
Facsimile: (02) 9351 6700
Email: gbreidy@med.usyd.edu.au
Rooms L4.14 & L4.13 Main Quadrangle A14

Human Secretary:
Telephone: (02) 9336 9309
(02) 9336 9308
(02) 9351 4474
Facsimile: (02) 9336 9310
Email: roben.todd@usyd.edu.au
todlerom@usyd.edu.au

14 August 2006

Dr P Waerakoon
School of Biomedical Sciences
Faculty of Health Sciences
Cumberland Campus – C42
The University of Sydney

Dear Dr Waerakoon

Thank you for your correspondence dated 31 July 2006 addressing comments made to you by the Human Research Ethics Committee (HREC). After considering the additional information, the Executive Committee at its meeting on 10 August 2006 approved your protocol entitled “The development of a model of sexual function and self perception in men following prostate cancer”.

Details of the approval are as follows:

Ref No.: 08-2006/9354
Approval Period: August 2006 – August 2007
Authorised Personnel: Dr P Waerakoon
Ms N Hanly
Dr I Juraskova
Dr D Skowronski

The approval of this project is conditional upon your continuing compliance with the National Statement on Ethical Conduct in Research Involving Humans. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

Chief Investigator / Supervisor’s responsibilities to ensure that:

1. All serious and unexpected adverse events are to be reported to the HREC as soon as possible.

2. All unforeseen events that might affect continued ethical acceptability of the project are to be reported to the HREC as soon as possible.

3. The HREC is to be notified as soon as possible of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:-
• Notifying the HREC of any changes to the staff involved with the protocol.
• Notifying the HREC of any changes to the Participant Information Statement and/or Consent Form.

(4) All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee and the following statement must appear on the bottom of the Participant Information Statement. Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gboddy@usyd.edu.au (Email).

(5) The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Your approval will expire on 31 August 2010. Investigators are requested to submit a progress report annually. Your first progress report will be due on 31 January 2007.

(6) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely

[Signature]

Associate Professor J D Watson
Chairman
Human Research Ethics Committee

cc: Ms Narelle Hanly, Urology Department, Level 4 West, Concord Hospital, NSW 2139
Encl.
Appendix 2

Human Research Ethics Committee
Concord Repatriation General Hospital (CRGH)
Approval Form

The Sydney South West Area Health Service Human Research Ethics Committee-CRGH, at its meeting of 27/07/2006 reviewed the proposal named below. APPROVAL has been granted for the research to be conducted by: Narelle Hanly at Concord Repatriation General Hospital.

The following documents were: Reviewed and Approved ☑ Reviewed and Noted ☐

Approval Number: CH62/6/2006-056 – N Hanly
(All further documentation addressed to this office must include the above approval number).

Protocol Title:
The development of a model of sexual self perception in men following prostate cancer management

Participant Information Sheet Version: 2 Date: 29/8/2006
Participant Consent Form Version: 1 Date: 7/7/2006

Other: (e.g. Advertisement)
Interview Questions – Version 1 dated 7/7/2006
Advertisement (Concord Hospital Prostate Cancer Support Group Newsletter) – Version 1 dated 7/7/2006

Expiry of Approval: 30/09/07

This Human Research Ethics Committee is duly constituted, operates, complies with and is conducted according to the National Health and Medical Research Council's (NHMRC) 'National Statement on Ethical Conduct in Research involving Humans', and is guided by the ICH Harmonised Tripartite, Good Clinical Practice Guidelines and the 'World Medical Association Declaration of Helsinki 2000'.

Please complete and return the attached form to the Concord Research Office as acknowledgment of your acceptance of the Conditions of Ethical Approval.

[Signature]

Date 7/7/06

Printed Name
HREC Chairperson/Delegate

Please keep this original copy for your records

Office/Postal
Concord Research Office
Level 1, Building 71
Concord Repatriation General Hospital NSW 2150

Phone (02) 9767 6233
Fax (02) 9767 5622

E-mail ethics@crgh@health.nsw.gov.au
Human Research Ethics Committee Concord Repatriation General Hospital
Conditions Applying To The Approval Of Research Proposals.

Re: CH62/6/2006-056 – N Hanly
The development of a model of sexual self perception in men following prostate cancer management

I will adhere to the study protocol at all times.

I will supply the Committee with brief annual progress reports on the research it has approved and a final report at the conclusion of the study. I understand that these reports should:-

- be accompanied by abstracts of articles or publications (if any) arising out of the study.
- confirm security of records.
- confirm compliance with approved consent procedures and documentation.

I understand that ethical approval is valid for four years and that progress reports are required annually. The first report should be sent to the Concord Research Office by 30/09/2007.

I agree to report immediately to the Ethics Committee any circumstance which might affect ethical acceptance of the protocol, including:-

- serious adverse events.
- proposed changes in the protocol.
- unforeseen events which may have relevance for ethical acceptability.

I will notify the committee of the study’s discontinuation and the reasons for its discontinuation.

I understand that if I (or my co-investigators) are undertaking this research on behalf of the University of Sydney or as part of a conjoint appointment to the University, I must inform the University of Sydney Risk Management Office, so that appropriate indemnification can be arranged. Contact details for the Risk Management Office are available through the Concord Research Office.

Printed Name: Hanly
Chief Investigator

Signature: Hanly
Date: 5/9/06

Please keep a signed copy of this document on your files and return the signed original to the Concord Research Office.
Level 1, Building 75, Concord Repatriation General Hospital NSW 2139
RESEARCH INTO MEN’S EXPERIENCE OF CHANGES IN SEXUALITY FOLLOWING TREATMENT FOR PROSTATE CANCER

Have you experienced any changes in:

- Sexual Function (eg erectile difficulties, sexual desire, sensation etc) or
- how you see your Sexual Self / Masculinity?

Does this:

- bother you?
- affect your intimate relationship/s?
- affect how you relate to women in general and even other men?
- (if currently single) affect your thoughts about starting a new intimate relationship?

If you answered “yes” to any of the above would you like to participate in a study exploring Sexual Function and Self Perception in Men Following Treatment for Prostate Cancer?

The aim of the study is to explore the experiences of men already treated for prostate cancer so that better education and support can be given to individuals and couples to assist in their management of, or adaptation to, changes in sexual function that result from their treatment.

What is involved?

You will be asked to complete a take-home questionnaire (approx 45min) and/or a face-to-face interview (1 hour). The interview will be conducted by Narelle Hanly, or if you prefer to be interviewed by someone not known to you, Dr Ilona Juraskova (Psychologists), will organise an alternative interviewer.

Why Participate?

This research may not benefit you directly however it is anticipated that, by gaining better knowledge and understanding of men’s experiences after treatment for prostate cancer, health professionals will, in the future, be better able to provide appropriate education and support to newly diagnosed men allowing improved adjustment for both individuals and couples to a new normal in sexual function.
The research is being conducted by Narelle Hanly, Clinical Nurse Consultant Prostate and Coordinator of the Concord Hospital Prostate Cancer Support Group as part of her Masters of Applied Science through the University of Sydney. For further information please contact Narelle during business hours on (02) 97675332.
PARTICIPANT INFORMATION STATEMENT

You are invited to take part in a research study into *The Development of a Model of Sexual Function and Self Perception following Prostate Cancer*. Many men who have been treated for prostate cancer experience sexual difficulties. This project aims to explore the experience of sexual activity and self-perception in men following prostate cancer treatment, particularly with regard to their sexual function, intimate relationships, sense of masculinity and overall wellbeing. It is anticipated that the obtained information will inform the development of a specific information tool for men and health professionals involved in their care, to provide support and better understanding of the “new normal” sexual function which occurs as a result of prostate cancer treatment. The ultimate goal of this study is to assist the process of acceptance and adjustment to changes related to prostate cancer diagnosis and treatment for men and their partners.

The study is being conducted by Narelle Hanly, Clinical Nurse Consultant (Prostate) and will form the basis for the degree of Masters of Applied Science at the University of Sydney under the supervision of Dr Patricia Weerakoon, Dr Ilona Juraskova and Dr Dariusz Skowronski.

If you agree to participate in this study, you will be asked to complete a questionnaire and participate in a face-to-face interview. **You can choose to participate by completing the questionnaire only or the interview only.** If you choose to participate by interview only, please return the signed consent form in the pre-paid self-addressed envelope provided, and discard the enclosed questionnaire.

The questionnaire will take approximately 45 minutes to complete. We would greatly appreciate if you would complete and return this questionnaire together with the signed consent form in the reply-paid envelope provided, within a week of receiving the study materials.
If you choose to participate in a one-on-one, face-to-face interview, the research coordinator (Narelle Hanly) will telephone you to arrange a suitable time for the interview. If you wish to participate but would prefer to be interviewed by a researcher not known to you, Ilona Juraskova will arrange this for you.

The interview will take approximately one hour of your time and will take place at Concord Hospital. The interview will be audio taped to allow accurate analysis of participants' views. During the interview, you will be asked about your experience of prostate cancer treatment, particularly with regard to any changes in your sexual life, intimate relationships, sense of masculinity and overall self-perception.

With your consent, the research team will also obtain information about your diagnosis and treatment from your medical records.

Most men find the opportunity to reflect on their experiences helpful, but we appreciate that this is a very personal and sensitive area. If the participation in the study raises any issues or concerns, you will be offered support and/or counselling.

All aspects of the study, including results, will be strictly confidential and only the investigator's named above will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

While we intend that this research furthers knowledge and understanding of men’s experience of prostate cancer and related side effects and may improve education and support for men diagnosed with the condition in the future, it may not be of direct benefit to you.

Participation in this study is entirely voluntary: you are not obliged to participate and - if you do participate - you can withdraw at any time. Whatever your decision, it will not affect your medical treatment or your relationship with medical staff.

If you would like to know more at any stage, please feel free to contact Narelle Hanly on (02) 9767 5332 or Ilona Juraskova on (02) 9036 5275. This information sheet is for you to keep.

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@mail.usyd.edu.au (Email).
Appendix 5

MEN’S SEXUAL FUNCTION AND SEXUAL SELF-PERCEPTION

FOLLOWING PROSTATE CANCER

QUESTIONNAIRE
This questionnaire is part of a large project investigating the effects of different treatments for prostate cancer on quality of life, and particularly on physical, emotional and sexual functioning. We hope that this information will help us to better prepare men for different treatments and assist them in adjusting once the treatment is over.

CONFIDENTIALITY:

We would like to ask you to complete the following questionnaire. All the information will be treated as strictly confidential and your identity will never be revealed in any reports. None of the clinicians treating you will see the answers. The completed questionnaires will be kept separately from any information that could identify you and will be kept securely under lock and key. There is no need for you to write your name on this questionnaire.

INSTRUCTIONS:
Thank you very much for your help in this important study.
Section 1: DEMOGRAPHICS AND MEDICAL HISTORY

The first section of the questionnaire asks some general background and health questions which will be helpful to us in analysing the data. It will not be used for identification.

Today’s Date: ____________________

1. **What is your current age?** Age: _______ years

2. **What was your age at the time of your prostate cancer diagnosis?** Age: _______ years

3. **What is your present marital status?**
   - [ ] 1 Single
   - [ ] 2 Married: Length of relationship: _______ years
   - [ ] 3 In a relationship, not living together: Length of relationship: _______ years
   - [ ] 4 De facto (not married but living together): Length of relationship: _______ years
   - [ ] 5 Separated/Divorced
   - [ ] 6 Widowed

4. **What is your sexual orientation?**
   - [ ] 1 Heterosexual
   - [ ] 2 Homosexual
   - [ ] 3 Bisexual
   - [ ] 4 I prefer not to answer this question

5. **Do you have children?**
   - [ ] 0 No.
   - [ ] 1 Yes. Number of children: _______

6. **What is the highest qualification you have obtained?**
7. What is your religious denomination / spiritual belief? __________________________

Is religion important in your life?

☐ 0 No.

☐ 1 Yes.

8. What is your current employment status?
(Please tick the box that best describes your employment status)

☐ 1 Full-time employed

☐ 2 Part-time employed

☐ 3 Unemployed

☐ 4 Self-employed

☐ 5 Full-time student

☐ 6 Part-time student

☐ 7 Permanently unable to work

☐ 8 Temporarily unable to work

☐ 9 Retired

☐ Other (please specify): __________________________

9. What is your occupation (if not currently working or retired, specify past occupation)?

Please continue on next page
10. Do you speak a language other than English at home?

- [ ] 1. No, only English
- [ ] 2. Yes, Italian
- [ ] 3. Yes, Greek
- [ ] 4. Yes, Chinese
- [ ] 5. Yes, Arabic
- [ ] Other (please specify): __________________________

11. Are you currently taking any anti-depressant or sedative medication(s)?

- [ ] 0. No.
- [ ] 1. Yes. Please specify the name of medication(s): __________________________

12. What form(s) of treatment for prostate cancer did you undergo? (you may tick more than one box where applicable)

- [ ] 1. Radical Prostatectomy with bilateral nerve sparing. How long ago? __________
- [ ] 2. Radical Prostatectomy with unilateral nerve sparing. How long ago? __________
- [ ] 3. Radical Prostatectomy with no nerve sparing. How long ago? __________
4. External Beam Radiotherapy. How long ago did you finish this treatment? __________

5. Seed Brachytherapy. How long ago did you finish this treatment? __________

6. High dose Rate Brachytherapy and external Beam Radiotherapy.

    How long ago did you finish this treatment? __________

7. Hormone Therapy. How long ago did you finish this treatment? __________

    Are you currently still on hormone therapy? __________

Describe Yourself

Below is a listing of 45 adjectives. For each word, consider whether or not the term describes you. Each adjective is to be rated on a 7-point scale ranging from 0 = not at all descriptive of me to 6 = very much descriptive of me. Choose a number for each adjective to indicate how accurately the adjective describes you. There are no right or wrong answers. Please be thoughtful and honest.

Considering 0 = not at all descriptive of me and 6 = very much descriptive of me,

to what extent does the term describe me?

Example

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</tr>
<tr>
<td>excitable</td>
<td>lazy</td>
</tr>
</tbody>
</table>
Section 2: GENERAL QUESTIONS ABOUT HOW YOU FEEL

This section is designed to help us know how you feel. Please read each item below, and place a tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don’t take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

1. I feel tense or ‘wound up’:
   - Most of the time
   - A lot of the time
   - From time to time, occasionally
   - Not at all

2. I still enjoy the things I used to enjoy:
   - Definitely as much
   - Not quite so much
   - Only a little
   - Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:
   - Very definitely and quite badly
   - Yes, but not too badly
   - A little, but it doesn’t worry me
   - Not at all

8. I feel as if I am slowed down:
   - Nearly all the time
   - Very often
   - Sometimes
   - Not at all

9. I get a sort of frightened feeling like ‘butterflies’ in the stomach:
   - Not at all
   - Occasionally
   - Quite often
   - Very often

10. I have lost interest in my appearance:
    - Definitely
    - I don’t take as much care as I should
    - I may not take quite as much care
    - I take just as much care as ever

Please continue on next page
4. I can laugh and see the funny side of things:
   - As much as I always could
   - Not quite so much now
   - Definitely not so much now
   - Not at all

11. I feel restless as if I have to be on the move:
   - Very much indeed
   - Quite a lot
   - Not very much
   - Not at all

5. Worrying thoughts go through my mind:
   - A great deal of the time
   - A lot of the time
   - From time to time but not too often
   - Only occasionally

12. I look forward with enjoyment to things:
   - As much as I ever did
   - Rather less than I used to
   - Definitely less than I used to
   - Hardly at all

6. I feel cheerful:
   - Not at all
   - Not often
   - Sometimes
   - Most of the time

13. I get sudden feelings of panic:
   - Very often indeed
   - Quite often
   - Not very often
   - Not at all

7. I can sit at ease and feel relaxed:
   - Definitely
   - Usually
   - Not often
   - Not at all

14. I can enjoy a good book or radio or TV programme:
   - Often
   - Sometimes
   - Not often
   - Very seldom
Section 3: GENERAL QUESTIONS ABOUT SEXUAL ACTIVITY

If you are not in a sexual relationship, please tick this box □ and answer the questions in part A which are marked with an asterisk (*) before moving on to Section 4.

Occasionally, men with prostate cancer notice changes which may affect them sexually. Although the following questions are sensitive and personal, they are important in determining how prostate cancer and its treatment affect this part of your life. Please be assured that your responses to these questions will remain strictly confidential.

**PART A**

<table>
<thead>
<tr>
<th>Question</th>
<th>Never / Almost never</th>
<th>A few times</th>
<th>Sometimes</th>
<th>Most times</th>
<th>Always / Almost always</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are you able to ejaculate when having sexual activity with your wife or main partner?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>In the past 4 weeks, when having sexual activity with your wife or main partner, how often did you feel that you took too long to ejaculate or come?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*In the past 4 weeks, if you were able to ejaculate, have you experienced any physical pain or discomfort when you ejaculated?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>*In the past 4 weeks, when masturbating by yourself or having sexual activity with your wife or main partner, how often have you felt like you were ejaculating but no fluid came out?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

*Please circle*

*Compared to the time before cancer diagnosis, would you say the physical pleasure you feel when you ejaculate has increased or decreased?*

<table>
<thead>
<tr>
<th>Satisfied with overall sexual relationship</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>How satisfied are you with the overall sexual relationship you have with your main partner?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>How satisfied are you with the quality of the sex life you have with your main partner</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>How satisfied are you with the number of times you and your main partner have sex?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
How satisfied are you with the way you and your main partner show affection during sex?  

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
</table>

How satisfied are you with the way you and your main partner communicate about sex?  

<table>
<thead>
<tr>
<th></th>
<th>None / Very poor</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
</table>

*In the past 4 weeks, if you were able to ejaculate, how would you rate the strength or force of your ejaculation?*  

|   | 0 | 1 | 2 | 3 | 4 |

*In the past 4 weeks, if you were able to ejaculate, how would you rate the amount or volume of semen when you ejaculate?*  

|   | 0 | 1 | 2 | 3 | 4 |

**Section 3, Part B**

By circling one number per line, please indicate how true each statement has been for you **during the past 4 weeks**, using the following response options:

- **Almost never / Never** ..................... 1
- **A few times** (much less than half the time) ..... 2
- **Sometimes** (about half the time) ............3
- **Most times** (much more than half the time) …. 4
- **Almost always / Always** ..................... 5

**During the past 4 weeks...**

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I felt relaxed about initiating sex with my partner</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>2. I felt confident that during sex my erection would last long enough</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. I was satisfied with my sexual performance</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. I felt that sex could be spontaneous</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I was likely to initiate sex</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. I felt confident about performing sexually</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. I was satisfied with our sex life</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. My partner was unhappy about the quality of our sexual relations</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. I had good self-esteem</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I felt like a whole man</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I was inclined to feel that I am a failure</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I felt confident</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. My partner was satisfied with our relationship in general</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I was satisfied with our relationship in general</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Section 4: QUALITY OF LIFE AND WELL-BEING QUESTIONS

Below is a list of statements that other people with your illness have said are important. By circling one number per line, please indicate how true each statement has been for you during the past 7 days.

### PHYSICAL WELL-BEING

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have a lack of energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have nausea</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Because of my physical condition, I have trouble meeting the needs of my family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am bothered by side effects of treatment</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel ill</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am forced to spend time in bed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### SOCIAL/FAMILY WELL-BEING

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel close to my friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I get emotional support from my family</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I get support from my friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My family has accepted my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with family communication about my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel close to my partner (or the person who is my main support)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box and go to the next section.

| I am satisfied with my sex life                                          | 0          | 1            | 2         | 3           | 4         |
EMOTIONAL WELL-BEING

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with how I am coping with my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am losing hope in the fight against my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I feel nervous</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I worry about dying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I worry that my condition will get worse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

By circling one number per line, please indicate how true each statement has been for you **during the past 7 days**.

FUNCTIONAL WELL-BEING

<table>
<thead>
<tr>
<th>Statement</th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am able to work (include work at home)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My work (include work at home) is fulfilling</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to enjoy life</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have accepted my illness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am sleeping well</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am enjoying the things I usually do for fun</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am content with the quality of my life right now</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
### ADDITIONAL CONCERNS

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Some-what</th>
<th>Quite a bit</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am losing weight</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have a good appetite</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have aches and pains that bother me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have certain parts of my body where I experience significant pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My pain keeps me from doing thing I want to do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am satisfied with my present comfort level</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to feel like a man</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have trouble moving my bowels</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have difficulty urinating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am able to have and maintain an erection</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have trouble controlling my urine</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am comfortable discussing my condition with friends</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I urinate more frequently than usual</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am afraid to be far from a toilet</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have to limit my social activity because of my condition</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have to limit my physical activity because of my condition</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I have to limit my sexual activity because of my condition</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I am embarrassed by my condition</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>My condition wakes me up at night</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I must urinate frequently to avoid leakage</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>I wear protection for leakage of urine</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Section 5: QUALITY OF LIFE AND WELL-BEING QUESTIONS

Below is a list of statements that other people with your illness have said are important. Please indicate how true each statement has been for you.

URINARY DOMAIN

Over the past 4 weeks, how often have you experienced the following:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Rarely or never</th>
<th>About once a week</th>
<th>More than once a week</th>
<th>About once a day</th>
<th>More than once a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>leaked urine</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>urinated blood</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>had pain or burning on urination</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

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

- 0  No urinary control whatsoever
- 1  Frequent dribbling
- 2  Occasional dribbling
- 3  Total control

How many pads or adult nappies per day did you usually use to control leakage during the last 4 weeks?

- 0  No pads
- 1  1 pad per day
- 2  2 pads per day
3 or more pads per day

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

<table>
<thead>
<tr>
<th></th>
<th>No problem</th>
<th>Very small problem</th>
<th>Small problem</th>
<th>Moderate problem</th>
<th>Big problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dripping or leaking urine</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Pain or burning on urination</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Bleeding with urination</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Weak urine stream or incomplete emptying</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Waking up to urinate</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Need to urinate frequently during the day</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Overall how big a problem has your urinary function been for you during the last 4 weeks?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Please keep going - you are over halfway 😊
## BOWEL DOMAIN

*Over the past 4 weeks, how often have you experience the following:*

<table>
<thead>
<tr>
<th></th>
<th>Rarely or never</th>
<th>About once a week</th>
<th>More than once a week</th>
<th>About once a day</th>
<th>More than once a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>rectal urgency</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>uncontrolled leakage of stool or feces</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>crampy pain in your abdomen, pelvis or rectum</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

*Over the past 4 weeks, how often have you had:*

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>About half time</th>
<th>Usually</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>stools (bowel movements) that were loose or liquid</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>bloody stool</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>painful bowel movements</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

*How many bowel movements have been painful during the last 4 weeks?*

- 0 Two or less
- 1 Three to Four
- 2 Five or more

*How big a problem, if any, has each of the following been for you during the last 4 weeks?*
<table>
<thead>
<tr>
<th></th>
<th>No problem</th>
<th>Very small problem</th>
<th>Small problem</th>
<th>Moderate problem</th>
<th>Big problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urgency to have bowel movement</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Increased frequency of bowel movements</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Watery bowel movements</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Losing control of your stools</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Bloody stools</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Abdominal/Pelvic/Rectal pain</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Overall how big a problem have your bowel habits been for you during the last 4 weeks?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
### SEXUAL DOMAIN

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

<table>
<thead>
<tr>
<th></th>
<th>Very poor to None</th>
<th>Poor</th>
<th>Fair</th>
<th>Good</th>
<th>Very good</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your level of sexual desire</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Your ability to have an erection</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Your ability to reach orgasm (climax)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Ability to function sexually</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**How would you describe the usual QUALITY of your erections during the last 4 weeks?**

- **0** None at all
- **1** Not firm enough for any sexual activity
- **2** Firm enough for masturbation or foreplay only
- **3** Firm enough for intercourse

**How would you describe the usual QUANTITY of your erections during the last 4 weeks?**

- **0** NEVER had an erection when I wanted one
- **1** I had an erection LESS THAN HALF the time I wanted one
- **2** I had an erection ABOUT HALF the time I wanted one
- **3** I had an erection MORE THAN HALF the time I wanted one
- **4** I had an erection WHENEVER I wanted one
During past 4 weeks, how often:

<table>
<thead>
<tr>
<th>Event</th>
<th>Not at all</th>
<th>Less than once a week</th>
<th>About once a week</th>
<th>Several times a week</th>
<th>Daily</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have you awakened in the morning or night</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>with an erection</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>did you have any sexual activity</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Did you have sexual intercourse</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Event</th>
<th>No problem</th>
<th>Very small problem</th>
<th>Small problem</th>
<th>Moderate problem</th>
<th>Big problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your level of sexual desire</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Your ability to have an erection</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Your ability to reach orgasm (climax)</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Overall how big a problem has your sexual</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>function or lack of sexual function been</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>for you during the last 4 weeks?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
HORMONAL DOMAIN

Over the past 4 weeks, how often have you experienced the following:

<table>
<thead>
<tr>
<th></th>
<th>Rarely or never</th>
<th>About once a week</th>
<th>More than once a week</th>
<th>About once a day</th>
<th>More than once a day</th>
</tr>
</thead>
<tbody>
<tr>
<td>experienced hot flushes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>had breast tenderness</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>felt depressed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>felt lack of energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

How much change in your weight have you experienced during the last 4 weeks?

0       Gained 4.5 kilograms or more
1       gained less than 4.5 kilograms
2       No change in weight
3       Lost less than 4.5 kilograms
4       Lost 4.5 kilograms or more

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

<table>
<thead>
<tr>
<th></th>
<th>No problem</th>
<th>Very small problem</th>
<th>Small problem</th>
<th>Moderate problem</th>
<th>Big problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hot flushes</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>0</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>Breast tenderness/enlargement</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of body hair</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling depressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Change in body weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall how big a problem has</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>your urinary function been for</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>you during the last 4 weeks?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

_Nearly there!!! 😊_
To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. **Put a circle around the number which best describes whether you have needed help with this in the LAST MONTH.**

There are 5 possible answers to choose from:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NO NEED</strong></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td><strong>Not applicable</strong> – This was not a problem for me as a result of having cancer.</td>
</tr>
<tr>
<td>2</td>
<td><strong>Satisfied</strong> – I did need help with this, but my need for help was satisfied at the time.</td>
</tr>
</tbody>
</table>

| **SOME NEED** |   |
| 3 | **Low need** – This item caused me little concern or discomfort. I had little need for additional help. |
| 4 | **Moderate need** – This item caused me some concern or discomfort. I had some need for additional help. |
| 5 | **High need** – This item caused me a lot of concern or discomfort. I had a strong need for additional help. |
In the **last month**, what was your level of need for help with:

<table>
<thead>
<tr>
<th>No need</th>
<th>Some need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not applicable</td>
<td>Satisfied</td>
</tr>
<tr>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.
In the **last month**, what was your level of need for help with:

<table>
<thead>
<tr>
<th>No need</th>
<th>Some need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not applicable</td>
<td>Satisfied</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>1.</td>
<td>Pain</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2.</td>
<td>Lack of energy/tiredness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3.</td>
<td>Feeling unwell a lot of the time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4.</td>
<td>Work around the home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5.</td>
<td>Not being able to do the things you used to do</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6.</td>
<td>Anxiety</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7.</td>
<td>Feeling down or depressed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8.</td>
<td>Feelings of sadness</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9.</td>
<td>Fears about the cancer spreading</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10.</td>
<td>Worry that the results of treatment are beyond your control</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>In the last month, what was your level of need for help with:</td>
<td>No need</td>
<td>Some need</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------</td>
<td>---------</td>
<td>-----------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not applicable</td>
<td>Satisfied</td>
<td>Low need</td>
<td>Moderate need</td>
<td>High need</td>
</tr>
<tr>
<td>11. Uncertainty about the future</td>
<td>Not applicable</td>
<td>Satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Learning to feel in control of your situation</td>
<td>Not applicable</td>
<td>Satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Keeping a positive outlook</td>
<td>Not applicable</td>
<td>Satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Feelings about death and dying</td>
<td>Not applicable</td>
<td>Satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Changes in sexual feelings</td>
<td>Not applicable</td>
<td>Satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Changes in your sexual relationships</td>
<td>Not applicable</td>
<td>Satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Concerns about the worries of those close to you</td>
<td>Not applicable</td>
<td>Satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. More choice about which cancer specialists you see</td>
<td>Not applicable</td>
<td>Satisfied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>No need</td>
<td>Some need</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---------</td>
<td>-----------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not applicable</td>
<td>Satisfied</td>
<td>Low need</td>
<td>Moderate need</td>
<td>High need</td>
</tr>
<tr>
<td>19.</td>
<td>More choice about which hospital you attend</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20.</td>
<td>Reassurance by medical staff that the way you feel is normal</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21.</td>
<td>Hospital staff attending promptly to your physical needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22.</td>
<td>Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23.</td>
<td>Being given written information about the important aspects of your care</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24.</td>
<td>Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>No need</td>
<td>Some need</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>---------</td>
<td>-----------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Not applicable</td>
<td>Satisfied</td>
<td>Low need</td>
<td>Moderate need</td>
<td>High need</td>
</tr>
<tr>
<td>25.</td>
<td>Being given explanations of those tests for which you would like explanations</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26.</td>
<td>Being adequately informed about the benefits and side-effects of treatments before you choose to have them</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27.</td>
<td>Being informed about your test results as soon as feasible</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>28.</td>
<td>Being informed about cancer which is under control or diminishing (that is, remission)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>29.</td>
<td>Being informed about things you can do to help yourself to get well</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>30.</td>
<td>Having access to professional counselling (e.g., psychologist, social worker, counsellor, nurse specialist) if you, family, or friends need it</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
In the last month, what was your level of need for help with:

<table>
<thead>
<tr>
<th>No need</th>
<th>Some need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not applicable</td>
<td></td>
</tr>
</tbody>
</table>

Satisfied

<table>
<thead>
<tr>
<th>Low need</th>
<th>Moderate need</th>
<th>High need</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

31. To be given information about sexual relationships

| 1 | 2 | 3 | 4 | 5 |

32. Being treated like a person not just another case

| 1 | 2 | 3 | 4 | 5 |

33. Being treated in a hospital or clinic that is as physically pleasant as possible

| 1 | 2 | 3 | 4 | 5 |

34. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up

| 1 | 2 | 3 | 4 | 5 |

Please write any comments about your experience (both positive or negative) which have not been covered by the questionnaire:

________________________________________________________________________________________

________________________________________________________________________________________

________________________________________________________________________________________
We greatly appreciate the time you gave in helping us with our study.

Please post this questionnaire with your signed consent form using the enclosed reply paid envelope.
Appendix 6

Men’s Sexual Function and Self Perception following Prostate Cancer

Interview questions

INTRODUCTION

Thank you for agreeing to take part in this interview. The main aim of this study is to find out as much information as possible about the impact that particular treatments for prostate cancer may have on various aspects of your life and on sexual functioning in particular.

I have in front of me a series of questions that I would like to ask you about your experiences with prostate cancer treatment. Everybody in the study is asked the same questions. Some questions may be less relevant to your situation, but as this is a research project it is important that we ask everybody exactly the same questions.

If any of the questions are unclear, it is my job to help you understand the content of these questions. So, please do not hesitate to ask me to repeat a question or provide further explanation of what is meant by that question.

The whole interview should probably take approximately one hour of your time.

Please let me know if any questions are upsetting to you, or if you would prefer not to answer any question. We can stop the interview or take a break at any time.

I’d like to remind you that we are going to audio-tape this interview so that we can analyse the information we collect. I’m going to put the tape on now.
INTERVIEW QUESTIONS

To start the interview I’d like to get a little background information with my first questions.

1. Which of the following treatments have you undergone?
   - Radical Prostatectomy/External Beam Radiotherapy/ Seed Brachytherapy/
     High dose Rate Brachytherapy/hormone therapy (androgen deprivation).

The following questions ask about the effects of the treatment on your quality of life – by the word ‘treatment’ I mean the combination of all treatments you have undergone for prostate cancer until now.

2. When did you commence treatment? How long since you finished the treatment?
   - If on hormonal treatment: For how long did you receive hormonal treatment?

   What were the reasons that hormonal treatment stopped?

3. Were possible effects on sexual life explained to you prior to commencing treatment?
   - Did you understand what they said?

4. How did you expect the treatment to affect your life?
   - Have your expectations changed?
   - Did you expect to experience any adverse effects?

I’d like to ask you some more personal questions now – is that ok with you? Remember, this interview remains confidential - no one else will be able to identify your answers to these questions.

5. How would you describe your interest in sex prior to treatment?
   - How would you describe your interest in sex now?

6. How would you rate your sexual activity prior to treatment?
   - How would you rate your sexual activity now?
7. What changes, if any, have you noticed in sexual activity over the course of your treatment?
   - If changes have occurred when did you first notice them?
   - If changes have occurred what made you notice them?
   - To what do you attribute any changes that may have occurred?

8. How do you manage your sexual activity since treatment?
   (If appropriate - enquire about specific techniques, erectile medications/aids etc.)
   - How do you feel about having to use different techniques/medications?

9. a) If currently in a partnership:
   How has your partner responded to your treatment?
   - Prior to diagnosis were you and your partner able to discuss relationship and sexual issues openly/easily?
   - Were you able to talk with your partner about your feelings during the diagnosis, decision making time and treatment?
   - Prior to treatment, did you ever talk with your partner about how you would manage any sexual difficulties that might arise as a result of treatment? If so, how did you plan to manage them? After treatment were you able to manage any sexual difficulties as you had planned?
   - In your opinion, has the diagnosis/treatment affected your relationship with your partner? Do you think your partner would agree?
   - How do you feel about your partner now? If your feelings about your partner have changed since diagnosis and treatment, how have they changed? Is there anything specific to which you attribute the change?

b) If currently NOT in a partnership:
   - After the diagnosis, did you think a lot about how the treatment might impact on establishing new potentially intimate relationships?
   - Since treatment, have you had the opportunity to establish new potentially intimate relationships? If YES: Have you experienced any difficulties related to your self-confidence, sense of masculinity or sexual function? Could you provide an example?
     Have these difficulties interfered with/prevented you trying to establish new potentially intimate relationships in the future? How?
If NO: Do you think you will experience any difficulties related to your self-confidence, sense of masculinity or sexual function? If so, what and why?

- *(If experiencing sexual difficulties)* Have the sexual difficulties you are experiencing since treatment prevented you making opportunities to establish a new potentially intimate relationship? How?

10. What are the easiest and hardest parts of the changes in sexual function to cope with?
   - What helps you cope best with the treatment effects?
   - Was there something your doctor, hospital staff said or did, or something your partner, family, friends said or did that helped you cope easier with the treatment?

11. With the benefit of hindsight, do you think the information you were given at the time of diagnosis was sufficient for you to understand the potential impact of treatment on your life?

12. Now that you have experienced prostate cancer, do you think that any amount of information prior to diagnosis would have been sufficient for you to understand the impact of treatment on your sexual function and therefore your quality of life?

13. Looking back, is there anything else you feel would help/would have helped you cope better with your diagnosis, treatment and side effects?

14. Is there any advice you would like to give to the health professionals involved in the care of men with prostate cancer to improve their care of men with a similar condition to you, in the future?
DEBRIEFING

That brings us to the end of our interview. On behalf of myself and the rest of the research team, I’d like to thank you for your time. We really appreciate the information you have given us, and we hope to use this information to improve our understanding of the impact of prostate cancer treatments on quality of life and sexuality in particular.

For all our research projects we offer to send a free summary of the results to participants. Would you be interested in receiving a summary of the results?

It is likely that these results will become available towards the end of the year. If you move or would like them to be sent elsewhere please update us with your new address details.

If you find that after our interview today you feel upset in any way, I’d like to remind you that there is a clinical psychologist on the Uro-oncology team whom you may wish to talk things over with.

(If participant is reporting partner sexual issues)

There is a Female Sexual Medicine Clinic at Concord Hospital. If your partner is interested in more details I will be happy to send some information to her.
**Appendix 7**

**TABLE 14 Men's Sexual Schema Items**

<table>
<thead>
<tr>
<th>MSS Item</th>
<th>n</th>
<th>Not descriptive (0-1)</th>
<th>Descriptive (2-4)</th>
<th>Very descriptive (5-6)</th>
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<tbody>
<tr>
<td>Conservative</td>
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<td>11 (46%)</td>
<td>12 (50%)</td>
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<tr>
<td>Soft-hearted</td>
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<td>1 (4%)</td>
<td>5 (21%)</td>
<td>18 (75%)</td>
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<tr>
<td>Powerful</td>
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<td>4 (17%)</td>
<td>15 (63%)</td>
<td>5 (20%)</td>
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<tr>
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<td>15 (63%)</td>
<td>8 (33%)</td>
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<tr>
<td>Independent</td>
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<td>5 (21%)</td>
<td>19 (79%)</td>
</tr>
<tr>
<td>Inexperienced</td>
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<td>16 (67%)</td>
<td>8 (33%)</td>
<td>0 (0%)</td>
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<tr>
<td>Domineering</td>
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<td>12 (50%)</td>
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<td>Loving</td>
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<td>Open-minded</td>
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<td>9 (37%)</td>
<td>15 (63%)</td>
</tr>
<tr>
<td>Feeling</td>
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<td>5 (21%)</td>
<td>19 (79%)</td>
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<tr>
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<td>10 (42%)</td>
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<td>Broad-minded</td>
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<td>17 (71%)</td>
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<tr>
<td>Aggressive</td>
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<td>9 (38%)</td>
<td>11 (46%)</td>
<td>4 (16%)</td>
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<td>16 (67%)</td>
</tr>
<tr>
<td>Exciting</td>
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<td>3 (13%)</td>
<td>17 (71%)</td>
<td>4 (16%)</td>
</tr>
<tr>
<td>Direct</td>
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<td>1 (4%)</td>
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<td>12 (50%)</td>
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<tr>
<td>Sensitive</td>
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<td>16 (67%)</td>
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<td>Reserved</td>
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<td>Experienced</td>
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<td>7(29.2%)</td>
<td>17 (70.8%)</td>
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<td>Romantic</td>
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<td>1 (4%)</td>
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<td>Compassionate</td>
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<td>6 (25%)</td>
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<td>Liberal</td>
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<td>14 (58%)</td>
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<tr>
<td>Sensual</td>
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<td>13 (54%)</td>
<td>11 (46%)</td>
</tr>
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<td>Outspoken</td>
<td>24</td>
<td>4 (17%)</td>
<td>12 (50%)</td>
<td>8 (33%)</td>
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</table>
### GLOSSARY OF TERMS

<table>
<thead>
<tr>
<th>Term</th>
<th>Description</th>
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<tbody>
<tr>
<td>ADT</td>
<td>Androgen Deprivation Therapy: chemical agent used in the treatment of some prostate cancer to reduce testosterone levels to castrate level</td>
</tr>
<tr>
<td>CT</td>
<td>Computerised Axial Tomography: a medical imaging method which generates a 3-dimensional image of a body structure</td>
</tr>
<tr>
<td>DRE</td>
<td>Digital Rectal Examination: physical examination of the prostate via the rectum to assess the prostate</td>
</tr>
<tr>
<td>EBRT</td>
<td>External Beam Radiotherapy</td>
</tr>
<tr>
<td>ED</td>
<td>Erectile Dysfunction</td>
</tr>
<tr>
<td>EPIC</td>
<td>Expanded Prostate Cancer Index Composite</td>
</tr>
<tr>
<td>FACT-P</td>
<td>Functional Assessment of Cancer Therapy-Prostate scale</td>
</tr>
<tr>
<td>FAIT-U</td>
<td>Functional Assessment of Incontinence Therapy – Urinary symptoms subscale</td>
</tr>
<tr>
<td>Gleason Score</td>
<td>System of summing the most common and second most common cancer cell patterns used by pathologists to assess the severity of prostate cancer in biopsied tissue samples. A score (1 to 5) is assigned to the most prominent cancer cell pattern and then the second most prominent cancer cell pattern is also scored (1 to 5). Those 2 scores are added e.g. Gleason Score =7 may be 3+4 or 4+3</td>
</tr>
<tr>
<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
</tr>
<tr>
<td>MSHQ</td>
<td>Male Sexual Health Questionnaire scale</td>
</tr>
<tr>
<td>MSS</td>
<td>Men’s Sexual Self-Schema scale</td>
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<td>Prostate Specific Antigen</td>
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<td>RT</td>
<td>Radiotherapy</td>
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<td>Supportive Care Needs Survey Short Form 34</td>
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<td>SEAR</td>
<td>Self-esteem and Relationship questionnaire</td>
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