Prostate cancer: Anglo-Australian heterosexual perspectives

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Submitted in total fulfilment of the requirements for the degree of Doctor of Philosophy at Deakin University.

Submitted 10/2003
Candidate Declaration

I certify that the thesis entitled *Prostate cancer: Anglo-Australian heterosexual perspectives*

submitted for the degree of **Doctor of Philosophy**

is the result of my own work and that where reference is made to the work of others, due acknowledgment is given.

I also certify that any material in the thesis which has been accepted for a degree or diploma by any other university or institution is identified in the text.

Full Name: **John L Oliffe**

Signed ..................................................................................……………….

Date......................................................................................……………….
Dedication

This thesis is dedicated to all the research participants. In memory of Bronch Oliffe, Bert Hole, Trevor Jennings, Royboy and Berti—all of whom were casualties of prostate cancer.
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Abstract

Prostate cancer is one of the most prominent diseases in men’s health. It is inherently “male”, given the exclusivity of the prostate gland to men’s bodies and its physiological connection to testosterone and male sexuality. The biomedical complexities of prostate cancer continue to be unravelled and researched and are often connected to identifying causes, the virtues of screening and treatment modalities. However, despite the biological male “sex” link, most of the prostate cancer research is not connected with research on gender relations, men and masculinities. The net outcome is that men’s lives and illness experiences are absent in much of the prostate cancer research.

This PhD thesis Prostate cancer: Anglo-Australian heterosexual perspectives, is an ethnographic study of thirty-five Anglo-Australian men diagnosed with prostate cancer. Participants shared their experiences of living with prostate cancer in the context of health promotion, health services and in relation to their sexuality and intimate relationships. Through participant photographic novella and in-depth semi-structured interviews, rich cultural insights are provided. A social constructionist gender analysis is used in this research that shows how the social constructions of masculinity interconnect and occasionally collide with prostate cancer throughout the illness trajectory.
Prologue

Moments that led me here

I am 10 years old, sharing a small room with my grandfather, Bronch. His snoring stops, he swears, wipes the sleep from his eyes, and enters a chilly cold June morning on his way to the outside toilet, to pass urine. It is his fourth journey for the night as his troubled “waterworks” continue to disrupt his (and my) sleep. This ritual continues for many years, until finally, a sleep deprived and exhausted Bronch seeks help from his general practitioner. Subsequently he is diagnosed with prostate cancer.

Bronch’s experience of prostate cancer was complex and multi-faceted, and affected his sense of self and constructions of being a man. In his final years, the frustrations he experienced and the anger he projected often obscured the qualities he possessed. In many ways he died a largely misunderstood man, as little was known about his experience of prostate cancer beyond the physical symptoms that accompanied the disease and its treatments. It occurred to me that there was, and is, so much to be learned from Bronch’s and other men’s lives and experiences of prostate cancer.

I am 21 years of age as I enter the world of health care as a student nurse. The meandering journey over the next 20 years provides me with a rich tapestry of clinical, teaching and research “moments”. Central to my clinical practice is the notion that nursing, and indeed the provision of all health care, is reliant on the delivery of both art and science in variable proportions. The art underpinned by a humanistic philosophy of care that focuses on patient individuality, and holistic science informed by biological systems. Clinically, my art/science blend depends on “patient” acuity and my sensitivity and capacity to “give” proportioned “care”.

Biomedical science tends to dominate my specialty area of emergency nursing. Emergency departments provide an environment in which snapshots, glimpses and moments make up the working lives of the health care providers. Diagnostic procedures and disease labels often replace patients’ names, and the focus is on preserving life. Increasing patient acuity and technological development have
served to justify and perpetuate this practice. I am not critical of the dominant scientific discourse in such health care environments; however I craved a greater understanding of the “person” known as the “patient”.

I am 38 years old, sharing a coffee and conversation with an elderly man. We talk about his life and his experiences of living with prostate cancer. At the conclusion of the interview he warns me that life goes quickly and that slowing down and “smelling the roses” is great, because “once you let go of the stress, life is so much better”. This research has provided me with the opportunity to get to know the participants not as “patients” but as “people”, to listen to their stories and gain an understanding of their experiences of living with prostate cancer. It has been a privilege to know and interview these “people” and move beyond the “moments” that led me here.
Chapter One

Introduction to the research

Introduction

Prostate cancer is the most frequently newly diagnosed cancer in Australian men (Australian Institute Health and Welfare [AIHW], 1998) and presents significant challenges for both patients and health care professionals. Many of the challenges are due to the uncertainty and ambiguity associated with prostate cancer and its treatments. Specifically, the cause of prostate cancer is unknown, symptoms are not always produced, the virtues of screening are unclear and most treatments result in significant side effects including impotence and urinary incontinence (President and Fellows of Harvard College, 2002a).

One factor associated with prostate cancer development is increased age. It is estimated that between 1996 and 2051 the proportion of older Australians—those 65 years and over—will increase from 12% to 23% of the total population (Australian Bureau of Statistics, 1997). Australia’s ageing population is likely to result in increased numbers of men being diagnosed and treated for prostate cancer. Furthermore, men are living longer with prostate cancer, as indicated by the death rate that has decreased by 1.4% per annum between 1990 and 1999 and is significantly lower than the incidence rate (AIHW, 2000). The current trends in the epidemiological data suggest that greater numbers of Australian men will be living longer with prostate cancer in the future.

Clearly prostate cancer, which is commonly cited in discussions about men’s health, is and will continue to be a significant health care issue. However, there has been little research about how prostate cancer is experienced by men or exploration of how prostate cancer and gender interconnect. The research presented in this thesis demonstrates complex, diverse and multi-faceted intersections between prostate cancer and masculinity. Reciprocal, dynamic relationships exist and participants construct, deconstruct and re-construct masculinity in response to, and because of, prostate cancer.
Men’s lives and their constructions of masculinity are intertwined with prostate cancer across the entire illness trajectory. When diagnosed with a potentially life threatening disease, uncertainty about mortality and suddenly “living with dying” (Schirm, 2002) affects the core of men’s masculine self. Control and self-reliance are undermined and death is considered, often for the first time (Charmaz, 1995). Traditional roles of breadwinner, husband, father and protector are altered, and socially affirmed masculine pursuits of work, leisure and sports are threatened. Furthermore, most prostate cancer treatments affect potency and urinary continence which directly impacts on men’s sexuality and intimate relationships.

Men’s reliance on dominant social constructions of masculinity also influences their experiences of prostate cancer. For example, men who request screening for prostate cancer in the absence of physical symptoms are at odds with dominant masculine ideals that create a code of invulnerability in which “real men” are not interested in health maintenance. When diagnosed with prostate cancer, men’s expectations about how they should gather and use information, rationalise treatment decisions and consider health care recommendations are also interconnected with masculinity. Impotence, should it occur as the result of prostate cancer and its treatments, can also dislocate men’s sexual performance of erection, penetration and climax.

The term masculinity refers to socially constructed gender performances and is not a fixed characteristic or abstracted concept constructed in isolation (Connell, 2000). In this research, masculinity intersects with participants’ social class, age, history and Anglo-Australian cultures. Moreover, masculinity is actively constructed by participants and involves concrete actions (Connell, 1995). This research shows diversity and contradictions as well as common patterns that afford some understanding of how masculinity is “done” in the context of prostate cancer. Therefore, the term “masculinities” is used in this thesis to demonstrate the diversity both within and between participants’ gendered performances (Connell, 1995, 2000).

**Rationale for the study**

Biomedical and epidemiological research confirms that prostate cancer is a significant health issue in terms of the number of men affected and the ways men
are affected. However, despite extensive research, some areas worthy of exploration are conspicuous by their absence. For example, there have been only a few psychosocial studies of men with prostate cancer (Gordon & Cerami, 2000; Green, 1987; Sharp, Blum & Aviv, 1993), and there is little utilisation of social constructionist gendered frameworks in men’s health or prostate cancer research.

The lack of gendered analysis research in Australian men’s health has been documented by Connell et al. (1999) who report that biomedical research, regardless of its topic, is not connected with research on gender relations, men and masculinities. The net outcome is that men’s lives and illness experiences are absent in much of the men’s health research in Australia. This thesis responds to an identified knowledge gap and is commensurate with a number of recommendations made by the Commonwealth of Australia in the *Men’s health research agenda and background report* including the need for:

- cultural and ethnographic research on men’s health knowledge and practice in a variety of ethnic groups;
- evaluation research on health education and public health interventions addressed to men, using a range of evaluation models, especially those implemented at community level;
- study of the relationships of men’s and women’s health to the combination of family and work responsibilities, in different family configurations;
- study of the body consciousness and understandings of health, diet and sexuality among diverse groups of men.

(Connell et al., 1999, pp. 4–6)

There is little understanding of how Anglo-Australian heterosexual men experience prostate cancer. This research interweaves social meanings with men’s illness experiences and informs a social model of prostate cancer. This is theoretically important and has implications for broader issues of Australian men’s health through examination of participants’ prostate cancer experiences. The findings from this research complement biomedical research and are integral to holistic health care and evidence-based clinical practice. Knowing how men
experience prostate cancer is especially crucial given that a cause or cure has yet to be identified.

**Purpose of the study**

The purpose of this study was to explore the gendered experiences of thirty-five heterosexual Anglo-Australian men, born between 1912 and 1956, who had prostate cancer. Exploration of diverse cultural meanings and perspectives and identification of common patterns were made through ethnographic methodology. The gendered analysis in this study extends beyond gender as advocated by Connell (2000) and was inclusive of factors such as participants’ ethnicity, age and class. This enabled cultural and gendered understandings through exploration of the social context in which participants experience prostate cancer and its treatments.

Contributing knowledge regarding the interconnections between masculinity, Anglo-Australian male cultures and prostate cancer is essential to developing understandings of how men experience illness. This research reports contextual understandings of complex and contradictory subcultures of men that are often collectively referred to in the general term of “men’s health”.

**Research questions**

The study’s research questions were:

1. What roles do health promotion services play in relation to prostate cancer for men in the cohort?
2. What recommendations do participants offer for the future role of men’s health promotion services in relation to prostate cancer?

The findings in relation to research questions 1 and 2 are described in chapter four of this thesis, *Australian men’s health promotion and prostate cancer*.

3. What roles do health services play in relation to prostate cancer for men in the cohort?
4. What recommendations do participants offer for the future role of men’s health services in relation to prostate cancer?
Research questions 3 and 4 are addressed in chapter five of this thesis, *Prostate cancer and health services*.

5. How does prostate cancer and its treatments affect the sexuality and intimate relationships of the men in the cohort?

The findings in relation to research question 5 are addressed in chapter six, *Sexuality, intimacy and prostate cancer*.

**Participant recruitment**

Twelve research participants were recruited through prostate cancer support groups (PCSGs) for this study. The PCSGs monthly meetings provided a forum for men with prostate cancer to talk about their illness experiences. Twenty-three participants were recruited through advertisements in regional Victorian and metropolitan newspapers, national prostate cancer newsletters and Australian based prostate cancer World Wide Web sites.

**Why ethnographic methodology?**

This research, by focusing on Anglo-Australian masculinities in the context of prostate cancer, contributed to what Connell (2000) described as the “ethnographic moment” in masculinity research. The ethnographic moment has lasted more than twenty years, and continues to provide realism to the debates on men and masculinity (Connell, 2000). This research utilised ethnographic methodology to facilitate the exploration of constructions of masculinity in a specific setting and context, and therefore enabled plausible explanations of particular patterns in a definite locale.

Ethnographic methodology was also commensurate with the specific aims and research questions in this study. The discovery of cultural frameworks, with subsequent analysis of their structure and content, informed the basis for explanation that was central to this research (Geertz, 1973). Ethnographic methodology provided a way of understanding that was informed by participants’ everyday experiences and practices of living with prostate cancer and their performance of masculinities (Connell, 1995; Gottfried, 1998). This was a legitimate methodology to adapt given that, despite a wealth of biomedical,
epidemiological and psychological research, little was known about how heterosexual Anglo-Australian men personally experience prostate cancer (Connell et al., 1999; Watson, 2000).

**What ethnographic methods?**

Prostate cancer is an emotive and sensitive issue for many men. Highly personal, intimate information and experiences were discussed in this research. The sharing of such information was reliant on trusting relationships between the researcher and the participants. The resultant “thick descriptions” (Geertz, 1973) that informed in-depth understandings were facilitated by the use of various ethnographic methods, including:

**Preliminary fieldwork**

Preliminary fieldwork was conducted while attending monthly meetings at two Melbourne-based PCSGs for six months. I learned a great deal from the men at the PCSGs, which Spradley described in ethnographic terms as “learning about the culture from the culture” (1980, p. 5). My observations and interpretations informed the specificities of the research design and provided me with the opportunity to establish relationships with potential research participants.

**Photographic novella**

Participants were offered a disposable camera containing colour film and asked to imagine that they were being paid to mount a photographic exhibition entitled “Living with my Prostate Cancer”. Nineteen participants took between three and twenty-seven photographs each, using this method. Sixteen participants who did not take photographs were also interviewed in this research.

The participants’ photographs were subsequently discussed during individual in-depth semi-structured interviews. Wang and Burris defined this method as photo-elicitation, and stated that when participants “described the photographs that were most important to them and why, interconnections about their personal health, community and family arose” (1994, p. 180). The photo-elicitation method also reduced the strangeness of the interview and facilitated in-depth discussion and insight to participants’ world views.
In-depth, semi-structured interviews

In-depth, semi-structured interviews were completed on one or two occasions with each participant. They were both inductive and deductive in that themes and questions were anticipated; however leads that emerged were also pursued. The interactions were similar to discussions and the focus was on the interviewees’ own meaning contexts (Schutz, 1967) in which participants were encouraged to talk about their feelings and experiences of living with prostate cancer.

Participant observations

Participant observations, descriptions of the interview settings and circumstances were documented during formal interviews. The notes were transcribed and interpreted following participant interviews. The field notes provided adjunct data to the interview transcripts, participant photographs and artefacts that Gifford (1996) defined as data triangulation. This method also enabled contextual accounts of participant observations and interactions to be analysed and reproduced. What I observed, how I observed, along with the feelings I had during interactions and interviews, help to make me visible in the research process.

The structure of the thesis

Chapter One has provided an outline of the research that was undertaken.

In Chapter Two, I present a review of the literature which informs this research in three sections. Section one, Prostate cancer disease provides an overview of the biomedical, health promotion prostate cancer research and an overview of Anglo-Australian men’s utilisation of health services. Section two, Masculinity, men’s health and prostate cancer illness, provides an overview of the masculinity framework used in this thesis and considers the applications to prostate cancer. Section three, Heterosexual Anglo-Australian culture and masculinity, provides a discussion about Anglo-Australian masculinity and heterosexuality and considers the interconnections with prostate cancer.

Chapter Three presents the methodology, research design and processes used in this project.
Chapters Four, Five and Six present the findings of the study. Each chapter details the findings and discussion for specific research questions. In Chapter Four, research questions one and two are addressed and the findings related to participants’ experiences and recommendations for health promotion are presented. In Chapter Five, the findings for research questions three and four pertaining to participants’ experiences of prostate cancer health services are presented. In Chapter Six, the findings pertaining to interconnections between sexuality, intimate relationships and prostate cancer, which addresses research question number five, are presented.

Chapter Seven, Conclusion and recommendations, reiterates the major findings from the research and recommendations and future avenues of research are discussed.
Chapter Two

Literature review

Introduction

A review of the literature did not reveal any previous research with the specificities of this study (i.e. ethnographic research on heterosexual Anglo-Australian men that explores the interconnections between prostate cancer and masculinity). However, there are three distinct areas that inform the research questions and theoretical underpinnings of this study. Although distinct, these three areas are connected, salient to this research and widely discussed throughout the thesis. The reviewed literature is predominately Australian, however relevant international research has also been included where appropriate. For example, recent studies completed in the UK and Canada that have investigated the connection between prostate cancer and masculinity are highly appropriate for the purposes of this study.

The literature review is presented in three sections. Section One provides an overview of Prostate cancer disease in three parts: (a) Biomedical prostate cancer research, (b) Health promotion and prostate cancer, and (c) Anglo-Australian men’s health and health service utilisation.

In Section Two, Masculinity, men’s health and prostate cancer illness, an overview of the social constructionist framework used in this research and its application to prostate cancer illness are presented. The four parts of this section are (a) Essentialist and social constructionist debates on Anglo-Australian masculinity, (b) Hegemonic masculinity, (c) Masculine hierarchies and marginalised masculinity, and (d) Masculinities.

Section Three, Heterosexual Anglo-Australian culture and masculinity, discusses historical and contemporary literature and research related to heterosexual Anglo-Australian masculinity and culture in two parts: (a) Historical analysis of Anglo-Australian masculinity, and (b) Male heterosexuality: relationships, gendered social constructions and sexuality.
Section One: Prostate cancer disease

The medical study of prostate cancer informs and influences many participants’ illness experiences and is therefore integral to this research. The following overview provides introductory, contextual information to familiarise the reader with various aspects of prostate cancer relevant to this research. Many of the concepts introduced in Part A, Biomedical Prostate Cancer Research, are developed throughout the thesis as participants explain their experiences of prostate cancer, often using biomedical language and referring to specific medical events. In Part B, Health Promotion and Prostate Cancer, recent Australian men’s health promotion and programs specific to prostate cancer are reviewed. In particular, an overview of the ongoing prostate cancer screening debate is provided. Part C, Anglo-Australian Men’s Health and Health Services Utilisation, discusses the profile of Australian men’s health and considers men’s utilisation of health services in the context of prostate cancer.

Part A — Biomedical prostate cancer research

Introduction

Extensive biomedical research exists across the entire prostate cancer disease continuum. This research includes investigation of potential causes, screening protocols, treatment modalities and side effects. From the biomedical perspective, the cause and cure for prostate cancer are yet to be discovered, and the trajectory of prostate cancer disease is void of definitive answers, and abounds with generalisations and explanations. However, there is optimism and perhaps expectation that bioscience will ultimately provide answers to the prostate cancer anomalies (President and Fellows of Harvard College, 2002a).

Biomedical research is not restricted to scientists or clinicians, and many men with prostate cancer utilise and critique research and information about the disease. Broom (2002) found that many men with prostate cancer communicate with other men and access prostate cancer research and information available on the World Wide Web. Men’s interest in prostate cancer is also fuelled by its public profile, which is potentiated by political and biomedical debate (Gardner, 2001). The outcome is that biomedical research is in the precarious position of
informing clinical practice and parties interested in prostate cancer with partial, inconclusive, and often preliminary findings. The following overview outlines the specificities of prostate cancer disease and current biomedical research.

**Epidemiological**
Statistically, prostate cancer is the most common newly diagnosed male cancer, and the mortality rate from prostate cancer is the second highest of mortality rates attributed to male cancer in Australia (Australian Institute of Health and Welfare [AIHW], 1998). It is the major cause of death in older men, with 83% of prostate cancer deaths occurring in males over the age of 70 years (AIHW, 2000). Old age is the most common predictor of prostate cancer development (Albertson 1997), while Australian men are now living longer with prostate cancer than ever before (AIHW 2000). The Australian Bureau of Statistics [ABS] (1997) estimated that between 1996 and 2051 the proportion of Australians aged 65 years and over will increase from 12% to 23% of the total population. Therefore, it is highly probable that as more men reach older age, both the number of men diagnosed with prostate cancer and the number of years they will have to live with the disease will increase.

**Cause**
No specific cause of prostate cancer has been identified. However, it has been established that the risk of developing prostate cancer increases with age (Albertson, 1997; Kozlowski & Grayhack, 2002; Meredith, 2000). Familial predisposition has also been implicated in the risk of developing prostate cancer. Approximately 9% of all prostate cancers are familial, and the risk of developing the disease depends on the number and the level of closeness to affected relatives (Albertson, 1997; Kozlowski & Grayhack, 2002). For example, men with an affected first-degree relative, such as a brother or father, have double the chances of developing prostate cancer than men with no prostate cancer in the family. If there are two first-degree relatives with prostate cancer in the family, a man's risk of developing the disease increases five-fold (Kozlowski & Grayhack, 2002).

Many potential causes of prostate cancer have been investigated with most research exploring diet and environmental factors. Numerous studies have found an association between fat consumption, particularly saturated animal fat, and
prostate cancer development (Liebman, 2001). According to Williams (2002) environmental factors such as exposure to synthetic chemicals—many of which have never been tested for health risks—may also increase the incidence of prostate cancer.

**Diagnosis**

Men are often asymptomatic, especially in the early stages of prostate cancer (Kozlowski & Grayhack, 2002). Routine or requested prostate specific antigen (PSA) blood tests, often in conjunction with a digital rectal examination (DRE), may reveal some abnormality that requires further investigation. Both the PSA and DRE provide numerical ‘scores’ related to the degree of prostate abnormality. For instance, a PSA level below 4 is considered normal, but a level above 4 may indicate prostate pathology. Similarly, the DRE findings are classified as T1, T2, T3, or T4 based on a continuum of the tumour development. T1 indicates no abnormalities, whilst T4 suggests that the cancer has spread beyond the prostate gland to adjacent organs such as the bladder and rectum (Australian Cancer Network, 2001). There is extensive, ongoing research regarding the accuracy and benefits of screening through the PSA blood test. A detailed discussion of prostate cancer screening is provided in the following Part B; *Health promotion and prostate cancer*.

Following PSA and / or DRE test results that indicate prostate abnormality the trans-rectal ultrasound prostate biopsy (TRUS-Bx) is often completed and is the definitive diagnostic test for prostate cancer. The TRUS-Bx is performed by placing an ultrasound probe in the rectum that transmits images of the prostate gland usually viewed on a television screen. A spring-loaded needle attached to the ultrasound probe enters the prostate gland through the rectum. Usually between six and 12 small tissue samples are removed from the prostate gland via the needles. The specimens are analysed and a ‘Gleason score’ ranked out of 10 is allocated. A low Gleason score (2, 3 or 4) is indicative of a well-differentiated cancer, or a lower potential for the cancer to spread. A high Gleason score (8, 9 or 10) indicates a poorly differentiated cancer, or a cancer more likely to spread (University of Toronto, 2000).
Two studies conducted by Zisman, Leibovici, Siegel and Lindner (1999, 2001) showed that many men undergoing TRUS-Bx without a local and/or general anaesthetic experienced pain and anxiety. Specific findings from their studies were that:

- before the TRUS-Bx, 9% of participants reported a sexual impairment resulting from anticipation of the scheduled TRUS-Bx and 65% of participants reported anxiety;
- during the TRUS-Bx, 96% of participants reported pain (42% mild pain and 16% severe pain) and 86% of participants reported discomfort (28% mild discomfort and 30% severe discomfort); and
- following TRUS-Bx, 21% of participants reported sexual impairment, 20% reported decreased libido, 48% reported pelvic pain one day post-biopsy, and 75% reported anxiety awaiting the biopsy results (Zisman et al., 1999, 2001)

Rectally administered lignocaine gel (local anaesthetic) has been shown to reduce TRUS-Bx pain (Kim, 2000). However, according to Kim (2000) many TRUS-Bx continue to be administered in the traditional way – without anesthetic. Numerous researchers including McCaffery and Pasero (1999) and Merskey (1996) have confirmed that pain during medical procedures is more than a single sensation caused by a specific stimulus, suggesting that pain can be physical and/or mental in nature. Furthermore, anxiety and pain are inextricably connected (Neff & Stinson Kidd, 1993). Anthropologists have emphasised the cultural dimensions of pain behaviour (Helman, 1990) and Williams and Bendelow suggest a sophisticated sociological approach to pain management inclusive of feelings and emotions, thereby “freeing pain from exclusive biomedical jurisdiction” (1998, p. 158).

According to Medicare, the national funding body for health in Australia, item 37219- TRUS-Bx, attracts an anaesthetic benefit, and has done so since at least 1998. Hence, the anaesthetic cost in TRUS-Bx administration is refunded to the provider by Medicare (Australian Department of Health and Ageing, 2001). However, diversity exists between and within the states and territories of Australia regarding the use of local or general anaesthetic for TRUS-Bx. Many participants...
in this study had TRUS-Bx without a local and or general anaesthetic. The
findings are presented in Chapter Five, Section One, Moving in.

**Treatment[s] for localised prostate cancer**
The Australian Prostate Cancer Collaboration (2001) listed watchful waiting (do
nothing but have scheduled check ups), prostatectomy (surgical removal of the
prostate gland) and radiation therapy as the treatment options for localised
prostate cancer. These options generally related to cancers diagnosed as confined
(localised) to the prostate gland and that had not spread to other parts of the body.

**Watchful waiting**
Under this strategy, treatment is reserved for symptoms or complications of
prostate cancer, while not necessarily attempting to bring about a cure. Ideally, it
would be used in those patients whose prostate cancer is not destined to progress
to morbidity or mortality. However, it remains difficult to predict the behaviour of
cancers in such a way and watchful waiting is often used for older men and those
with more advanced prostate cancer disease (Australian Cancer Network, 2001).

**Prostatectomy**
Prostatectomy is a major operation, with an average operating time of two to four
hours and an average length of stay in hospital of three to six days (American
Urological Association, 1995). Prostatectomy offers the best prospect of complete
removal of prostate confined tumours (Australian Cancer Network, 2001). The
two most common complications of prostatectomy are urinary incontinence and
impotence, the duration and severity of which vary between patients. The
Australian Cancer Network (2001) listed the incidence of impotence as 30-90%
and urinary incontinence as 5-35% following prostatectomy.

**Radiation Therapy**
Radiation therapy is a relatively non-invasive procedure in which external beams
of radiation are used to reduce the prostate tumour. The treatment is usually
administered daily for up to six weeks. Acute complications include rectal
bleeding, cystitis and diarrhoea. In the longer term, the most common
complications are urethral stricture, impotence, rectal and bladder ulceration and
urinary incontinence (Australian Cancer Network, 2001). The Australian Cancer
Network (2001) listed the incidence of impotence as 40-80%, urinary
incontinence 5% and predicted that 0-10% of patients experience diarrhoea and blood loss in faeces following radiation therapy.

**Treatment decision-making**

Once diagnosed with localised prostate cancer many men decide if they want to be treated and choose which treatment they will have. Chapple, Ziebland, Herxheimer, et al. (2002) suggest that choosing to be treated is particularly difficult because no randomised controlled trials have shown whether or not active intervention increases survival. There is an increasing trend toward active patient involvement in treatment decision-making. Research has focused on the evaluation of various decision-aids and on documenting patient preference for involvement in the clinical decisions that affect them (Davison, Degner & Morgan, 1995; Davison & Degner, 1997; Davison et al., 2002). Although these studies found that most men preferred to be collaborative with their doctors and share treatment decision-making, there are significant variations between individual patients regarding what might constitute collaborative communication. There is also little research reported about how masculinity is constructed and enacted during communications between doctor and patient as prostate cancer unfolds.

Fowler et al. (2000) and Donovan, Frankel, Faulkner, Gillatt, & Hamdy (1999) report that specialists overwhelmingly recommend the treatment they themselves deliver—urologists recommend prostatectomy and radiation oncologists recommend radiation therapy. Chapple, Ziebland, Herxheimer, et al. (2002) found that watchful waiting was not considered a viable option by most men, and those who did choose ‘watchful waiting’ were often pressured by family and doctors to have active interventions. Laws, Drummond and Polijak-Fligic (2000) suggest that it is unlikely that Australian men make informed decisions when consenting to screening procedures and treatment[s] for prostate cancer. A study of non English speaking background (NESB) Italo-Australian men by Drummond, Laws and Polijak-Fligic (2001) indicated that informed consent could be inhibited by cultural beliefs and language difficulties. The Australian Prostate Cancer Collaboration (2001) published a ‘patient’ guide to treatment options for localised prostate cancer to assist men to make informed treatment choices. The research
participants in this study provide insight to their communication with doctors and treatment decision-making in Chapter Five, Section Two, *Moving on.*

**Treatment for metastasised prostate cancer**

Metastasis refers to the process by which tumour cells spread from the prostate gland to other parts of the body. Ninety per cent of prostatic metastases involve the spine, 50% the lungs and 25% the liver (Bubendorf et al., 2000). Brain metastasis is rare in prostate cancer and occurs late in the course of the disease (Ramsis, 2002). Androgen deprivation therapy (ADT) is used to treat prostate cancer that is suspected to have metastasised outside of the prostate gland (Waldman & Eliasof, 1997). Prostate cancer vaccines have also been trialled, and preliminary findings suggest that vaccines may be effective in the treatment of advanced prostate cancer, when the patient’s immune system is severely challenged (Anonymous, 2002).

**Androgen Deprivation Therapy (ADT)**

Prostate cancer cell growth initially depends on the presence of androgens such as testosterone (Meredith, 2000). One common treatment is to block testosterone production through ADT and enhance oestrogen hormone levels, and slow the growth and spread of prostate cancer. ADT is usually administered by a three monthly injection (Meredith, 2000) and results in many side effects including diminished libido, impotence, muscle wasting, increased body fat, weight gain, labile mood, reduced concentration, hot flushes, fatigue and gynecomastia [breast development] (Australian Cancer Network, 2001).

Combinations of treatments are also used in the management of prostate cancer. For example, if the cancer is initially thought to be confined to the prostate gland, a single treatment (either radiation therapy or prostatectomy) is usually administered. However, if the cancer is subsequently found to have spread outside the prostate gland, ADT can be prescribed. Therefore, some patients receive two or more prostate cancer treatments depending on the pathology and progression of the disease.

**Treatment side effects**

Many men experience prostate cancer treatment[s] side effects of impotence and urinary incontinence. According to Coleman (1998) biomedical advances have
created several options for the treatment of impotence including the vacuum erection device (VED), Sildenafil (Viagra), Alprostadil Intracavernosal (Cavaject injections), topical gels and penile implants. Basson (1998) warns that clinicians should focus on the cognitive and affective aspects of impotence despite the advances of such biomedical treatments. She claims that misunderstanding, misinformation and miscommunication are the major contributing factors to men’s non-adoption of medical treatments for impotence (Basson, 1998). Treatments are also available for urinary incontinence and include surgical implants, pelvic floor exercises (Kegel exercises) and absorbent pads.

There is extensive ‘quality of life’ research related to the effects of impotence and incontinence on men following various prostate cancer treatments. Kirschner-Hermanns and Jakse (2002) found that men’s quality of life was significantly adversely affected by impotence and incontinence following prostatectomy. Palmer, Fogarty, Somerfield and Powel (2003) surveyed 114 men following prostatectomy and found that incontinence affected social, physical and emotional aspects of men’s lives. When both incontinence and impotence exist, Kirschner-Hermanns and Jakse (2002) found that the lack of urinary control may embarrass patients and result in them withdrawing from sexual activity. Meuleman and Mulders (2003) in a review of the quality of life research found a mismatch between the high rate of erectile dysfunction and low impact on sexual quality of life reported by men following prostatectomy. Based on their finding Meuleman and Mulders (2003) concluded that quality of life is something many people talk about but nobody very clearly knows what it is and what to do about it.

Some researchers have found disparity between the reported incidences of urinary incontinence following various prostate cancer treatments. For example, reports of post prostatectomy urinary incontinence are conflicting due to the different surgical techniques used, the definitions of urinary incontinence, different methodologies in data collection and source of incontinence information (Palmer 2000). Palmer et al. (2003) found a discrepancy between patients’ and physicians’ definitions of urinary incontinence. According to Kirschner-Hermanns and Jakse (2002), depending on the definition of urinary incontinence that is used, the incidence varies between 5 and 74%. Fitch, Gray, Franssen and Johnson (2000)
conducted a survey of men undergoing prostatectomy and found that many men were not prepared for incontinence, and only 37% of participants had received adequate information about incontinence.

Yong (1998) found that men were accepting of impotence and incontinence when initially diagnosed and treated for prostate cancer. However, many men experienced difficulties accepting and coping with their long term or residual urinary incontinence and impotence. According to Butler, Downe-Wamboldt, Marsh, Bell and Jarvi (2001) little research has been done that investigates how men experience and manage incontinence and impotence following prostatectomy. Many participants in this study experienced impotence and incontinence following treatment[s]. The findings are presented in Chapter Six, Sexuality, intimacy and prostate cancer.

In summary, biomedical research confirms the idiopathic, unpredictable and complex nature of prostate cancer and its treatments. Commensurate with such uncertainty, men face many decisions and adjustments when diagnosed and treated for prostate cancer. Health promotion is also challenged in how it works with this information, the details of which are discussed in the following Part B, Health promotion and prostate cancer.

Part B — Health promotion and prostate cancer

Introduction

Health promotion is one of the key concepts in the contemporary vision of Australian public health (O’Connor-Fleming & Parker, 2001). Nutbeam (1998) suggests that health promotion embraces actions directed at strengthening the skills and capabilities of people and changing social, environmental and economic conditions that create and sustain health. Congruent with this aim the mandate of World Health Organization’s [WHO] (1998) ‘Health-For-All’ policy for the twenty-first century was to improve health and well-being through social and economic development and promote health by addressing the basic determinants and prerequisites for health. In the Australian context, O’Connor-Fleming and Parker predict the means of achieving ‘health for all’ can occur through “the process of enabling people to increase control over and improve their health”
While the broad aims of health promotion are often similar, the theories which underpin and inform specific programs vary. The following information provides a brief overview of four theories that commonly underpin health promotion.

**Theories of health promotion**

The application of health psychology to health behaviour change is one of the major influences on contemporary health promotion resulting in four influential health promotion theories (Nutbeam & Harris, 1999). First, the *health belief model* (HBM) predicts individuals will take action to protect or promote health if they perceive themselves to be susceptible to a condition or problem, and if they believe it will have a potentially serious consequence. People believe a course of action is available which will reduce their susceptibility, or minimise the consequences, and that the benefits of taking action outweighs the costs and barriers (Nutbeam & Harris, 1999).

Second, the *theories of reasoned action and planned behaviour* are underpinned by the assumption that people are usually rational and will make predictable decisions in well-defined circumstances. People’s attitudes are informed by the belief that a desired outcome will occur if a particular behaviour is followed, and that the outcome will be beneficial to health (Nutbeam & Harris, 1999).

Third, the *transtheoretical (stages of change) model* utilises different stages of change which appear common to most behaviour change processes. The model is based on the premise that behaviour change is a process, not an event, and that individuals have varying levels of motivation, or readiness to change (Nutbeam & Harris, 1999).

Fourth, *Social learning theory* examines both the underlying determinants of health behaviour, and methods of promoting change. Social learning theory was built on an understanding of the interaction that occurs between an individual and their environment. It acknowledges the dynamic and reciprocal relationship between an individual, their behaviour, and the environment (Thorogood, 2002). According to Nutbeam and Harris (1999) this appreciation avoids overtly simple
solutions to health problems that focus on behaviour in isolation from the social environment.

**Australian men’s health promotion**

With the exception of physical activity, men are less likely (than women) to engage in all health-promoting behaviours (Lee & Owens, 2002). Furthermore, most men seek out situations where there is a high probability of illness or accident, rather than engage in health-protecting behaviours (Taylor, Stewart & Parker, 1998). These characteristics often inform two generalisations about men’s health promotion. First, that men are unlikely to care enough about their health to become involved in health promotion programs (Taylor, Stewart & Parker, 1998). Second, that existing programs are automatically meeting men’s needs (Huggins, 1998). Men’s reluctance to maintain their health is often premised on men being “too macho” to allow themselves to publicly care about their health (Bilmes, 1992).

**Australian men’s health programs**

According to Taylor, Stewart and Parker (1998) the overall aims of men’s health promotion is to encourage:

- health-promoting behaviours, where rather than preventing disease, individuals pursue wellbeing because it is satisfying;
- health-protecting behaviours, that incorporate the avoidance of situations where there is a probability of encountering illness.

One of the major challenges for achieving the aforementioned aims in men’s health promotion is that little is known about men’s health care beliefs (Lloyd, 2001). It follows that information about target groups of men could increase the effectiveness of health promotion campaigns. Two approaches have been used to uncover men’s health beliefs, attitudes, interests and concerns and inform the design of Australian men’s health promotion programs.

First, the *social marketing* approach explores the social circumstances of men as a means of identifying how to engage them in health promotion programs (Nutbeam & Harris, 1999; Gibbs & Oliffe, in press). Blair (1995) explains that social marketing is premised on an understanding of how men’s motivations can be used...
to develop an approach to reach men based on the traditional business marketing of product, price, promotion and place. Ultimately, social marketing is intended to influence how men think and behave (Nutbeam & Harris, 1999) by discovering men’s motivating factors for achieving well-being for reasons other than ‘good’ health (Taylor, Stewart & Parker, 1998).

Two recent Australian men’s health programs based on the social marketing approach include ‘Men’s Health Nights’ and The ‘Gutbusters’ program. ‘Men’s Health Nights’ is a series of men’s health seminars conducted in hotels and sporting venues where men would ordinarily meet. The presentation format includes a number of guest speakers, often high profile sportsmen, who exhibit hegemonic masculine characteristics of dominance and success. The speakers talk about their health problems and men’s health issues. The seminars provide a pathway for the education and empowerment of men to deal with their health needs preventatively rather than reacting to symptoms. The seminars are both social and informal.

The ‘Gutbusters’ program evolved from focus group research among steelworkers that informed the initial design of the Gutbusters program. Researchers found that men in the focus groups were interested in losing weight and had definite ideas about what sort of weight loss would suit men. The ‘waist’ loss program was designed and was different to traditional diet-based approaches to weight loss (Fletcher, 2001). The program focused on male vanity rather than health benefits of weight loss. More than 40,000 men completed the course in the first three years, which were often conducted at hotels (Fletcher, 2001).

The second approach to men’s health promotion is The communication-behaviour change model which is useful in conceptualising and designing mass communication strategies (Nutbeam & Harris, 1999). The source of the message is often someone respected by the men most at risk and with whom they can identify. The health message is portrayed in an acceptable masculine or humorous way and is communicated through media used by the target group of men. Two recent examples of the communication-behaviour change model are ‘Quit’ smoking campaign and ‘Men’s Health Tune Up’.
The Quit smoking campaign was established in 1971 and offers smoking cessation support through telephone advisory service, a World Wide Web site and television commercials. The 2001 Quit television commercial was entitled *you should have been there dad*. It presented a man in his 40’s in a hospital bed having difficulty breathing. He was visited by his wife and young daughter. The daughter spoke excitedly about various activities she had been doing that day and summated ‘*you should have been there dad*’. Regret and anguish swept across the man’s face as he continued to gasp for air. The commercial used traditional masculine roles of breadwinner, protector and father to encourage men to cease smoking. Rather than health benefits, social benefits and the notion of ‘quitting’ for somebody else was introduced.

The ‘Men’s Health Tune Up’ program (Pfizer Drug Company, 2003) (Advertisement 1) continued the men and machine analogy that encourages men to ‘maintain’ their health like they would their car. This program offers men a free ‘tune up’ to ‘keep you firing on all cylinders’ and masculinises health maintenance through language and performance contexts. The ‘tune up’ is promoted by high profile Australian motor car racing driver Dick Johnson. The pamphlet cover (Advertisement 1) features Dick Johnson having his men’s health ‘tune up’.
Men’s health promotion programs are more effective when they focus on male motivational factors (Lloyd, 2001; Blair, 1995; Gibbs & Oliffe, in press). However, as Nutbeam and Harris assert “health promotion has strong foundations in public health and is fundamentally directed towards improving the health of populations, and not merely of individuals” (1999, p. 35). Many researchers are critical of politically motivated and articulated models of health promotion. Watson asserts that “health promotion does not pay attention to the lived experience of healthy or unhealthy bodies” but rather, submerges men “beneath risk profiles and other anonimizing [sic], but morally loaded, features of public health discourse” (2000, p. 140-1). Watson (2000) is critical of approaches that ignore the cultural and social reasons for men’s under utilisation of health promotion programs and activities. Hindess (1988) and Lambevski et al. (2001) are critical of health promotion discourse that constructs men as rational beings, fully capable of making reasonable decisions based on having adequate knowledge. Pease (2002) recommends that health promotion models that hold
individuals fully responsible for maintaining their health must be critically examined.

Watson (2000) proposes that health promotion be considered in the context of individual men's lives. By this, he means moving beyond the current men’s health promotion profile, to meet, know and ultimately understand the men that it claims to represent (Watson, 2000). Hence, there is a need to locate men’s health promotion within social and economic contexts (Watson, 2000) and to recognise that gender analysis needs to go beyond gender (Connell, 1995) to include specificities of class, ethnicity, culture and sexuality.

Commensurate with Watson (2000) and Connell’s (1995) recommendations, the current research explores broader contexts of participants’ lives and the implications of growing up during a period when health promotion, as it is currently conceptualised, was largely absent in Australia. The findings are presented in Chapter Four, Section One, Victims or suspects: Australian men and health promotion.

Prostate cancer health promotion

Only a few health promotion programs specifically related to prostate cancer were located in a review of the literature. Summer, Dolan, Thompson and Hundt (2002) conducted a survey by questionnaire study of 2730 men in the UK. The questionnaires were designed to evaluate the effectiveness of various prostate cancer health promotion interventions conducted with men at their place of employment. Summer et al. (2002) found that the workplace was an ideal environment to promote the prostate health of men. However, they acknowledged that the 17% (n= 458) return rate of the questionnaires was a limitation of the study and their finding was preliminary and tentative.

Fletcher (2001) reports that the Prostate Health Information Line, operating in Australia since 1994, receives many phone calls from men requesting prostate information. The service provides support and acts as a conduit between patients and physicians. The Pre-op Education for Radical Prostatectomy Program also established in Australia in 1994 provides services to men prior to their prostatectomy. The services include printed materials and an introductory talk at
which information and medical equipment (e.g. urinary catheter) are explained. The men return one week prior to their surgery to review their understandings (Fletcher, 2001).

Although prostate cancer is acknowledged as a significant health problem in regards to mortality and morbidity rates, prostate cancer and health promotion continue to be somewhat estranged. The Health for all Australians Report in 1988 listed five priority areas that included the prevention of cancer—particularly lung, skin, breast and cervical (Health Targets and Implementation Committee, 1988). The choice to target specific cancers is often informed by their prevalence and known avoidable risk factors. Prostate cancer may have been excluded from such targeted cancers because of its unknown aetiology and asymptomatic nature early in the course of the disease (Kozlowski & Grayhack, 2002).

Prostate cancer is often perceived as an ‘older man’s’ disease, that men die with, rather than of (Gorman, 2002; Albertson, 1997)—which may have made it difficult to situate prostate cancer in a biomedical health promotion framework. Lee and Owens (2002) predict that older men who grew up between 1920 and 1940 continue to enact prescribed, relatively inflexible masculine roles and health care behaviours. Therefore, limited scope exists to change the health care practices of older men through health promotion (Lee & Owens, 2002).

Many researchers and theorists are critical of various facets of health promotion programs and discourse. For example prostate cancer is a potentially life threatening disease and promoting the health of men who have a poor prognosis may be perceived as being too late to make a difference to their outcomes. Buetow and Kerse (2001) argue that health promotion should not be just for the healthy and frame health as a life trajectory interpenetrated by ill-health. Morris (1998) affirms that health does not happen in the absence of illness, but rather in its presence.

The view that the “major barrier to men’s health promotion is the lack of concern about their health and a disregard of the consequences of their behaviours and lifestyles” (Taylor, Stewart, & Parker1998: 22) offers little contextual application to prostate cancer. After all, no direct links between health behaviours and
prostate cancer incidence have been conclusively established. Therefore, prostate health and prevention of prostate cancer through avoidance of known risk factors is poorly understood.

Many contemporary definitions of health promotion incorporate screening programs (O’Connor-Fleming & Parker, 2001). Given the asymptomatic nature of prostate cancer, screening is the most likely health promotion application.

Screening was defined in 1951 by the US Commission on Chronic Illness as:

*the presumptive identification of unrecognized disease or defect by the application of tests, examinations or other procedures which can be applied rapidly. Screening tests sort out apparently well persons who probably have a disease from those who probably do not. A screening test is not intended to be diagnostic. Persons with positive or suspicious findings must be referred to their physicians for diagnosis and necessary treatment.*

(cited in Last, 2001, p.165)

Last (2001) differentiates between three types of medical screening:

- Mass screening in which the whole population is screened.
- Multiple screening which includes a variety of screening tests, completed on the same occasion.
- Prescriptive screening, the aim of which is early detection, in presumptively healthy individuals, of a specific disease that can be controlled better if detected early in its natural history.

According to Lee and Owens (2002), men are poor users of medical screening services. Chapple, Ziebland, Shepperd, et al. (2002) found that men are motivated to participate in prostate cancer screening by the perceived benefits of early detection. Factors such as spousal opinion (Volk, Cantor, Spann, Cass, Cardenas & Warren, 1997), appointment scheduling and reminder cards (Lee, 2002) and knowledge about prostate cancer (Weinrich, Weinrich, Boyd, & Atkinson, 1998) also increase the likelihood that men will participate in prostate cancer screening. Barriers to screening include cost and a lack of knowledge about prostate cancer (Weinrich, Reynolds, Tingen, & Starr, 2000).
The specific screening methods (particularly the DRE) have been found to affect some men’s decisions to be screened for prostate cancer. The DRE, in which the doctor inserts a gloved finger into the rectum and palpates the prostate gland through the bowel wall, has historically been the common screening test. Underwood (1991), and Shelton, Weinrich and Reynolds (1999) found that men’s negative feelings and embarrassment about DRE are barriers to prostate cancer screening through this method. The accuracy of DRE is also debated, Kozlowski and Grayhack (2002) suggest tenderness, enlargement or hardening indicative of prostate gland pathology may be identified through DRE. However Littrup, Lee and Mettlin (1992) and Lee et al. (1998) report that DRE has limited effectiveness in detecting anterior to midline lesions and small lesion prostate cancers.

Health promotion programs have attempted to overcome the negative images and encouraged men to participate in DRE prostate cancer screening. A recent Cancer Society (2001) campaign used the image of Australian National Rugby League (NRL) footballer, John Hopoate to encourage men to have DRE. John Hopoate was suspended for twelve weeks after being found guilty of unsportsmanlike interference. Article 1, entitled “Finger poker out for 12 weeks” published by the Herald Sun newspaper, Melbourne, reported:

Hopoate, 27, was found guilty on three separate counts of deliberately sticking his fingers up the anus of North Queensland players in Saturday night’s match in Townsville.

(Anonymous, March 29th 2001:92)
Hopoate’s 12-week suspension was handed down on March 28\textsuperscript{th} 2001. In Wellington, New Zealand, The Dominion newspaper published advertisement 2 on the 3\textsuperscript{rd} April 2001 for the Cancer Society, which showed Hopoate putting his finger up the anus of an opposition player during the game.
Advertisement 2 "Prostate problems?"

Source: Cancer Society, 2001

The caption accompanying advertisement 2 read:

*Prostate problems – A bloke’s chances of developing prostate cancer increases as he gets older. If you have symptoms that you’re concerned about, consult your local doctor. It won’t hurt a bit – promise.*

(Cancer Society, Dominion Newspaper April 3rd, 2001, p.4)

The advertisement was removed from circulation after lawyers representing John Hopoate threatened legal action over the unauthorised use of their client’s image. Hopoate was sacked by his NRL club. In an interview with Australian TV current affairs program *60 Minutes* entitled “Conduct unbecoming” he was asked to publicly explain his “unmanly and abnormal actions” and given the opportunity to apologise to a nation of viewers. Hopoate was remorseful for his actions and by the following season was playing with his ‘new’ NRL club.

The use of Hopoate’s image by the Cancer Society (the controversial advertisement also appeared in the Australian National News) and the *60 Minutes* ‘confessional’ may have served to distance men from voluntary DRE screening
through heteronormative discourses that the male anus and its penetration is unmanly, deviant and suspect. Furthermore, the caption accompanying the advertisement encouraged men to wait for symptoms before consulting a doctor. One of the challenges of health promotion is to produce resources and provide information in ways that are sensitive to people’s expectations, beliefs, preferences or skills (O’Connor-Fleming & Parker, 2001). Participants in this study share their experiences of DRE and the findings are presented in Chapter Four, Section Two, Part b: To DRE or not to DRE: Is that a penetrating question?

In the early 1990s, the PSA blood test became available and could detect prostate abnormalities. A small amount of PSA is released constantly in the bloodstream and if the prostate gland is irritated or damaged, more PSA is released. An elevated PSA level reflects abnormalities of the prostate, including prostate cancer that can be detected before the onset of clinical symptoms (Bickert & Frickel, 2002). Since its inception the accuracy, appropriateness, and effectiveness of screening men for prostate cancer with the PSA blood test has been debated amongst health organisations and professionals (Gardner, 2001; Lee, 2002; Tannock, 2002). The PSA blood test was not specifically designed to detect prostate cancer and inaccuracies resulting in ‘false negatives’ and ‘false positives’ have been reported. Therefore some benign conditions result in elevated PSA levels, whilst some prostate cancers exist despite a PSA value within the normal range (Foxhall & Von Eschenbach, 2002).

The AIHW (2000) reported a dramatic rise in the number of new cases of prostate cancer between 1990 and 1994, following the introduction of the PSA test. Smith, Armstrong and Saunders (1998) found that following the initial controversy about the appropriateness of PSA screening, fewer PSA tests were completed in Australia and there was a fall in the number of prescriptive prostate cancer cases. Dr. Tom Pickles, a Radiation Oncologist in Vancouver, suggested a similar trend occurred following the introduction of PSA screening in Canada (T. Pickles, personal communication, 25th January 2002). Pickles (2002) explained that inadequate Canadian health resources existed to treat the increased number of new prostate cancer cases following the introduction of PSA screening, subsequently many men diagnosed in Canada were treated in the United States.
Controversy about the widespread prescriptive screening of asymptomatic men with PSA has continued. Two opposing views regarding the appropriateness of PSA screening are presented and contested in the literature. Advocates of PSA screening argue that prostate cancer could be detected at an earlier and potentially more treatable stage that may improve men’s chances for survival (Gardner, 2001). Those against widespread PSA screening argue that there is a lack of scientific evidence that early diagnosis and treatment of prostate cancer results in men living longer, and that treatment side effects impact adversely on men’s quality of life (Tannock, 2002).

The issue of whether men need to know they have prostate cancer underpins much of the debate about PSA screening. Prostate cancers do not act predictably and the progression varies greatly between men. Some cancers are indolent, slow growing tumours that cause few changes to men’s lives, whilst others are aggressive and lethal. The decision to screen and subsequently treat the middle band of intermediate tumours is particularly challenging because there is no precise way to tell which tumours in this group will ultimately be slow growing or lethal (President and Fellows of Harvard College, 2002b). Professional uncertainty about the appropriateness of screening may discourage some men from being routinely, voluntarily ‘screened’ for prostate cancer.

The PSA test has been available for use as a cancer-screening tool in Australia for more than a decade. On June 29th 2001, a public debate about the use of PSA as a screening tool was held at the Garvan Institute for Medical Research. Phillip Stricker, a urological surgeon from Sydney, argued that the Australian death toll of 2,600 men every year from prostate cancer was potentially avoidable if men were more aware of the disease and were screened every two years from age 50 to 70. He suggested that a screening process would facilitate the identification of aggressive prostate cancers. Alternatively, Dr. Geoff Hirst, a urologist from Brisbane, profiled prostate cancer as a relatively slow developing disease in which no convincing evidence existed to prove men derived any benefit from treatment. He advised men with no symptoms or family history of the disease not to request the PSA blood test.
Max Gardner, the master of ceremonies at the debate, summated that there was almost complete disagreement between Hirst and Stricker and that it was “difficult to believe these two eminent urologists were discussing the same disease” (Gardner, 2001, p. 2). Furthermore, the Australian government removed the PSA blood test from the ‘free list’ in May 2001, which resulted in a financial cost to men requesting a PSA screen for prostate cancer. Chapple, Ziebland, Shepperd, et al. (2002) found most men with suspected or confirmed prostate cancer subscribed to the argument that early identification through PSA reduced mortality and improved quality of life. The underlying debate about ‘men’s need to know’ and the patient cost associated with screening for prostate cancer seems contradictory to the philosophical underpinnings of empowerment central to contemporary health promotion. The participants in this study share their experiences of, and recommendations for, PSA screening. The findings are presented in Chapter Four, Section Two, Part C, To PSA screen or not to screen: Is that a political question?

In the absence of mass communication strategies to advise men about prostate cancer and screening, mainstream media has contributed to public awareness primarily by testimonials. In a study of North American print media depictions of prostate cancer from 1974 to 1995, Nancarrow Clarke (1999) found that prostate cancer is embedded in themes related to masculinity, sexuality, competition, brotherhood and machismo. She argues that such imaging can alienate men if they do not fit into the hegemonic masculine ideals as they are portrayed in media-generated information about prostate cancer (Nancarrow Clarke, 1999). Many Australian media depictions of prostate cancer use testimonials depicting traditional masculine ideals, three of which are now discussed.

On June 17, 1995, a crowd of 64,186 watched an Australian Rules Football (AFL) game played between Victoria and South Australia at the Melbourne Cricket Ground (MCG). Before the game commenced, the crowd, along with a television audience of more than a million people, witnessed ‘the king’ of interstate football, E.J. (Ted) Whitten, hear the roar of the crowd one last time. Exactly two months later, Ted Whitten died of prostate cancer, aged 62.
“Ten things about football you'll never forget” (Article 2) was written by Peter Hanlon and published in The Sunday Age, Melbourne, Victoria on September 22, 2002. Ted Whitten’s last lap in 1995 was rated number one by the majority of people interviewed for the article. His son Ted Whitten Jnr, who supported his father during his last lap atop the back seat of an open-top car, recalled that his father couldn’t see much (he was blind as a result of the spread of prostate cancer) and was very weak. As they drove onto the ground the song ‘Hero’ came on. Ted Whitten Jnr. suggested that “Whatever everybody thought of him over the years, whether they loved him or hated him, I think they appreciated the fact that he wasn’t well and it was their opportunity to say goodbye… it was unbelievable to see grown men and women crying” (Hanlon 2002: 25). Ted Whitten Jnr. has since established the E.J. Whitten Foundation, which raises money for prostate cancer research.

Article 2 "Ted Whitten"

Source: Hanlon, 2002, photographer unknown

More recently, mainstream media continued the use of high profile sportsmen to increase prostate cancer awareness. On April 7th, 2001, The Herald Sun newspaper, Melbourne, Victoria, ran a front page story written by Mike Sheahan about former AFL footballer, Robbie Flower, who was diagnosed with prostate cancer after a routine check (which he took at the urging of a friend) at age forty-five (Article 3). The article states that Robbie’s “decision to take the dreaded digital rectal examination probably saved his life, and certainly prolonged it. Like many before him, Flower experienced no symptoms of the insidious disease” (Sheahan, 2001, p.1). Robbie assured readers that “the reason I’m talking about it
is not for people to say ‘poor fella’...Not to be a martyr. It’s just the awareness factor” (Sheahan, 2001, p.11). The article acknowledged that many men are reluctant to undergo the necessary tests to exclude prostate cancer—however, early detection of prostate cancer was possible. Robyn Metcalfe, a senior employee and prostate cancer expert with the Cancer Council of Victoria, reported phone calls to their information line regarding prostate cancer doubled in the month following the three-page article on Robbie Flower (R. Metcalfe, personal communication, 20th July 2001).

Article 3 "Robbie Flower"

Source: Sheahan, 2001; Picture Jay Town.

One recent testimonial presented a grieving daughter who encouraged men to request prostate cancer screening. On August 30, 2002 the Herald Sun newspaper, Melbourne Victoria featured an article by Evonne Barry about Jo Bailey, former TV personality and wife of former AFL footballer Steve Silvagni (Article 4). In the article, Jo Bailey revealed the pain of losing her beloved father to prostate
cancer. She hoped that her story would help remove the “stigma surrounding prostate cancer” (Barry, 2002, p.3). She recalled how her father always put on a “brave face and never complained” and despite being ill with prostate cancer, was able to “walk her down the aisle, party harder than anybody at the wedding reception” (Barry, 2002, p. 3). Sadly he “lost his battle 18 months later”, Bailey urged men to be tested for prostate cancer by saying “It’s only a couple of simple tests...Imagine what you could lose, what your family could lose” (Barry, 2002, p.3). The closing sentence in this article encourages men to “Ask your GP for the two tests to diagnose the disease- a blood test and a DRE (digital rectal examination)” (Barry, 2002, p.3).

Article 4 "Jo Bailey"

Jo Bailey tells of her father’s illness and concurrently describes the stoicism central to his masculine illness performance. Her testimonial is about ‘losing’ her father and she speaks to a female readership about considering the health needs of the men in their lives. Furthermore, Bailey reminds men that in middle and older age they are important to their families (or daughter in this scenario) by referring both directly and indirectly to traditional masculine roles of breadwinner, father and protector. A similar tactic was used by the American Cancer Society (2001),
which featured Harry Belafonte and his daughter Shari pictured together encouraging men to be aware of prostate cancer. Shari’s caption stated, “Some see an accomplished actor, I see my father, a man who survived prostate cancer…If not for yourself, for someone you love. Prostate Cancer. Get the facts” (American Cancer Society, 2001 [Billboard]).

In 2002, the Queensland Cancer Fund (2002) launched a campaign to encourage men to be screened for prostate cancer. Advertisement 3 shows a man sculpting. The front of the advertisement (Advertisement 3) (A) reads:

Of Course, After Cancer, There Are Some Things You Just Have To Give Up. Like Taking Life For Granted.

On the back of Advertisement 3 (B) a vignette provides the following detail:


This advertisement suggests that there can be positive life changes through a diagnosis of prostate cancer and many characteristics of dominant masculine performance, such as career and athletic prowess, can be maintained. The advertisement predicts that it is advantageous for men to know if they have prostate cancer regardless of how their lives might change.
As stated previously, the risk of developing prostate cancer increases with age and family history (Albertson, 1997; Kozlowski & Grayhack, 2002). One possible application for prostate cancer health promotion is selective or targeted PSA screening based on familial predisposition and/or age. However, reaching the most-at-risk population takes time, especially given the lack of inter-sectoral cooperation and clearly defined prostate cancer messages (Cockburn, White, Hirst & Hill, 1991; AIHW, 1998). A detailed discussion of the findings from this study regarding participants’ experiences, practices and recommendations for prostate cancer health promotion is included in Chapter Four, Section Two, Part D, *Spreading the word: Screening advocacy.*
Part C — Anglo-Australian men’s health and health service utilisation

Australian ‘men’s health’

Connell (2000) suggests that the construction of men’s health has arisen from the critique of patriarchal medicine by the women’s movement. However according to Hayes (2001) many aspects of men’s health have been problematic and challenging, as noted during the period 1985-1994 when the margins of men’s health were explored. This resulted in groups of men, such as Aboriginal men and men with HIV/AIDS, being the focus of much men’s health research (Hayes 2001). Division continued to dominate ‘men’s health’, which resulted in further, sub categorisation based on men’s sexual identity, ethnicity and age. At one level, subcategories illustrate diversity in men’s health needs commensurate with Connell’s (1987; 1995) plurality of masculinities. However, the risk with division rather than unity is that competing masculinities can inform hierarchies that serve to further marginalise the majority of men in the context of men’s health (Hayes, 2001). Although men’s health is informed by feminism it seems naïve to suggest that it could follow a model of women’s health. As Connell asserts “given both the material interests of men, and the hierarchy of masculinities, the democratic reconstruction of the gender order is more likely to divide men than to unite them (in gender terms)” (2000, p. 8).

In 1995, many new articles, books and government support appeared promoting men’s health. However, since that time government support has been sporadic, a situation exacerbated by political party changes and increasing consideration of the cost for a government funded health system (Hayes, 2001). Without targeted funding, support and structure, the diversity and interconnectedness of men’s health issues has not evolved. Instead, distance and differentiation from women’s health has dominated much men’s health discourse (Hayes, 2001).

A definition of Australian men’s health has also been problematic due to the uncertainty of what constitutes ‘men’s health’ (Fletcher, 2001). In 1997, the New South Wales Men’s Health Advisory group adapted the following definition from the United States Public Health Service Action Plan for Women’s Health (1991):
A men’s health issue is a disease or condition unique to men, more prevalent in men, more serious among men, for which risk factors are different for men or which different interventions are required for men.

(cited in Fletcher, 2001, p.68)

This definition is based on biomedical constructions of ‘disease’ and ‘sex’ difference in which men are ‘more’ representative and affected in ‘different’ ways to women. Consequently, men’s health is different to women’s health, but exactly what men’s health represents or hopes to achieve is often unclear. The men’s health profile is often informed by biomedical quantitative methods that outline the ‘numbers’ of men afflicted by specific disease rather than the illness experiences of men (Connell, 2000).

Ambiguity about the focus of men’s health continued at the fourth Australian National Men’s Health conference in September 2001. Delegates were provided with a commemorative T-shirt at the conference. On the back of the T-shirt was the inscription “Men’s Health Matters” (Diagram A). On the front there was a picture (Diagram B) of a doctor shining a light up the anus of a ‘patient’, as a rainbow of colours leaves his mouth. Is the inscription and picture contradictory or complementary? That is, do we say men’s health matters but not really believe it? Or, are men’s health matters all related to the anus?

Diagram A

Diagram B


Perhaps it is as a colleague (L. Gibbs, personal communication, 24th September 2001) suggested, Diagram B is simply an irreverent reference to the Pink Floyd album cover ‘Dark Side of the Moon’ (Diagram C, Thorgerson, 1973). Regardless of the intended message (assuming there was one) men’s health ‘looked’
somewhat uncomfortable in its own skin, especially in the context of a national conference attended by many health care professionals.

Diagram C

Many researchers, regardless of their definition of men’s health and subscription to quantitative methods, discuss the profile and defence of men’s health via statistical comparisons with women’s health. Gibson and Denner (2000), Huggins (1998), Taylor, Stewart and Parker (1998), Ziguras (1998), amongst others, premise the significance of men’s health on the following characteristics of men, in that they:

- die younger than women, and suffer higher rates of injury and most illnesses
- exhibit more health-risk behaviours
- are poor health care service consumers
- are generally not receptive to health promotion messages

Some researchers suggest that the epidemiological profile of men’s health is an oversimplification (Connell, 2000; Hunt & Annandale, 1999; MacIntyre, Hunt & Sweeting, 1996). Connell (2000) claims that there is no sex difference in a good proportion of Australian research on health. MacIntyre, Hunt and Sweeting (1996) challenge assumptions that gender differences described in one decade and in one culture are generalisable to other decades and cultures. Hunt and Annandale advocate that future health and gender researchers “make overt, assumptions about the production, experience and expression of men and women’s health”
(1999, p. 2) and provide a more thorough understanding of the social production of gender and health.

Regardless of the statistical validity, men’s health researchers often study the unhealthy lifestyles, poor use of medical services and late acknowledgement of symptoms of illness (Lee & Owens, 2002) as a way of explaining men’s poor health outcomes.

**Men’s health service utilisation**

Gibson and Denner (2000) suggest that, despite the efforts of the Australian health care industry to raise men’s awareness and contribution to their own health needs, men continue to be poor consumers of health care services. Lambevski et al. (2001) state that the sense of men’s unnecessary or preventable illness and death has helped create a sense of crisis in Australian men’s health among medical professionals, health department officials, and academics. Theorists, commentators and researchers often describe two reasons for men’s poor consumption rates of health care services.

First, according to Huggins (1998) and Woods (2001) Anglo-Australian men’s utilisation of health care services is affected by the ‘service’ itself. Practical issues of extended GP waiting room times are suggested by Aoun and Johnson (2000) and Wright (1999) as inhibiting men’s use of health services. Inequitable access and poor education levels have been identified by Woods (2001) as systematic barriers that preclude some men from accessing health care services.

Researchers have also found that men’s interactions with men’s health services can be problematic. Watson (2000) suggests that it has become orthodoxy among professionals and policy-makers to assume men’s susceptibility to ill health and disease is caused by adoption and maintenance of lifestyles that are profoundly destructive of body and self. Furthermore, he argues that changing men’s health behaviours has become a pre-occupation for health professionals and is an “altruistic gendered practice based around pragmatic interpretations of culturally appropriate scripts such as breadwinner, guardian or the sturdy oak” (Watson 2000:142). Moynihan (1998) confirms that masculinity is contextual and a floating signifier that may be a puzzling concept for medical professionals.
Courtenay (2000) suggests that health care institutions subordinate men, and therefore men’s reluctance to consult a doctor is a way of establishing and expressing their masculinity.

Second, men’s health care behaviours are consistently linked to poor utilisation of health care services. Jones (1996), in a study of rural Australian men, found that health only became a priority for men when it was under threat of illness or injury. Ziguras (1998) defines this as ‘reactive self-care’ and explains it typically includes responding to illness with the use of some form of self treatment, asking friends for advice, and finally seeking professional help. Furthermore, Ziguras (1998) predicts that men engage in reactive self-care much later than females and therefore seek professional medical help later, when disease may be advanced.

White, Young and McTeer (1995) explain that men’s denial of illness relates to the ideals of hegemonic masculinity, which prescribe suppression of affect—particularly in relation to pain. Therefore, men’s reluctance to utilise health services is informed by persistent myths of masculinity such as the perception that it is tough to hold on to symptoms of ill health in the hope they will disappear, and that only weak men respond to stress (O’Hehir, Scotney & Anderson, 1997).

Men’s cognitive ability to interpret, identify and act on physical ‘symptoms’ are hypothesised by some researchers. Corbin (2003) argues that people do not talk a language of symptoms; they talk about a change in sensations or appearance. She suggests that the word ‘symptom’ is a different language synonymous with medical interpretation of what is going on with the body. Hayes (2001) claims that there is a real issue around men’s development of their own embodied experience and Williams and Bendelow (1998) state that men separate reason and feeling. Pease (2002) emphasises conceptual knowledge deficit, in that many men know very little about their body or what makes it work, and why it sometimes doesn’t work.

**Recommendations for men’s health services**

Huggins (1998) suggests that men’s poor health outcomes should not be taken for granted as a cultural norm and men’s health problems will not be solved by biomedicine alone. Fletcher, Higginbotham and Dobson (2002) report that little
documentation exists about Australian men’s identification of their health needs. Many researchers predict that a sociological informed model of men’s health inclusive of men in decision making processes about men’s health services would best overcome men's traditional relationships with their health (Fletcher, Higginbotham & Dobson, 2002; Huggins, 1998; Gibson & Denner, 2000).

In this study, participant experiences of prostate cancer health services provide contextual information about their experiences of health services and professionals. The findings are presented in Chapter Five, *Prostate cancer and health services*.

**Section 2: Masculinity, men’s health and prostate cancer illness**

A sociologically informed understanding of men’s ‘illness’ experiences is salient to this research. Only a modest number of qualitative studies focused on men’s health, or specifically related to men’s experiences of prostate cancer, have been undertaken in Australia (Gordon & Cerami, 2000; Green, 1987; Sharp, Blum & Aviv, 1993). They include research on the sociology of cancer (Yong 1998), urinary symptoms (Ward & Sladden, 1994), older men’s concerns about their urological health (Pinnock, O’Brien & Marshall, 1998), bereavement (Byrne & Raphael, 1997) and GP use (Jacomb et al., 1997; Jones, 1996; Woods, 2001).

Moynihan (1998), Gordon and Cerami (2000) advocate social constructionist research of male cancers, rather than seeing men with cancer as passive recipients of the effects of biological, psychological, or social factors.

A few international researchers have conducted social constructionist gendered analysis studies of men with prostate cancer. A UK study by Chapple and Ziebland (2002) reported the effects of various prostate cancer treatments on men’s masculinity and recommended the male ‘body’ be included in future social constructionist analysis of men with prostate cancer. A Canadian grounded theory study by Fergus, Gray and Fitch (2002b) used a masculinity framework to investigate men’s adjustment to sexual dysfunction following prostate cancer. A narrative analysis of three men’s experiences of prostate cancer and the interconnections with hegemonic masculinity was also completed in Canada by Gray, Fitch, Fergus, Mykhalovskiy and Church (2002). The findings from these studies are discussed further in the following sections.
This study addresses a gap in the research, by providing culturally informed contextual insights to the experiences of thirty-five heterosexual Anglo-Australian men who have prostate cancer. A social constructionist gendered analysis is used in this research and an introduction to the framework is presented in two parts.

Part A, *Essentialist and social constructionist debates on Anglo-Australian masculinity*, presents an analysis of the sex versus gender, nature versus nurture debate. This research is situated in the social constructionist gendered paradigm. However, essentialist notions of sex and the biological body are contrasted with social constructionist frameworks and considered in the context of prostate cancer and its treatments.

In Part B, Hegemonic masculinity, Part C, Masculine hierarchies and marginalised masculinity and Part D, Masculinities, explanation of the social constructionist masculinity frameworks and variations of masculinity are discussed in the context of men’s health and prostate cancer.

**Part A — Essentialist and social constructionist debates on Anglo-Australian masculinity**

**Essentialism**

DeLamater and Shibley Hyde (1998) explain that essentialism is the philosophical foundation for positivism and consists of a belief that certain phenomena are natural, inevitable, and biologically determined. The term essentialism is often used to loosely refer to research and theory presuming a biological basis; however, it includes a number of theories, three of which are outlined herewith and linked to prostate cancer disease.

First, *evolutionary theory* is premised on the belief that all living things have acquired their present form through gradual changes in their genetic endowment over successive generations. Evolutionary theories include the application of evolutionary biology to understanding the social behaviours of humans (DeLamater & Shibley Hyde, 1998). Biomedical explanations of prostate cancer disease are strongly linked to evolutionary theory through increased familial incidence in which prostate cancer is inherited through biological constructions.
Second, *biological theories* distinguish between proximate and ultimate causes of behaviour. Proximate causes, such as testosterone, have an immediate impact on behaviour. Ultimate causes claim evolution and particular circumstances of ancestral populations will lead to particular traits or tendencies (DeLamater & Shibley Hyde, 1998). Prostate cancer tumours are initially under the influence of testosterone, and treatments for metastatic prostate cancer, such as ADT, act by blocking the production of testosterone to slow the cancer spread. Therefore, hormones are used to explain both the pathology and ADT treatment of prostate cancer disease.

Third, *neuroanatomical structures* describe and contrast male and female brains to explain behaviour differences in men and women. Such sex-based differences are used to explain engendered health behaviours in which men think differently about health and adopt poor health care behaviours as a result of cognitive structures (Phillips, 2001).

Although essentialism may take many different forms, DeLamater and Shibley Hyde confirm that three assumptions underpin essentialist positions:

- belief in underlying true forms or essences
- discontinuity between different forms
- constancy, that is the absence of change over time. (1998, p. 5)

In the context of “manliness”, essentialism emphasises that there are true forms of masculine behaviour that reside within the individual, influenced by hormones and inherited personality traits (DeLamater & Shibley Hyde, 1998). Male characteristics such as sexual initiative, action, intelligence and interest in career are ‘natural’ and instinctual (Van Den Wijngaard, 1997). Essentialism is also used to explain men’s health and health promotion behaviours. For instance, Archer (1996), Buss (1995), and Phillips (2001) suggest that testosterone causes male aggression, competitiveness and independence. Such intrinsically-driven characteristics result in men proving or testing manhood, which risks their health (Phillips, 2001). When the essentialist position is relied upon to explain men’s disregard and indifference to their health, most strategies are intended to change the ‘instinctual’ male behaviours which result in injury and illness.
Subscription to essentialist positions also situates male health behaviours as ‘naturally’ occurring that will result in men reaching their expiry date early in life (Lee & Owens, 2002). This is especially true in men’s health promotion, where essentialism can portray male risk taking behaviours and ambivalence to health messages as pre-programmed, unchangeable and outside men’s conscious control (Gibbs & Oliffe, in press).

In summary, men’s health behaviours, prostate cancer disease and its treatments are often constructed through essentialist frames by both health care professionals and patients.

**Social constructionism**

One of the topics of greatest interest to social constructionists has been gender and its social construction (Connell, 2000). According to Larsson (1997), social constructionism is an umbrella of ideas that represents a broadly defined perspective in the social sciences, rather than a distinct theory. Bohan (1992) reports that one common misunderstanding of social constructionist frameworks is that gender-typed attributes are simply the result of socialisation. Many authors, including Connell (1995; 2000), DeLamater and Shibley Hyde (1998) and Larsson (1997), assert that the social constructionist argument is considerably more complex. Larsson (1997) differentiates between a ‘weak form’ of social constructionism, *male gender role socialisation* and the ‘strong form’ *gender relations perspective on masculinity*.

Gender role socialisation is understood as patterns of social expectation, norms for the behaviour of men and women which were transmitted to youth in a process of socialisation (Connell, 2000). Therefore, role theory explains gender patterns by appealing to the social expectations that define proper behaviour for women and for men (Larsson, 1997). Much of the sex role research has focused on theorising and empirically verifying the constitutive elements of the male role, and the effects of a restrictive role on individual men (Larsson, 1997). Connell (2000) explains that the intellectual weakness of gender role theory is that it provides no grasp on issues of power, violence or material inequality and misses the complexities within femininity and masculinity. He concludes that role theory was a massive display of conformity, which somehow seemed appropriate in the
1950s, but has since been radicalised by feminism and become an object of dismay rather than celebration (Connell, 2000).

The strong form of a social constructionist, gender relations perspective on masculinity, is used in this research and is concerned with the social context of gender relations in which masculinity is constituted and reproduced (Larsson, 1997). It invites an understanding of gender as a complex and complicated dynamic which extends beyond the individual into a social realm. Therefore, masculinity is a social artefact constructed through the social practices of everyday life (Larsson, 1997). It presupposes differences between individuals and defines masculinity as a relative term that does not exist independently or without being contrasted to femininity (Connell, 2000).

Masculinity is contextually bound and actively produced using the resources and strategies available in a given setting. As Larsson (1997) remarks, masculinity is not about being but rather about doing. Men create their social realities and identities, including their gender, through their actions with others - their families, friends and colleagues (Lorber, 2000). Connell (2000) also emphasises the contradictory desires and conduct that exist between and within masculinities that reflect the complexity rather that uniformity within a single culture.

The patterns of conduct our society defines as masculine may be seen in the lives of individuals, but they also have an existence beyond the individual and are sustained in institutions (Connell, 2000). Social constructionists see gender not as a trait of the individual, but rather as a process external to the individual. Therefore, masculinity is defined by interactions between people, by language and by the discourse of culture (DeLamater & Shibley Hyde, 1998).

This research subscribes to the theoretical frameworks described by numerous social constructionist researchers. These include:

- Bergman (1995) and Pleck (1995) who argue that masculinity is primarily socially constructed whereby men learn to adapt and adhere to culturally defined standards for masculine behaviour.
Lorber’s assertion that “gender and sex are not equivalent, and gender as a social construction does not flow automatically from genitalia and reproductive organs” (1994, p. 17).

Coltrane’s (1994) identification of gender as neither sex organs nor sex acts, but the socially constructed ideals of what it means to be a man or woman.

Cheng’s (1999) recognition that the performance of gender is not necessarily based on sex, although it appears that way, because most individuals conform to biologically essential definitions of what their gender performance ‘ought to be’.

In conclusion, the current thesis research demonstrates that masculinity is actively constructed and influenced by class, culture, ethnicity, age and history.

**Social constructionism and men’s health**

Although slowly adopted, men’s health is increasingly being recognised as an issue that is socially constructed and depends greatly on how men and their community define masculinity (Connell, 2000). Many researchers agree that men are influenced by externally prescribed, acceptable masculine behaviour and performance in the context of health and illness (Connell, 1995, 2000; Courtenay, 2000; Huggins, 1998). One common application is to link men’s irreverent attitude and poor health care practices to dominant social constructions of masculinity. Examples include Huggins (1998) who suggests that dominant social constructions of Anglo-Australian cultures deem it ‘unmanly’ for men to publicly maintain their health, avoid health risks and voluntarily seek regular medical ‘check ups’. Skord and Schumacher (1982) claim that men have higher death rates and report less illness than women because it is ‘unmanly’ to be ill, weak or disabled. Kimmel (1994) reports that men perform heroic feats and take enormous health risks, all because they want other men to grant them their manhood. Men’s level of reliance on dominant social constructions of masculinity can inform their risk taking behaviours as they seek to emulate the masculinity to which they aspire. Courtenay (2000) summates that men’s poor health promotion practices are socially constructed and influenced by society, history, class and culture, all of which intersect with masculinity.
Cultural assumptions about masculinity and femininity also prescribe that men are strong, stoical and insensitive to pain, whilst women should take responsibility for the health and health behaviours of the men in their lives (Lee & Owens, 2002). These dominant social constructions of gender prescribe the incongruence of health maintenance and masculinity and situate health expertise as feminine. According to Huggins (1998) and Lee and Owens (2002) such gender stereotypes need to be challenged if men’s health practices are to change. To this end Huggins (1998) recommends a ‘ground up’ approach that considers gender issues in the planning stages of men’s health promotion and services.

**A social construction of health promotion**

Many researchers and theorists are critical of health promotion programs based on the Health Belief Model and Theories of Reasoned Action and Planned Behaviour because they do not take into account men’s individual circumstances and advocate sociologically informed men’s health promotion programs (Buchbinder, 1995; Courtenay, 2000; Huggins, 1998; Lambevski et al., 2001; Thorogood, 2002; Watson, 2000; Woods, 2001). Lee and Owens (2002) recommend a gender-culture sensitive life course perspective of older men’s views of their health, because a lifetime of gendered experiences are inextricably embedded in men’s health practices.

**A social construction of men’s illness**

Men’s illness has sporadically been researched through social constructionist gendered analysis. Most recently, Lee and Owens published *The Psychology of Men’s Health* and suggested the central issue for their book was “the social construction of gender as it impinges on the behaviour of men and thus their physical and emotional health” (2002, p. 4). The cause – effect analysis through exploration of how men’s replication of dominant forms of masculinity are detrimental to health is a common approach to contemporary social constructionist gendered analysis. However, almost a decade after being published Charmaz’s (1995) study of chronically ill men and Gordon’s (1995) research of men with testicular cancer strongly influence social constructionist research in men’s health. The strength of their research is the ability to demonstrate the interactions between illness and constructions of masculinity, rather than
depicting a myopic, one way relationship. This study is influenced by their approach and demonstrates how prostate cancer interacts with masculinity, and how masculinity interacts with the participants’ experiences of prostate cancer.

**Conjoint theories**

Long-standing debate continues about the oppositions, tensions and connections between essentialist and social constructions of masculinity. DeLamater and Shibley Hyde (1998) explored the feasibility of attempts to synthesise (theoretically and empirically) essentialist and social influences in a single theory, a process they referred to as ‘conjoint’. They found that the basic definitions of essentialism and social constructionist theories prohibit their compatibility. Essentialism relies on a notion of essences, with an implication (found in positivism) that the true essences can be known directly and objectively. Social constructionists argue the opposite— that we cannot know anything about true essences or reality directly, but rather that humans always engage in socially constructing reality (DeLamater & Shibley Hyde, 1998).

The incompatibility of essentialism and social constructionism is less coherent in the context of illness, especially when research data rather than theoretical frameworks are examined. One example, of particular relevance to this research, is illustrated in a study by Chapple and Ziebland (2002) of the embodied experiences and perceptions of masculinity in a cohort of 53 men with prostate cancer. They found that participants treated with ADT experienced profound effects on their libido, energy, ability to work, body shape and competitiveness. Based on their findings, Chapple and Ziebland (2002) concluded that gender is largely a social construction, but hormones and therefore essentialism subtly affects the way men and women react to each other and how gendered roles are played. Moreover, they concluded “we do not think there should be an absolute dichotomy between culture and nature, or between constructionist and anti-constructionist epistemologies” (Chapple & Ziebland 2002, p. 822). The ‘middle ground’ between essentialism and social constructionist theory has previously been described by Turner (1992) who remarked that it appears ‘bizarre’ to argue that there are no organic foundations to human activity.
Prostate cancer, especially when treated with ADT, potentially situates the male body in the conjoint of essentialism and social constructionist theories. Therefore this research explores participant responses to dominant social constructions of masculinity when they perceive emasculated bodies following ADT. The findings from this study, detailed in Chapter Six, *Sexuality, intimacy and prostate cancer*, contribute to the discussions begun by Chapple and Ziebland (2002).

**The Masculine Body and Social constructivist theory**

**Theory**

Turner claims that “sociological theory has effectively neglected the importance of the human body in understanding social action and social interaction” (1992, p. 822). According to Fleming (1999) male embodiment has been given little attention in masculinity studies. However, Chapple and Ziebland (2002) challenge such assertions and suggest that over the past ten years the body has been ‘brought back in’ to sociological debate about gender. Similarly, Evans reports that “an important theorising of masculinity and gender has been to recast people’s thinking about the status of the body in analyses of gender and power” (2001:132). Chapple and Ziebland (2002) recommend that future research—inclusive of the physical body, as well as culture—be taken into account when trying to explain what it means to be masculine, and how illness may affect men’s sense of masculinity.

Connell explains that “masculinity refers [original emphasis] to male bodies, sometimes directly, sometimes symbolically and indirectly, but it is not determined [original emphasis] by male biology” (2000, p. 29). Men’s bodies are addressed, defined and disciplined and given outlets and pleasures, by gender order of society (Connell, 2000). Furthermore, bodies are arenas for the making of gender patterns and “gender is social practice that constantly refers to bodies and what bodies do” (Connell, 2000, p.27). Connell summates masculinity is a “social pattern that refers to male bodies” and states that:

> masculinity does not exist prior to social behaviour, either as a bodily state or a fixed personality. Rather, masculinity exists in everyday behaviour in social contexts, as a configuration of social practice. This structure defines
a particular pattern of conduct as masculine and another as feminine.
(1994, p. 6)

**The body, masculinity and prostate cancer**

Utilising Connell’s (2000) concept of masculine bodies as arenas, participants in this study’s conduct of everyday life is organised in relation to an illness arena, defined by the social structures and processes of human recovery. This arena may include changes to the body aesthetics and functionality, and the search for masculinity, intimacy and sexuality in a body that is simultaneously different and familiar. For example, this research explores the social construction of body changes such as urinary incontinence and impotence which can accompany prostate cancer and its treatments. By examining the social construction of the masculine body, I have responded to Chapple and Ziebland’s (2002) assertion that relatively little attention has been paid to men’s perceptions of their bodies, or their changing sense of masculinity when disease affects their genital organs. Furthermore, this research does not define and confine the masculine body by its genitalia.

The muscularity of the masculine body, which is also affected by prostate cancer and its treatments, is considered in this research. As Loeser states:

> the postures, tensions and texture of a muscular body are one of the main ways in which the power of men is seen as part of the order of nature...A man’s presence (fabricated or real) is dependent upon the promise of power he embodies. (2002, p. 56)

Martino and Pallotta-Chiarolli (2003) confirm that physicality, muscularity and bodily posturing are implicated in the self-regulatory policing practices of a normative masculinity. Control and discipline of the masculine body is a deeply cultured expectation of dominant forms of masculinity according to Morgan (1993). There is also a high value associated with the ‘ideal’ male body and associated qualities of physical strength and physical aggression, which are in marked contrast to the feminine (Evans, 2001). In these ways the masculine body is socially constructed as strong, enduring and self-reliant and a complex relationship between men, their bodies, and sociocultural expectations exists (Lee and Owens 2002). For example, men can be simultaneously too fat and too thin because in comparison to the hegemonic masculine ideal they have less muscle
and more fat (Lee & Owens, 2002). Peterson (1998) suggests that men are presented with the concept that a real man is large, hard and strong. There can be intense social pressure on men to compete with other men and to be perceived as successful, and for many men their body provides opportunities to demonstrate these ideals (Lee & Owens, 2002).

Prostate cancer can affect the aesthetics and functionality of the masculine body, which Corbin (2003) predicts can result in a loss of body pleasure through now denied and or unattainable experiences. Furthermore a discordant body-mind relationship often exists when the body cannot perform despite the willingness of the mind (Corbin, 2003). Loeser (2002) specifies that the disabled male is subjugated to the realm of the ‘abnormal’, the ‘feminine’, the ‘not male’ and Devins (1994) suggests that a profound sense of loss and changed identity occurs when the ill body of the present is compared to the body of the past.

The participants in this research thesis were older men and Fleming (1999) proposes that the masculinities and bodies of older men are conspicuously absent in Australian society and gender studies. He attributes this to the dominant public and popular culture discourses of younger and middle-aged men (Fleming, 1999). Thompson remarks that the pre-death older men have already lost out in the aging stakes, are “stereo-typified as genderless, even emasculated”, such that the “social construction of older men maintains that old men are not men at all” (1994, p. 2). Buchbinder (2002) challenges the assertion that the aged male body, divested of health, vigour, its sexual potency and eroticisation renders older men powerless. Instead older men transfer their power from the body to other aspects of their life such as family, social status, accumulation of wealth and consumerism (Buchbinder, 2002). As a result “the body becomes less significant than the context in which the body is represented, or the props, as it were, with which the body is invested” (Buchbinder, 2002, p.17). The aging process can also become acceptable as long as it is rendered invisible and free of effects (Buchbinder, 2002).

Participants’ relationship to hegemonic masculinity in the context of being older men with prostate cancer and the connections with their sexuality and intimate relationships is discussed in Chapter Six, Sexuality, intimacy and prostate cancer.
Summary

A social constructionist, gendered analysis of men with prostate disease is adopted for this study. However it is acknowledged that men’s health practices are influenced by the interaction between essentialist (biological) and social (behavioural) expectations and regulations (Van Den Wijngaard, 1997). The masculine body as it is socially constructed is included in this research. This is a relevant, necessary aspect of the exploration of prostate cancer and masculinity. The following Parts B, C, and D explore the variations in masculinity from a social constructionist perspective.

Part B — Hegemonic masculinity

Tosh (2002) and Flood (2002) suggest a number of usages of the term ‘hegemonic masculinity’ can be distinguished in current work. First, hegemonic masculinity may mean no more than those masculine attributes which are most commonly subscribed to in a social formation (Tosh, 2002). These include characteristics such as domination, aggressiveness, competitiveness, sexual and athletic prowess, control and stoic emotional display (Cheng, 1999). The adoption of such attributes may also inform improper displays of emotions such as love, affection, pain, and grief (Nicholas, 2000).

Theorists suggest, the performance of some characteristics of hegemonic masculinity may negatively affect men’s decisions about health behaviours (Courtenay, 1998; Eisler, 1995). Good, Borst and Wallace (1994) note that society’s expectation of men’s toughness and independence informs men’s sense of invulnerability, social isolation, withdrawal, and hesitancy or unwillingness to ask for help. They also point out that individuals differ in how strongly they hold hegemonic masculine attitudes and beliefs.

Nicholas (2000) suggests it is important to clearly distinguish between the harmful effects and potential strengths in what he describes as traditional gender roles. Some characteristics of hegemonic masculinity may assist men in conceptualising and coping with illness—as illustrated in Gordon’s (1995) study of men with testicular cancer. Some participants in the study presented in this
thesis constructed their recovery from prostate cancer using hegemonic masculine ideals. The findings are discussed in Chapter Five, Section Three, *Moving out*.

Second, Connell (1987, 1995, 2000) suggests that hegemonic masculinity signifies a position of cultural authority and leadership, not just in relation to other masculinities, but in relation to the gender order as a whole. Hegemonic masculinity is the type of masculinity the dominant group performs, which is the “culturally idealised form of masculine behaviour” (Connell, 1987, p. 83). He argues that it is not a fixed character type but rather the masculinity that occupies the “hegemonic position in a given pattern of gender relations, a position always contestable” (Connell, 1995, p. 76). Therefore, alongside historical changes, the definition of hegemonic masculinity also shifts (Connell, 1987). Carrigan, Connell and Lee acknowledge that most men’s gender performance varies to some degree from the prescribed hegemonic masculine gender role, “The hegemonic model… may only correspond to the actual characters of a small number of men. Yet very large numbers of men are complicit in sustaining the hegemonic model” (Carrigan, Connell & Lee, 1985, p. 92). Connell (1987) also suggests that hegemonic masculinity is centrally related to social control and cultural othering, since its rationale is to maintain authority over women and over subordinated masculinities.

In this research participants discussed their ‘illness’ experiences and revealed diverse, complex and sometimes contradictory subscriptions to hegemonic masculinity. The findings are presented throughout the results Chapters Four, Five and Six.

**Part C — Masculine hierarchies and marginalised masculinity**

Some masculinities are dominant while others are subordinated or marginalised (Connell, 2000). Kimmel states the hegemonic definition of manhood is a “man in power, a man with power, and a man of power” (1994, pp. 124–125). Hence, manhood is equated with being successful, capable, reliable, and in control (Cheng, 1999). The definitions of manhood developed in our culture maintain the power that some men have over other men, and that men have over women (Connell, 1987). Hence, cultural definitions of masculinity and the existence of a
dominant form of masculinity create hierarchies within the male gender. Connell (1994) points out that masculine hierarchies are created by concrete actions.

Men who do not reach cultural ideals of manhood or admit weakness are often referred to as having marginalised masculinity and described as emasculated (Cheng, 1999). Marginalised masculinity is defined as a sense of insufficient hegemonic masculinity resulting in “peripheral or disadvantaged unequal membership and disparate treatment” (Cheng, 1999, p.2).

Martino and Pallotta-Chiarolli (2003) report that illness often renders men vulnerable, passive and dependent—traits traditionally assigned as feminine and thus in direct opposition to hegemonic masculinist constructs of invulnerability, activity and independence. Skord and Schumacher confirm that “sickness is seen as a departure from being masculine” (1982, p. 285). Marginalisation is not static and Courtenay (2000) proposes that masculinities are continually contested and renegotiated in each context that a man encounters; they require compulsive practice because they can be undermined at any moment such as in illness and hospitalisation.

In a study of men with chronic illness Charmaz (1995) found that illness can undermine men’s taken-for-granted place in the gender order and alter or end participation in work, sports, leisure and sexual activities. Furthermore illness “can reduce a man’s status in masculine hierarchies, shift his power relations with women, and raise self-doubts about masculinity” (1995, p. 268). Roles such as father, husband and worker by which an individual’s masculinity and health is socially affirmed, can also be affected by illness. Farrell (1986) identified two major masculine roles: the breadwinner role within the family and the work role within society. Removal from the role of breadwinner can disturb a man’s self-esteem, sexual potency, and sense of being loved. Just as working is a source of positive male identity, not working is usually stress producing. Furthermore Mata and Gingras (1960) report that disabled men who rely greatly on the breadwinner role to control their family experience greater loss of status and power when they are no longer the breadwinner. They suggest that such ‘role rigid’ disabled men often become overly dependent, irritable, hostile and aggressive to compensate for feelings of shame and emptiness.
Marginalisation can also occur as a result of prostate cancer treatment side effects such as impotence and urinary incontinence. Steginga, Occhipinti, Dunn, Gardiner, Heathcote and Yaxley (2000) conducted a survey of men with prostate cancer and found that sexuality was a primary supportive care need, particularly for younger men. Fergus, Gray and Fitch (2002b), in a study of men with impotence following prostate cancer, found that most men redefined their sexuality and moved beyond phallocentric sex when potency was lost. Many participants in the present thesis study experienced impotence and urinary incontinence following prostate cancer and its treatments. The findings are detailed in Chapter Six, *Sexuality, intimacy and prostate cancer*.

Cheng (1999) specifies that marginalised men have multiple group memberships—some marginalised, some dominant—and that marginalisation can be intergroup and/or intragroup. Furthermore, he suggests that some men escape marginalisation by joining groups, such as support groups, where their marginalisation is normative (Cheng, 1999). Alternatively, Thorne and Paterson (1998) suggest that men who join support groups are ‘active agents’ who contribute to their treatments independently. Some participants in this study are prostate cancer ‘activists’ and attend prostate cancer support groups. Their constructions of ‘support’ roles are considered throughout the results Chapters Four, Five and Six in this thesis.

**Part D— Masculinities**

Connell (1997) states that there is no one pattern of masculinity, offering the concept of plural masculinities based on different cultures and periods of history that construct gender differently. There is massive proof of the plurality of masculinities through comparisons of various gender studies (Connell, 2000). Diversity exists between and within a given setting and there will be different ways of enacting manhood (Connell, 2000). The exploration of the varieties of masculinities moves away from the essentialist notion of ‘natural’ masculinity (Connell, 1995). In multicultural Australia, there are considerable diversities in understandings and practices of masculinity. This is also reflected in the coexistence and multiple definitions of masculinity, with no one kind of masculinity found in men experiencing illness.
Research participants’ similarities in having female partners and being Anglo-Australian potentially minimised cultural variations in health practices and knowledge within the cohort. However, multiple masculinities existed between and within men. Connell confirms that:

- masculinity is never fixed; there is room for manoeuvre
- the practice of an individual may depart from that of the group
- there is often tension within a given pattern of masculinity
- there are usually multiple definitions of masculinity in any setting

(1994, p.6)

Section Three: Constructions of heterosexual Anglo-Australian masculinity

In this section I present an overview of the theoretical and historical literature about Anglo-Australian heterosexual masculinity. Some authors claim Australian culture as homogenous, while other authors emphasise cultural diversity. An in-depth discussion of ‘culture’ is included in Chapter Three, Methods. Therefore, the following overview is intended to provide information about research participants’ cultural backgrounds. This is commensurate with ethnographic methodological approaches, in which an understanding of culture is sought (Vidich & Lyman, 1994). The following content does not necessarily represent all, or for that matter any of the research participants. Rather participants subscribe and respond in varying ways to the historical influences and dominant social constructions of what it is to be a heterosexual Anglo-Australian man.

Part A, Historical analysis of Anglo-Australian Masculinity explores Australian masculine cultures over time and considers potential connections with health care practices. Part B, Male heterosexuality: relationships, gendered social constructions and sexuality, discusses dominant social constructions of masculinity in the context of heterosex, sexuality and intimate relationships. Gerschick and Miller’s (1994a, b) reformulation, reliance and rejection framework is also described and used in the presentation of the findings in Chapter Six, Sexuality, intimacy and prostate cancer.
Part A — Historical analysis of Anglo-Australian masculinity

Much of the literature presents a narrow view of Anglo-Australian masculinity that implies few, if any, variations in masculinity existed during the first half of the twentieth century. Historically many characteristics of masculinity were prescriptive and diversity was not encouraged or publicly accepted (Oliffe, 2002). In a classic text, ‘The Australian Legend’, Russel Ward suggested:

> According to the myth the ‘typical Australian’ is a practical man, rough and ready in his manners and quick to decry any appearance of affection in others. He is a great improviser, ever willing ‘to have a go’ at anything, but willing too to be content with a task well done in a way that is ‘near enough’. ... He swears hard and consistently, gambles heavily and often, and drinks deeply on occasion.... He is taciturn rather than talkative, one who endures stoically rather than one who acts busily. He is a great knocker of eminent people unless, as in the case of his sporting heroes, they are distinguished by physical prowess... He is a fiercely independent person... Above all he will stick to his mates through thick and thin.... No epithet in his vocabulary is more completely damning than ‘scab’, unless it be ‘pimp’ used in its peculiarly Australian slang meaning of informer. He tends to be a rolling stone, highly suspect if he should chance to gather much moss.

(1958, pp. 1-2)

Much of Australia’s history depicts heteronormative masculinity and makes little reference to non-heterosexual masculinities. However, as Moore (1998) suggests, when viewed across time and in mixed cultures (as in a settler society like Australia) masculine identities become complicated. Rather than unity, diversity and contradictions are found in what is often collectively espoused as Australian masculinity. Coad (2002) theorised and deconstructed the heterosexual masculinity of many celebrated Australian men throughout history and argued that they were homosexual. Although his findings were homonormative in totality, Coad challenged many heteronormative assumptions about celebrated convicts, bushrangers and film characters. Murrie (1998) asserts that since the 1960s there has been unparalleled troubling of dominant masculinity in Australia.

A brief review of Australian masculinity shows that history has informed and intersected with dominant gender constructions in complex ways. By the nineteenth century, although Anglo-Australia had created a mainly urban society, the pastoral frontier yielded images that fuelled the national masculine myth.
Symbolic images emerged, including the bush worker with the ethic of mateship, the bush rebel Ned Kelly, and the bushman turned Anzac digger on the killing fields of Gallipoli (Conway, 1985). The Anglo-Australian identity was constructed via these images of masculinity, which were acclaimed and emulated by other men because men need to seek respect and approval of their masculine identity from other men (Leverenz, 1994).

Despite being billed as the land of opportunity, there were and remain marked class inequities. Private schools and universities were founded at a remarkably early period in Anglo-Australian history (Connell et al., 1999). Men were the breadwinners in that they supported a dependent wife and family (Crotty, 2001). In the early 20th Century women’s wages were set at 54% of men’s (Connell et al., 1999). The innate assumption was that men should work outside the home, and women should not. The gender division of labour saw masculine communities in mining, railway, shipping, agriculture, on the wharves and in pastoral work. Subcultural masculinities emerged within heterosexual working class youth such as bodgies, surfies, bikies, punks and homeboys (Connell et al., 1999).

By the Second World War, sport (predominantly ‘Australian rules football) became an important arena for the display of hegemonic masculinity and the yardstick by which most men were judged (Epstein, 1998). Fuelled by a mass media focus, competitive sport became the key Australian symbol of masculinity. High average wages and eight-hour working days ensured leisure time was accessible for most men (Connell et al., 1999). Drinking in the pub established a masculine pattern of high alcohol consumption and binge drinking, swapping yarns, laughing raucously, literally wallowing in the rituals of Aussie mateship (Conway, 1985).

In the 1970s Australian men felt the impact of feminism, and faced changing work practices that made them less economically autonomous and challenged public and domestic patriarchy (Moore, 1998). Men were under pressure to change, to assess the behaviours that had informed hegemonic masculinity, and analyse their relationships and their role in the family (Connell et al., 1999).
Moore summates, “the Australian male is a constructed creature, born of woman, created by masculine hegemony and living in a changing environment” (1998, p.15). Moore (1998) is critical of simplistic images of Australian masculinity that suggest direct heterosexual ancestry from convicts via swaggies, Anzacs, footballers and lifesavers. However, the ‘Australian legend’ (Ward, 1958) continues to be perpetuated by both men and media which depicts the Aussie male as adventurous, authoritative, independent and strong.

The participants in this study grew up in Australia and had been exposed to changing ideals of masculinity over their lifetime. The findings from this study are presented in Chapters Four, Five and Six and provide contextual accounts of participants’ experiences of prostate cancer that demonstrate shifting constructions of masculinity.

**Part B — Male heterosexuality: relationships, gendered social constructions and sexuality**

Richardson (1996) suggests little research attention has been given to theorising heterosexuality, largely because it has been treated as an unquestioned paradigm. Therefore, heterosexuality has remained formless, a silent signifier against which other sexualities are subordinate (Smart, 1996). The institution of heterosexuality is inherently gendered and rests upon the assumed normality of specific forms of social and sexual relations between women and men (Kilmartin, 2000). However, prescribed heterosexual performance and practice have, at times, suppressed members who operate in a heterosexual framework. Pease (2002) challenges the unity of heterosex and asserts that despite being commonly presented as natural, fixed and stable, diversity of meaning and social arrangements exists within the category ‘heterosexuality’. Kitzinger and Wilkinson (1994) and Smart (1996) agree that heterosexuality is not fixed and there is no one heterosexual identity, but rather the plurality of ‘heterosexualities’.

It follows that heterosexuality can be many things, even if at times there is a need to collectivise this diversity [for example when recognising heterosexual privilege and its naturalisation] (Smart, 1996). Male heterosexuality itself is not merely a matter of specific sexual desires and practices, but is perpetuated by the regulation
of marriage and family life, divisions of waged and domestic labour and patterns of economic support (Jackson, 1999).

Research participants in this study had female partners at the time being diagnosed and treated for prostate cancer. They described characteristics that typically signify heterosexual identities, such as intimate relationships with female partners and roles of father and husband. As such, participants were heteronormative in that their heterosexual ‘status’ was a given that did not require clarification. However, participants’ heterosexual identities became fragile as a result of prostate cancer and its treatments.

The following literature review presents an overview of male heterosexuality under the subheadings of relationships, gendered social constructions and sexuality.

**Relationships**

*Relationships with female partners*

According to Edgar, the process of finding a female partner for the ordinary ‘Aussie bloke’ is trial and error, but ultimately he settles for someone “who may not be a beauty but is prepared to share your bed, put up with your ugly face and bad habits and be willing to struggle on together on a low and uncertain income” (1997, p. 166). In this union, romance is a lucky add-on, sex a persistent issue and money an ever-present source of likely conflict (Edgar, 1997). Australian men have often been depicted as unthoughtful partners and lovers, more likely found in the company of their mates drinking beer than with their wives (Ward, 1958). The gendered division of labour has also prescribed that the family home is the domestic domain and territory of the female, whilst the male works for a wage in order to support his wife and family (Pease, 2002).

Over 90% of all Australian men and women entering young adulthood in the 1950s and 1960s formalised their heterosexual relationships through marriage at some stage of their lives (Edgar, 1997). The major shift in twentieth-century marriage came in the 1960s, after the oral contraceptive pill rendered marriage more a licence for cohabitation and less a declaration of intent to become parents.
The union of men and women through marriage is reported to alter many aspects of men’s lives.

Married men tend to disclose less to their male friends than single men do (Tschann, 1988) and the most important social relationship in most men’s lives is with their marriage partner (Lee & Owens, 2002). Married men also tend to rely solely on their wives for filling their intimacy needs (Kilmartin, 2000) and marriage provides a greater degree of emotional support by tying the less social male to wider social supports through female networks (Edgar, 1997). Marriage is also beneficial to men’s health and protects them from premature death and mental disorders (Edgar, 1997). In the context of prostate cancer, Hu and Goldman (1990) found direct benefits for married men in that unmarried men have twice the incidence of prostate cancer when compared to married men.

Intimacy can be threatening for men because it involves connecting, being vulnerable and sharing power, all of which have been labelled as feminine attributes. Sex and intimacy are different in that “true intimacy involves letting someone in to the most private and vulnerable parts of the self”, which makes intimacy possible without being sexual, through shared communication and experience (Kilmartin, 2000, p. 214). Dominant forms of masculinity require men to be competitive, non-communicative, non-giving and inexpressive (Harrison, Chin & Ficarrotto, 1989) which impact on their intimacy with female partners (Rowan 1997). Trust is central to men’s intimacy issues and, in order to love, men must trust partners; however this renders men vulnerable in that they must give up some control (Pease, 2002). In order to minimise the loss of control, some men disclaim or suppress their feelings as the person who needs the relationship least tends to have the most power (Lips, 1997). Sustained suppression of emotions leads to the eventual loss of men’s ability to experience emotions (Kilmartin, 2000).

Most participants in this study had long-term heterosexual marriages. Prostate cancer and its treatments affect participants’ intimate relationships in complex ways. The findings are presented in Chapter Six, *Sexuality, Intimacy and prostate cancer*. 
Relationships with family
Smith et al. (1998) state contemporary images of Australian men include caring, sensitivity and high involvement in child care—a significant shift from the historical image of fathers. Despite this trend, the sexual division of labour in the home remains very rigid and only a minority of men engage in the level of child care implied by the ideology of the ‘new father’ (Pease, 2002). Diehardt (1998) agrees that men’s involvement in child care has increased only marginally in spite of women’s increased participation in paid labour. Traditional gender demands prescribe the father’s role as one of absent provider and protector, involved in work outside the home, and paid work that often reduces the time spent with their children (Lee & Owens, 2002, Kilmartin, 2000).

Relationships with other men
Men are usually seen as competitors and mates are not necessarily exempt (Edgar, 1997). It follows that most heterosexual men are not emotionally intimate with men and have difficulty disclosing things about themselves because they are often locked into competitive relations with each other (Nardi, 1992; Seidler, 1997). Homophobia is a common foundation for heterosexual masculinity and precludes men from having more intimate relationships with other men (Pease, 2002). Dominant constructions of masculinity are taboo on introspection, which inhibits self-disclosure and demands self-sufficiency and hyper-independence (Webb, 1997). The notable exception to this rule is the sports arena (Edgar, 1997), where men’s friendships with other men focus on shared activities, mutual pursuits and interests (Lips, 1997; Seidler, 1992).

Many participants in this research discussed various aspects of their prostate cancer with other men. The findings are included in Chapter Four, Section Two, Part D, Spreading the word: Screening advocacy.

Gendered social constructions

Men at work
Edgar (1997) suggests that men love their children and would die for them. However the problem is they are dying for them through overwork and a lack of balance in their lives. The heterosexual family man in full-time paid employment often pursues work as the central life interest (Pease, 2002). Although many
Women work outside the home, traditional masculine roles of breadwinner are followed and paid employment is the primary source of identity in which men work for their wife and family (Bradley, 1989). Success in the work role has come to define masculinity and men are judged by the standard of living they provide for their families (Pease, 2002). Marriage and work are synonymous for many men and 90% of married men with children participate in the paid work force (Australian Bureau of Statistics, 1995).

Men are also defined by the type of work they do which often reflects their social class (Lee & Owens, 2002). According to Kilmartin (2000) ‘career’ is a reimbursable means of expressing an important part of the self, alternatively a ‘job’ is the provision of labour solely for economic survival. The opportunity for men to access career or job is often reliant on social class and therefore influences the type of work men can undertake. Connell (2000), Courtenay (2000), Donaldson (1991) and Hayes (2001) report that social class impacts on men’s health and that working class men are more likely to encounter illness and injury through the physical work they perform. Donaldson (1991) explains that working class men have basically one asset, their bodily capacity to labour, and over time those bodies are consumed by the labour they do.

Social relationships and a sense of identity are intertwined with paid employment and retirement is also a major life event for many men (Lee & Owens, 2002). Solomon (1982) suggests retirement is one of the greatest stresses that older men face. Alternatively Sanford and Lough (1988) suggest that many men experience retirement as productive years. However the circumstances of retirement are important to men’s levels of satisfaction and it can be problematic for men forced to retire through ill health without the financial resources to cover costs (Lee & Owens, 2002).

Oppositions as a result of illness such as “active versus passive, independent versus dependent, autonomy versus loss of control, public persona versus private self and domination versus subordination” are often most visible in men’s ability to work (Charmaz, 1995, p. 267). Illness can impact, both short and long term, on breadwinner roles and masculine ‘working’ identities. Workmen become patients,
subordinate through a loss of independence, control and public persona ordinarily affirmed through paid employment (Charmaz, 1995).

**Men at play**

Sport is an important arena in which boys and men are socialised into manhood (Edgar, 1997; Pease, 2002) and contributes to the formation and perpetuation of hegemonic masculinity (Drummond, 2002). Sport is an arena for the promotion of values of independence, pride, resilience, self-control, fitness, competitiveness and strength (Gilbert & Gilbert, 1998), and legitimises aggression and violence through the glory and rewards of ‘winning’ (Messner, 1992). Physical suffering and pain performance is learned and practised by many men through engagement in competitive sport (White Young & McTeer, 1995; Young, White & McTeer, 1994). Men’s ‘body performance’ can inform lifelong perceptions that pain is to be overcome and body changes are the result of age and previous physical exertion or injury.

Sports, men and relationships are uniquely interrelated (Drummond, 2002) and there is a long association between sport and dominant constructions of masculinity in Australia (Connell et al., 1999; Drummond, 2002; Edgar, 1997; Pease, 2002). Advertisement 4 for Foxtel Cable Football Channel was published in the Herald Sun newspaper, Melbourne Victoria, April 12th 2002. It shows Anthony Koutoufides, a highly paid AFL footballer clutching his injured knee. The caption superimposed over the picture says:

*It’s not how many goals you kick, or how many marks you take, or how many games you win, that makes you a legend. It’s how many times you get knocked down, and then get back up.*


The advertisement demonstrates how sport is philosophical as well as physical. Commitment, competitiveness, endurance, recovery and ‘grit’ are demonstrable on the field by elite athletes and revered and replicated by spectators. Even if unable to play the game yourself, dedication and commitment to support ‘your’ team is possible. The media, as well as many Australian men and women, are complicit in sustaining hegemonic masculinity through corporate sport. Messner
(1992) and more recently Drummond (2002) have considered the connections between social constructions of masculinity and sport.

Advertisement 4 Foxtel Cable Football Channel

Source: Foxtel, Herald Sun Newspaper, Melbourne Australia April 12, 2002

The Foxtel sales pitch that accompanied the full page advertisement reads:

Dedication is not measured in small amounts. Every game, every team, every week, uninterrupted play from siren to siren. These are our Aussie rules. Contact today and make them yours.

(Foxtel advertisement, Herald Sun Newspaper April 12th 2002:113)

Some of the philosophical underpinnings of sport can be applied to illness, and in particular, cancer. Frank (1991) suggests that people with other diseases are sick, but people with cancer fight it; and Gordon (1995) found that men with testicular cancer interpret their survival as a fight they have won by displaying courage and toughness. Seale (2001) found that the language of official sport is commonly
used in media stories of cancer. He argued that the claim that such ‘struggle’ language is harmful to people with cancer is unsubstantiated (Seale, 2001). Sporting constructions are used by some participants in this study and the philosophical underpinnings of competitiveness and performance are considered in how they experience their prostate cancer. The findings are detailed in Chapter Five, Section Three, ‘Moving out’.

**Sexuality**

Connell suggests that “masculinities as cultural forms cannot be abstracted from sexuality, which is an essential dimension of the social creation of gender” (2003, p. 47). Furthermore he asserts that whilst “sexuality addresses the body, it is itself social practice and constitutive of the social world” (2003, p. 47). Likewise, Weeks, Holland and Waites (2003) acknowledge that gender is extremely powerful in relation to the constitution of sexuality and suggest that “these relationships inevitably shift over time and over the life course of individuals” (p. 43). Weeks outlines the problematic nature of ‘sexual identity’ as fixed and suggests that there is much “uncertainty about the stability and fixity of our sexual belongings and identifications, hence of who we are and should or could be” (2003, p. 123). Heterosexuality is a site of struggle and contested meanings for those who are heterosexual as well as those who are not (Jackson, 2003, p. 72). The research participants in this study had female partners and their sexuality included intimate relationships with female partners. As such, research participants’ sexual identity or sexual categories are not the area of interest in this research. Rather, how their heterosexuality and intimate relationships are constructed and enacted are salient to this research.

**Desire**

The belief that men have biologically stronger sex drives than women is scientifically unsupported (Lips, 1997; Rathus, Nevid & Finchner-Rathus; 1997). However, dominant constructions of masculinity prescribe that men should initiate sexual activity, determine the form of such activity and decide when the sexual episode will cease (Kilmartin; 2000; Lee & Owens, 2002). Desire provides a measure of manhood in terms of the capacity for penetrative sex (Edgar, 1997) and failure to ‘desire’ and initiate sex and enact dominant cultural expectations
Equipment
The penis and testes are bodily signifiers of distinction from femininity (Martino and Pallotta-Chiarolli, 2003). Moreover the size of a man’s penis and its penetrative, ejaculate ability represents his masculine status and power (Edgar, 1997). A study by Lee (1996) showed that many married men have concerns about their penis being smaller than that of the average man. Men’s concerns about inadequacy related to penis size are influenced by cultural expectations (Lee & Owens, 2002).

Performance
There are strong cultural assumptions that proper sexual activity must be initiated by a man and involve the insertion of the penis into the female partner’s bodily orifice (Lee & Owens, 2002). Most heterosexual men’s dominant pattern of sex is erection, penetration and climax, which Metcalf suggests is due to “men’s inability to express themselves and their lack of emotional language” (1985, p.4). There is also a general expectancy that women should be passive and men active sexually (Lee & Owens, 2002). Boys learn early that “their manhood is tied to their penis, and having and using erections has something to do with masculinity” (Zilbergeld, 1992, p. 32). This penis centred sexuality can create confusion between personhood or identity and sexual organ, and when the penis does not operate according to dominant ideals, men equate this with loss of manhood (Zilbergeld 1992). Physical performance forms the basis for this construction of sex, a version that relies heavily on sexual competence, focused on the penis, including activities orientated toward coitus.

Unless the penis is erect, insertion is impossible and, according to Flood (2002), Lee and Owens (2002) and Tiefer (1987), men who are unable to gain an erection and perform sexually are affected in deeply gendered terms that threaten their manhood and result in humiliation and despair. Similarly, Kimmel (1987, 1990) suggests that male sexuality confirms gender and masculinity is enacted through sexuality. Thus, failure to perform sexually can challenge the fundamentals of masculinity, and make heterosexual men believe they are not ‘real men’.
Potts (2000) suggests that impotence interferes with culture to produce the ‘fiction’ of a dysfunctional male heterosexuality. Edgar (1997) clarifies that on its own, sex is not enough, but the emotional bond and mutual satisfaction often leads to a deeper negotiated intimacy on the level of shared understanding and appreciation of the other’s individuality. Connell rejects the construction of sexuality based on the notion that the sexual encounter begins with an erection and ends with ejaculation. He labels such constructions as phallocentric and argues that “the culture that symbolises the penis as the overriding principle in sex, and a sex model based on the biological explanation, serve to separate men from their sexuality” (1983, p. 24). Men may learn to appreciate possibilities and reconceptualise expressions of their sexuality in new and different ways. According to Edgar, intimacy for Australian men does not necessarily rely exclusively on sex, he suggests it means something broader, “a closeness, a sharing of ideas, of secret corners of the self” (1997, p. 205).

When men’s sexuality is affected by illness various reactions occur. Yong found that some men with impotence following treatment for prostate cancer label themselves as “inferior, not a full man anymore, inefficient and less than a man” (1998, p. 105). Gordon (1995) found that men with sexual dysfunction following testicular cancer were able to maintain clear masculine identities both by drawing on traditional concepts of manliness and by redefining masculinity to include traditionally feminine characteristics such as emotional expressiveness, concern for personal relationships, and empathy. Gritz et al. (1989) and Fergus, Gray and Fitch (2002a) report that cancer can bring married couples closer together, especially when men’s constructions of sex exist outside the boundary of intercourse.

Many research participants in the present thesis study experienced impotence, urinary incontinence and embodied changes that affected their sexuality and intimate relationships. The coping strategies that participants developed were constructed in relation to the ideal masculine performance, and thereby in relation to hegemonic masculinity (Wienke, 1998). Gerschick and Miller (1994a,b) developed a framework of reformulation, reliance and rejection as a way of describing men’s relationships to hegemonic masculinity.
Gerschick and Miller (1994b) originally developed the framework using an analytic induction approach to investigate the tensions between physical disability and dominant constructions of masculinity. They state that the bodies of men with disabilities are continual reminders that they do not reach the expectations of dominant masculinity culture. Hence, the physically disabled man is unequipped to claim the privileges of hegemonic masculinity, which ultimately leaves him “at the crossroads of marginalization and stigmatization” (1994b, p. 25). As such, Gerschick and Miller’s framework is used to describe various responses by men to their disability.

As stated earlier, prostate cancer disease and its treatments result in incontinence and impotence for many men. Arguably, such ‘losses’ could be labelled ‘disability’. However it is not my intention to situate prostate cancer in a disability framework, or for that matter in any other category, as prostate cancer could be positioned within chronic illness or aged care categories. Instead, I adopt Gerschick and Miller’s framework to critically assess how participants adjusted to the discrepancy between the ideal masculinity and the real masculinities as a result of prostate cancer and/or its treatment in relation to the body, sexuality and intimate relationships.

Gerschick and Miller’s (1994a, b) framework includes three strategies, “reliance, reformulation and rejection”. They note that one response is to strive to meet the cultural ideals of masculinity. Gerschick and Miller identify this strategy as reliance in which “men embrace dominant conceptions of masculinity as a way to gain acceptance, yet they are continuously reminded in their interactions with others that they are incomplete” (1994a, p. 34). Some participants in the present thesis relied on penetrative sexual standards of hegemonic masculinity and attempt to regain potency when they become impotent as a way to reduce the disparity between their erectile dysfunction and dominant masculine ideals of penetrative sex.

Gerschick and Miller define ‘reformulation’ as a pattern in which men “select those dominant masculine traits they wish to or are able to accommodate and reformulate alternative ideals for those traits they are unable to comply with” (1994a, p. 34). Some participants in the present thesis exhibited reformulation in
that they recognised their inability to gain an erection and expressed their sexuality and intimacy in alternate ways.

The third strategy identified by Gerschick and Miller is rejection in which men “realise that it is societal conceptions of masculinity, rather than themselves that are problematic” (1994b, p. 29). A few participants in the present thesis study dismissed impotence and renounced erection, penetration and climax as society’s dominant construction of masculinity.

Research participants established a range of responses in reference to cultural masculine standards and no participant exhibited one pattern exclusively. Instead, one pattern often dominated while the other two presented to a lesser degree (Gerschick & Miller, 1994a). In Chapter Six, *Sexuality; Intimacy and prostate cancer*, the findings from this study are presented using Gerschick and Miller’s (1994a, b) framework.

In summary, the literature review has informed the rich tapestry of this research that connects biomedical, social constructionist and Anglo-Australian cultural research and theory in the context of prostate cancer and masculinity. Although diverse, these areas inform and are reliant on each other and the present thesis study illustrates the connectedness through participants’ experiences of living with prostate cancer.
Chapter Three

Methods

Chapter three is presented in two sections; Section One, Methodology and Section Two, Research design and processes used in this project. In Section One, I discuss the use of qualitative ethnographic methodology in this research and situate myself as an ethnographer. In Section Two the specific research processes used in this study are discussed. I have integrated excerpts from my field notes (indented in italics) throughout this chapter. Writing myself in helps to make me visible in the research and is underpinned by my commitment to reflexivity.

Section One: Methodology

Qualitative methodology

Biomedical quantitatively informed research took centre stage again today. The Prostate Cancer Support Group (PCSG) members talked about recent trial results of a relatively new treatment – Brachytherapy.

Observation PCSG 4/2001 - Field work journal entry

I suspect the pre-occupation with numbers and statistically informed research is entrenched in the search for the cause and / or cure for prostate cancer. I will have to assure research participants that their experiences of living with prostate cancer will also help to improve the understanding of prostate cancer.

Interpretation PCSG 4/2001 – Field work journal entry

Why does qualitative methodology have to be continually justified?

Question PCSG 4/2001 – Fieldwork journal entry

As the above entries from my journal illustrate, the qualitative-quantitative dualism is debated and contested, not only in academic literature, but also by potential research participants, as I found during my fieldwork. Perhaps this is especially so in the context of health research in which epidemiological methods have traditionally been the gold standard (Baum, 1995). Qualitative methodology
is still regarded with scepticism by the medical community and its subjectivity has been looked down on (Malterud, 2001). Therefore, qualitative research is often criticised for not being something it never intended to be—absolute scientific truth or objective fact (Borman, LeCompte & Goetz, 1986). An explanation of what qualitative research is and the context and rationale for its use in this study are integral to the methodology ‘defence’ that is so often required.

So what is qualitative research? Strauss and Corbin (1990) propose that qualitative research is any kind of research that produces findings not arrived at by means of statistical procedures or other means of quantification. A greater sense of what qualitative research is not, rather than what it is, prevails. Denzin (1994) affirms that qualitative research is not a single entity but an umbrella term which encompasses enormous variety. Furthermore “qualitative research is defined by a series of essential tensions, contradictions and hesitations….which work back and forth among competing definitions and conceptions of the field” (1994, p. ix). Debate and tension exist between and within qualitative approaches whereas quantitative methods tend to be uniform and agreed upon.

Despite this ‘great divide’, Malterud (2001) suggests that a broad base of medical and scientific knowledge is needed for biomedicine to maintain its identity as expert. Therefore “rather than thinking of qualitative and quantitative strategies as incompatible, they should be seen as complementary” (Malterud, 2001, p. 483). Nations elaborates that “although statistical calculations may be built on valid mathematical models, they run the risk of being inaccurate by excluding the human element: the way people really (original emphasis) approach illness and cope with death” (1986, p. 97). Clearly, a range of tools are needed to investigate complex health problems (Baum, 1995).

Many authors, including Baum (1995), Malterud (2001) and Penn Handwerker (2001) call for a ‘truce’ to the ‘persisting dualisms’ and argue that generic qualities exist for all good research. Specifically, the best research answers specific questions; the best answers come from researchers who use their imagination to frame questions and select tools for collection and analysis of data capable of answering the question at hand (Penn Handwerker, 2001). Goodrick (2001) clarifies that methodology refers to the strategies used to think through and
design research, and that the methodology should be chosen on the basis of what suits the research questions.

Following Penn Handwerker (2001) and Goodrick’s (2001) lead, the answer to the question of ‘why qualitative methodology was chosen for this study’ resides in the research questions / themes. This research unpacks emotive and sensitive issues and encourages participants to share what is important to them about living with ‘their’ prostate cancer. It is unlikely that such sensitive issues could have been studied through structured questionnaires or surveys underpinned by a positivist philosophy. The diversity, complexity or intricacies of participants’ experiences, and their context, would not have been elicited through pre-coded and pre-classified responses. Indeed, it would have been unlikely that survey questions could have been anticipated without interviewing the participants.

The ‘thick descriptions’ (Geertz, 1973) in this research involved me being there—to facilitate the moment, catch the nuance and observe the multiplicity of human sensibilities as they were revealed (Beckett, 1998). Participant interviews facilitated conversation and dialogue that allowed for the elicitation of depth, intimate and intricate detail of how participants experience, make sense of, and live with prostate cancer (Miller & Crabtree, 1992). I was active in the interviews and encouraged participants to talk, conversations developed, dialogue was exchanged and experiences of both the interviewee and researcher were shared (Oakley, 1981). By being there, I was able to observe, document and interpret the diverse ways in which participants made sense of their illness experiences (Miller & Crabtree, 1992). In brief, the broad aims of this research were suited to, and the research questions / themes best explored by, qualitative methodology.

Ethnographic methodology

*I love those Indiana Jones movies, the adventure and excitement. They say he is an archaeologist but I reckon he’s a traditional anthropologist. He experiences far away, foreign cultures and searches for artefacts and cultural symbols such as the Ark of the Covenant, Sankara Stone and the Holy Grail. He returns to the field through sequels to discover new cultures, whilst remaining true to his methods – now that’s extended time in the field.*

Thought 12/2000 – Pre first PCSG meeting
**Historical perspective**

“Ethnography has its genesis in cultural anthropology through early 20th century anthropologists such as Boas, Malinowski, Radcliffe-Brown, and Mead and their studies of comparative cultures” (Creswell, 1998, pp. 58–59). The term ethnography comes from, and has a long tradition in, anthropology (de Laine, 1997; Punch, 1998; Savage, 2000). Traditionally, the focus was on small-scale communities that were thought to share culturally specific beliefs and practices (Savage, 2000). One of the most cited and significant examples is Bronislaw Malinowski (1961) who went to live with the Trobriand Islanders in order to get information, first hand (de Laine, 1997). The distinctiveness of Malinowski’s approach lay in his concern to document the everyday social life of the Islanders (Burgess, 1982). In breaking with the tradition of ‘armchair’ anthropologists, the need for systematic approach to fieldwork and value of participant-observation was revealed (de Laine, 1997). Subsequently, participant-observation became the hallmark of anthropology for promoting an understanding of culture (de Laine, 1997).

The historical practice and underpinnings of ethnography, although not replicated in totality, directly inform and influence this research. Specifically, this study utilises traditional ethnographic methods, including participant observation and fieldwork, and is also philosophically underpinned by a commitment to the exploration of culture.

**Contemporary Ethnography**

The methodological approach of ethnography used in this study is one of the most important and well established approaches to qualitative research (de Laine, 1997). It is both a process and a product, and the term ethnography can apply to both a methodology and to the written account of a particular project (Hughes, 1992; Punch, 1998; Savage, 2000; Wolcott, 1990). Vidich and Lyman (1994) define ethnography as the science of description (graphic) of a group of people and their culture (ethno) (Vidich & Lyman, 1994). The overarching characteristic of ‘genuine’ ethnographic approach is its commitment to cultural interpretation (Patton & Westby, 1992; Punch, 1998; Wolcott, 1990). Punch elaborates that the
point of ethnography “is to study and understand the cultural and symbolic aspects of behaviour and the context of that behaviour” (1998, p. 60).

Hammersley suggests the following characteristics differentiate ethnography from other approaches:

- *people’s behaviour is studied in everyday contexts rather than under unnatural or experimental circumstances created by the researcher*
- *data are collected by various techniques but primarily by means of observation*
- *data collection is flexible and unstructured to avoid pre-fixed arrangements that impose categories on what people say and do*
- *the focus is normally on a single setting or group and is small-scale.* (1990, pp. 1–2)

Despite prescriptive ethnographic characteristics such as those aforementioned by Hammersley, ongoing debate continues about the specificities of contemporary ethnography. Modified ethnographic approaches underpinned by the researcher’s experiences, assumptions and philosophies, stimulate much debate around three areas.

First, there has been tension within ethnography, between science and the humanities, that Atkinson and Hammersley argue “has been present from the start” (1994, p. 50). Structured forms of data collection and quantitative data analysis are frequently employed in ethnographic work; however quantitative methods have been rejected as the only legitimate approach (Atkinson & Hammersley, 1994). Scientific methods have been perceived as oppressive and associated with male aggression and patriarchy. This has in part led to the move away from the model of science toward exploring alternatives that re-open links with the humanities (Atkinson & Hammersley, 1994).

Second, the practicalities of undertaking ‘traditional ethnography’ have resulted in the focus for many Western ethnographers shifting from remote communities to settings ‘at home’ such as corporate organisations (Savage, 2000). Wolcott suggests this is because “traditional ethnography is too culture-and-context oriented, too holistic, and too time-consuming for most purposes” (1990, p. 52). Therefore ethnography is not inclusively the work of anthropologists who are
totally immersed in foreign, far-away cultures for extended periods of fieldwork. Moreover, ethnography has developed as the central strategy to study culture (Punch, 1998), in which the emphasis has gradually shifted from a study of societies as wholes to particular communities or segments of societies (Van Valsen, 1967).

Many authors, including de Laine (1997) and Punch (1998), support more flexible approaches to ethnography in which every tenet of traditional anthropological ethnography does not need to be followed. Wolcott describes one adaptation as ‘microethnography’ that:

zeroces in on particular settings, cultural events or scenes, drawing on the ways that a cultural ethos is reflected in microcosm in selected aspects of everyday life, but giving emphasis to particular behaviours in particular settings rather than attempting to portray a whole cultural system. (1990, p. 64)

Similar ‘narrowed’ ethnographic approaches have been described using different names, such as ‘mini-ethnography’ (Leininger, 1985), ‘focused ethnography’ (Muecke, 1994) and ‘particularistic’ ethnography (Boyle, 1994).

Ethnography has witnessed great diversification in recent years, with somewhat different approaches being adopted in different areas, guided by different concerns (Atkinson & Hammersley, 1994). All these approaches have helped us understand the cultural rules, norms and values and how they are related to health and illness behaviour (Boyle 1994). Most ethnographers today would agree that the term ethnography can be applied to any small scale social research that is carried out in everyday settings; uses several methods; evolves in design throughout the study; and focuses on the meanings of individuals’ actions and explanations, rather than their quantification (Hammersley, 1990).

Third, much of the critique of ‘traditional ethnographies’ has centred on problems of representation and the assumptions of ‘traditional ethnographies’ that purported to accurately represent particular cultures (de Laine, 1997). Much of the early ethnography was motivated by western interest in the characteristics of non-western societies (Atkinson & Hammersley, 1994). However the neutrality of the
white male ethnographer in an era of western imperialism is now viewed with some scepticism (Said, 1994).

Specifically, traditional ethnographic work has been criticised for embodying a hierarchical and undemocratic relationship between researcher and researched, “because it is the former who makes the decisions about what to study and how to study it, and whose voice is represented in the ethnography” (Atkinson & Hammersley, 1994, p. 254). Post modernism and feminist theory, both globally and within the academic world, has meant that the ethnographer's authority to provide the only, or most legitimate, account is no longer accepted (Ahmed & Shore, 1995).

Health research and ethnography
The ethnographic approach has a long history and tradition within public health that has focused on describing aetiology and transmission of infectious diseases (Gifford, 1998b). However, more recently, ethnography has been “particularly useful for explicating the interactions between people and their physical environment as well as the ways in which cultural beliefs and practices and social relations impact on health outcomes” (Gifford, 1998b, p. 504). Anthropologists commonly accept illness is a social and cultural construction (de Laine, 1997), best understood at the socio-cultural level in its own cultural and social terms. The strength of ethnography lies in its ability to provide detailed descriptive information about complex socio-cultural contexts and processes that impact on health status and disease outcomes (Gifford, 1998b).

Similarly, in this research, I explored social and cultural constructions of prostate cancer in a cohort of heterosexual Anglo-Australian men. Through ethnographic methods participants shared detailed information that revealed commonality and diversity in their experiences of prostate cancer.

The cultural focus means the researcher engages with “the process of linking, bridging, negotiating or translating between the biomedical health care system and the patient’s health cultural orientation” (De Santis, 1994, p. 712). Therefore ethnography potentially grounds other kinds of public health research in the everyday realities of the people concerned (Gifford, 1998b). It provides a method
of discovery; particularly useful when dealing with something new, different or unknown (Punch, 1998). The understandings gained can sensitize health care workers to the cultural context and symbolic significance of behaviour and “improve cultural appropriateness of professional practice” (Muecke, 1994, p. 200).

There is increasing interest in modifying ethnographic methods to suit the shorter time demands of public health project planning and evaluation (Gifford 1998b). For example, Scrimshaw, Carballo, Ramos and Blair (1992) modified more intensive ethnographic approaches by using the Rapid Assessment Procedures (RAPs). Gifford confirms that such approaches “have been used with some success when applied within more focused public health research” (1998b, p. 508). However, Gifford warns the RAPs has critics, such as Deh-Vecchio Good (1992), who argues that such approaches often produce superficial and misleading information (Gifford, 1998b). Perhaps this is in part the reason why ethnography is sometimes portrayed “as a means of gaining a first insight into a culture or social process, as a source of hypothesis for detailed investigation using other methods” (Fielding, 1993, p. 155).

**Gender and ethnography**

In the 1990s gender became a central theme in discussions of ethnographic research methodology (Pink, 2001). An integral part of ethnographic research of gender is the recognition that gender is constructed in interaction and illuminated through social practice (Connell, 1995). This research disrupts many of the gendered constructs and cultural ‘norms’ that it actually sets out to investigate. For example, I interviewed men about private emotional matters which dislocated cultural assumptions that heterosexual Anglo-Australian men do not self-disclose about such private matters. Therefore, the ethnographic experience also disrupts a positivist definition of masculinity and forces us to think our way into a very different universe of meaning about gender (Connell, 1995). Through ethnographic exploration of participants’ experiences of prostate cancer, the differences and similarities demonstrate the contradictory and dynamic character of masculinity.
It is important to acknowledge the pioneering and ongoing role of feminist research to gender investigations. Feminist thinking has reshaped qualitative research practices (Punch, 1998). The 1970s second-wave feminism gave rise to the fresh work on the anthropology of gender in which women documented women’s lives (Connell, 1995). Since the 1980s the key intellectual underpinning of ethnographic approaches to masculinity research has been “feminist analysis of gender as a structure of power relations; sociological concerns and issues of marginalization and resistance” (Connell, 2000, p. 8). Furthermore, Connell (1995) notes that feminist investigations of gender were followed by research on masculinity. Clearly, beyond traditional ethnographic methods such as participant observation and in-depth interviews, feminist methodology and philosophy informs and influences masculinity research committed to understanding diverse gender constructions and performances (Cornwall & Lindisfarne, 1993). Dr. Damien Ridge, a research fellow at Deakin University, suggests that masculinity research is also informed by men and the disappointment that feminism can silence men, even though men are ‘powerful’ (D. Ridge, personal communication, 8th June 2003).

Feminist theory also acknowledges the researcher / researched hierarchical binary and advocates that the researcher’s class, race, culture, and gender beliefs and behaviour are placed within the same historical moment, or critical plane, as the research participants (Brah, 1996). Both parties (researched and researcher) work together to co-produce knowledge (Abu-Lughod, 1993). Central to this position is feminist standpoint epistemology which rejects positivist research methods, acknowledges the characteristics of researchers as important determinants of the way they see and interpret realities, and is committed to seeing issues from the participants’ perspectives (Punch, 1998). This includes a refusal to ignore the emotional dimension in the conduct of the research, and its acknowledgement of the role of affect in the production of knowledge (Punch, 1998).

The challenge to positivist, universalist, objective claims of research methods is also commensurate with feminist theory. The feminist critique of science is that it is based on a masculinist way of viewing the world rather than being grounded in human experience (Punch, 1998). In ethnography, examination of the difficulties
of translating particular meanings of masculinity from one social setting to another challenges the existence of any straightforward, apparently universal, category; it also raises questions about the social contexts in which such categories are used (Cornwall & Lindisfarne, 1993). Connell (1995) summates that positivist methods which presuppose masculinity is a stable object are naïve.

Regardless of the origins and diversity in ethnography, the exploration of culture remains central to ethnographic endeavour. Therefore, constructs and definitions of ‘culture’ are fundamental to ethnographic research.

Culture

Culture is one of the two or three most complicated words in the English language. Raymond Williams (1983, p87)

English backpacker: What’s the difference between yogurt and Australia?
Mr. Oliffe: ??
English backpacker: If you leave yogurt for one-hundred years it will grow a culture!

Memory of a discussion (and beers) Turf Hotel, North Melbourne, 1992.

Helman describes culture as:

...a set of guidelines which an individual inherits as a member of a particular society, and which tells him how to view the world, and how to behave in it in relation to other people, to supernatural forces or gods, and to the natural environment. It also provides him with a way of transmitting these guidelines to the next generation- by the use of symbols, language, art and ritual. To some extent, cultures can be seen as an inherited “lens”, through which the individual perceives and understands the world that he inhabits, and how to live within it. (1984, p. 2)

Helman’s description insinuates that people passively ‘inherit’, ‘transmit’ and reproduce culture via an homogenous ‘lens’. Similarly, Spradley (1980) suggests that culture can be thought of as a shared set of meanings, or a cognitive map of meanings. Phenomena such as information technologies, new national and local identities, and the development of theoretical perspectives that reject assumptions about social coherence have challenged the traditional view that ‘culture’ is a matter of shared beliefs and practices (Wright, 1998). Ingold (2001) argues that human beings grow into cultural knowledge, within a social and environmental context, rather than receiving it ready made.
Contemporary social sciences view the notion of culture as flexible and constantly in the making (Gifford, 1998b). Culture is socially learned ways of living in human societies and it embraces all aspects of social life including thought and behaviour (Harris, 1999). Recognition is given to diversity and multiculturalism that exist in social groups. Some social scientists argue that ‘culture’ marks a process of struggle to determine meaning on the part of individuals with unequal access to power (Wright, 1998). Gifford suggests, “regardless of how culture is conceptualised, contemporary theory would argue that we inhabit worlds of many cultures and we are the makers of our cultures as much as they are the makers of us” (1998b, p. 509). Therefore culture always constitutes a complex whole for individuals and each individual exists as a multicultural being (Penn Handwerker, 2001).

Whilst culture has many definitions it usually consists of origins, values, roles, and material items associated with a particular group of people (Byrne, 2001). Ethnographic research, therefore, attempts to fully describe a variety of aspects and shared cultural meanings of the group to enhance understanding of the people being studied (Byrne, 2001). Any group develops their own culture that becomes reasonable and meaningful once you get close to it, and one of the challenges of ethnography is to work with cultural diversity (Goffman, 1961). Culture is an amorphous term, not something tangible and lying about (Wolcott, 1990). It is something the researcher attributes to a group as they search for patterns of daily living and inferred from the words and actions of the members of the group (Creswell, 1998). It consists of what people do, say, make and use (Spradley, 1980). Therefore, the ethnographer observes and listens to uncover cultural patterns.

Congruent with Gifford’s predictions, I observed that participants inhabited the worlds of many cultures. For example, during my initial fieldwork at PCSG meetings, the culture encouraged information sharing and support amongst members. In this ‘prostate cancer culture’ men spoke openly about ordinarily ‘private’ health matters in contrast to traditional cultures of masculinity which inhibit and discourage self-disclosure. When I interviewed participants at their homes, they often introduced me to their female partners and pointed out (and
explained) various possessions that were important to them. In these instances, participants subscribed to traditional male heterosexual cultures by revealing aspects of their relationship with female partners and showing symbols of their breadwinner status. As Harris suggests, the instructions of culture “do not contain only rules for guiding behaviour; they also contain rules for breaking those rules” (1999, p. 2). As such, participants in this study subscribed to diverse cultures dependent on context and some of them ‘broke the rules’ of traditional hegemonic hetero masculinity.

**Naturalism**

Naturalism or naturalistic inquiry refers to the research being done in natural and not artificial settings (Lincoln & Guba, 2000). Beyond the centrality of culture to ethnography is the practice in the social sciences to observe people in their own territory (de Laine, 1997). The researcher uses methods that are “sensitive to the nature of the setting, and the primary aim is to describe what happens in the setting, and how people involved see their own actions, other’s actions, and the context” (Punch, 1998, p. 157). The researcher also becomes part of that natural setting (Fielding, 1993).

The initial fieldwork at PCSGs provided an opportunity to observe groups of men in what was their own territory. Interviews conducted in participants’ homes and workplaces also yielded rich data through ‘naturalistic’ observation opportunities that were not possible when participants were interviewed by telephone or in my office. However, the claim of naturalistic settings has become less definable in contemporary society. Telephone and office interviews may constitute artificial settings but both are still part of society (Silverman, 2000). Therefore, participants in this study that requested telephone or office interviews have defined ‘naturalistic’ on their own terms rather than that of the researcher.

**Data collection methods**

In ethnography, data collection techniques are eclectic, not restricted (Punch, 1998). Any techniques might be used, but participant observation and fieldwork are always central (Savage, 2000). Data collection is typically prolonged and repetitive because the culture being studied exists on several levels. It takes time for a researcher to gain access to the deeper levels of this culture, ethnographic
records need to be comprehensive and detailed, and typically focus on things that happen again and again (Woods, 1992).

As stated in Chapter One, *Introduction to the research*, data collection methods in this study included preliminary fieldwork, photographic novella, in-depth semi-structured interview[s] and participant observation. The theoretical underpinnings for the use of these methods follow. However the specificities of the methods used in this research are discussed in Section Two of this chapter, *Research design and processes used in this research*.

**Preliminary fieldwork**

Wolcott (1999) argues fieldwork is central to the practice of ethnography. Fieldwork entails watching, listening, asking questions and forming hypotheses that enable ethnographers to acquire some sense of the social structure of the setting and begin to understand participants’ cultures (Hammersley & Atkinson, 1995). The preliminary fieldwork for this study was conducted at PCSG meetings, provided me with information about two cohorts of men with prostate cancer, and helped inform the specificities of this study. Hammersley and Atkinson suggest that ethnographers should “suspend common sense and theoretical knowledge” in order to minimise the danger of developing misleading preconceptions about the fieldwork setting and the people in it (1995, p. 101). This may be achievable when studying unfamiliar settings through fieldwork and when the ethnographer is a novice in a position of ‘acceptable incompetent’ (Lofland, 1971). However, Hammersley and Atkinson (1995) note that the ethnographer may not be allowed to take on a novice role and be cast into the role of expert or critic. Some PCSG members positioned me as an expert during the fieldwork, however I had perceived myself as acceptable incompetent. Details of the preliminary fieldwork are included in Section Two of this chapter, *Research design and processes used in this project*.

**Photographic novella**

Sociology remains essentially uninterested in visual culture or visual methods for two reasons (Harper, 1998). First, during the nineteenth century the notion of ‘seeing as believing as knowing’ facilitated by visual mediums that included photography was a widely held belief (Harper, 1998). However, now images can
be created or changed digitally using electronic technologies, with the consequence that “the connection between image and truth has been forever severed” (Harper, 1998, p. 719). Second, the traditional use of photography in anthropology placed the image making in the hands of the researcher. This was contentious in that the power of authoritative voice and pictures was dependent on the researcher, rather than the participant or cultural insider (Pink, 2001). Despite these issues, Flick (2002) claims that a revival of second-hand observations through photographs, both as topic and as method is occurring in qualitative research.

The use of photographic novella in this research is premised on a number of philosophical underpinnings. The participants were the image-makers in this study and they used photography to investigate their own cultures. As such, participant photographs are visual objects through which they reference aspects of their experience and knowledge (Pink, 2001). Philosophically, this is congruent with feminist standpoint epistemology in that participants were empowered through their choice to photograph what was important to them. The photographs were not intended to ‘capture truth’ but rather provide a snapshot and initiate further discussion about participants’ experiences of living with prostate cancer. Many of the research interviews integrated participants’ photographs, narratives and text that expanded upon the images. Ewald refers to this process as “inspired reflection” in which the photographs do not “speak for themselves” but are reliant on the participants’ ”reading” and explanation (1985, p.15). The power of the photograph also lies in its ability to unlock the subjectivity of those who see the image differently from the participant and researcher (Harper, 1998). Participants used the content of their photographs “to produce and represent their knowledge, self identities, experiences and emotions” (Pink, 2001, p. 68). As Pink states “the meanings of photographs are arbitrary and subjective; they depend on who is looking” (2001, p. 51).

By using photographic novella in this way, participant observation is partly controlled by the research participant. In effect, as the researcher you are shown only what the participant wants you to see. Flick (2002) describes the researcher as spectator and the participant as demonstrator in this interaction. It is
acknowledged, accepted and welcomed that the decision of the participant image-maker has profound effects on the kinds of sociological statements that result from their images (Steiger, 1995). Arguably, this method is less invasive than traditional fieldwork where the researcher observes, photographs and participates directly in their culture. Another advantage of photographic novella is that the participant has control over the process; in effect they are challenged to take charge as an expert (Schwalbe & Wolkomir, 2001). Participant photographs provided opportunity for the men in this research to describe and explain rather than answer direct questions that may “put control, autonomy, or rationality into doubt, if only implicitly” (Schwalbe & Wolkomir, 2001, p. 91). From a practicality viewpoint it was not possible to undertake extended fieldwork with some participants, therefore many of the photographs provided insights that may have otherwise not been observable. For example, family gatherings may not have been accessible and participant bodies may not have been as visible or so readily exposed by the men through traditional fieldwork and participant observation.

By using photographic novella I sought to integrate seeing into the ethnographic research process. As Harper predicts, there is the possibility of visual sensibility leading an “energised social science that is experimentally ethnographic and theoretically interdisciplinary” (1998, p. 730).

**In-depth, semi-structured interviews**

The interview is one of the most powerful qualitative methods which takes us into the mental world of the participant and allows us to see the content and pattern of daily experience (McCracken, 1988). In-depth semi-structured interviews offer access to participants’ ideas, thoughts and memories in their own words (Reinharz, 1992). They are an excellent way of discovering the subjective meanings and interpretations that participants give to their experiences (Denzin, 1989). The approach is advocated by feminist researchers in which control over others is avoided and a sense of connectedness is facilitated through free interaction between the researcher and participant (de Laine, 1997). Whilst I planned to ask questions about participants’ experiences of prostate cancer, in-depth semi-structured interviews allowed the conversation itself to determine how the information was obtained (de Laine, 1997). Reinharz labels this “interviewee-
guided investigation” as it encourages participants’ experiences and audibility of multiple voices in a person’s speech to be central to the interview (1992, p. 21).

Oakley (1981) is opposed to the specialised form of conversation in which one person asks the questions and the other gives the answers. She argues that such interactions result in the participant being a passive member of unequal status. In this research, participants were provided with transcripts from their interviews and asked for personal perusal. They were invited to comment and give corrective feedback, and answer additional questions. Acker, Barry and Esseveld (1983) advocate this technique, often referred to as ‘member checking’, because it provides participants with equality in the co-production of the final transcript.

Series approaches to in-depth interviewing are often premised on the assumption that it facilitates the promotion of strong interviewer-interviewee bonds (de Laine, 1997). In this research, a series of two in-depth semi-structured interviews with each participant was planned. However, after the first fourteen participants, the series approach was modified and subsequent participants were interviewed once. The transcripts from the series approach provided little new information and tended to replicate the discussions from the first interviews. Contact and ‘bonding’ with participants was not confined to the formal interviews. Information sharing occurred prior to interviews through phone conversations, fieldwork, participant camera ‘drop offs’ and ‘pick ups’, and after the interviews through written notes that accompanied transcript returns, emails and follow up phone calls and letters. I have noted through the current research that bonds and trust can exist outside multiple formal in-depth interviews.

**Participant observation**

In this research, I used participant observation in the preliminary fieldwork and during participant interviews, the specificities of which I describe in Section Two, *Research design and processes used in this project*. From a theoretical perspective, the historical or traditional approach to ethnographic research includes the study of specific communities through long-term participant observation. Wolcott (1999) describes three distinct aspects of participant observation as ‘experiencing’, ‘enquiry’ and ‘examining’. He suggests the term ‘experiencing’ for ethnographers’ first hand experience as passive observers of
“what is going on” (Wolcott 1999:46). ‘Enquiry’, by contrast, often occurs during participant interviews when the ethnographer takes an active role in asking, “what is going on?” (Wolcott, 1999, p. 6). ‘Examining’ refers to an activity in which the researchers turn their attention to what has been produced by participants. This includes personal possessions such as documents, letters and photographs that might be shared with the ethnographer but are not necessarily available to anyone else (Wolcott, 1999).

Through the processes Wolcott (1999) describes, the ethnographer enters the everyday world of the participant in order to grasp socially constructed meanings (de Laine, 1997). Patton (1990) describes five dimensions of participant observations:

- **The role of observer**
  This includes the participant-observer having two distinct but interrelated roles, that of participation and observation. Patton describes a continuum ranging from the researcher undertaking “full participant observation” to “onlooker-as-outsider” with an intermediate position defined as “partial observation” (1990, p. 217).

- **Portrayal of the role**
  Patton (1990) states the portrayal of the ethnographer’s role varies on a continuum of overt / covert dimensions. Woods (1992) is critical of covert participant observation in which people are unaware of the research or their involvement in it. However Woods (1992) notes that through interaction, implicit understandings of the researcher about how and why and for whom research is being done are built up over a period of time.

- **Duration of observations**
  Traditionally, long-term engagement and observations were a feature of ethnographic research. However, Patton (1990) is less prescriptive and suggests the duration of observations can range from single observation, limited duration (e.g. one hour), to long-term, multiple observations (e.g., months, years).
Participant observations can entail a broad focus and holistic view where all elements are sought, which is particularly useful in preliminary fieldwork and unfamiliar environments (Patton 1990). Participant observations during participant interviews can also be focused, for example, on body movements, facial expressions and affect.

**Participant observation and context**

Patton (1990) suggests that the context of participant observations is also important. Hammersley and Atkinson (1995) note the structure of the ethnographic interview forces participants to be aware of the ethnographer as audience. Observations of participants are recorded in field notes and the flow of conversation is commented upon (de Laine, 1997).

**Situating myself as an ethnographer**

*Good ethnographies show the hand of the ethnographer... therefore a key part of the ethnographic ethic is how we account for ourselves. (Altheide & Johnson, 1994, p. 493)*

One of the main issues in the ethnographic literature has been the claim for the ‘real’ which I discussed earlier in this chapter under the subheading, Contemporary ethnography. The notion of reality is an ontological question, in which the “form and nature of reality and therefore what can be known about it” is asked (Guba & Lincoln, 1994, p. 108). Ontologically I subscribe to relativism, in that I assume “multiple, apprehendable sometimes conflicting social realities” (Guba & Lincoln, 1994, p. 111). As an anti-realist ethnographer I recognise both the impossibility of ‘telling it like it is’ (since there is more than one ‘telling’ and more than one ‘is’) and the desirability of going beyond people’s words (Brewer, 2000). For me, the question is not which type of ethnography is closest to truth but rather the belief that there is room for truths with different insights and uses, where truth is always understood as partial and incomplete (Clifford, 1986).

According to Denzin, the ethnographer must also address the epistemological question that asks “How do we know the world?” and “What is the relationship between the inquirer and the known?” (1994, p. 503). There is no overall
consensus among ethnographers about epistemology, or theory of knowledge, that underpins an ethnographic account. Instead, different kinds of ethnographies rest on different ideas of what constitutes legitimate knowledge (Atkinson & Hammersley, 1994). In this research, the participants and I linked to produce information and knowledge through interactive, collaborative research processes.

The concept of interactivity and connectedness between researcher and researched is partially explained through the application of emic and etic. In ethnographic studies, the orientation of the researcher is termed etic or emic (Byrne, 2001). The emic view refers to the participants’ view of that world and investigates how participants think. The ethnographer is sensitive to the meanings that behaviour, actions and contexts have in the eyes of the people involved. The insider’s emic perspective on those events, actions and contexts is elicited from participants (Spindler & Spindler, 1992). An etic view shifts the focus of the research to the ethnographer’s or outsider’s view and analysis of the experiences of a cultural group.

This research oscillates between emic and etic strategies and integrates insider and outsider views in an effort to ‘translate’ between cultures. Emic and etic views are interconnected. Emic views are discovered by the researcher, as reactions of research participants to specific events. The participants discover these reactions, for example, by being diagnosed with prostate cancer and suddenly finding themselves in a series of events which they do not comprehend at first (Pike, 2002). Etic views are created by the researcher, conceptual tools ready to be applied to data, so that one can observe them as an outsider and reach toward an appreciation of the emic structuring of that data (Pike, 2002). In the example of participants’ recount and / or reflection on their diagnosis of prostate cancer, the etic view facilitates analysis, explanation and understanding of the diverse participant reactions.

Furthermore, every culture has self-conscious elements, partially conscious elements, and unconscious elements that seem ‘natural’. An emic/etic perspective is likely to capture such diverse elements of culture. Tacit knowledge, defined as deeply-embedded cultural beliefs that are rarely or never discussed explicitly by members of the culture, can be discovered via an etic view. For example, some
participants’ embedded cultural beliefs included subscription to public stoicism, which I observed during some PCSG meetings. However, privately (especially during participant interviews), dialogue, conversation, self-disclosure and emotion rather than stoicism were evident. This may have been due to preceding negotiations and agreement to talk about their prostate cancer. However, for some participants stoicism appeared to be self-regulated and contextual, given the disparity between public and private gendered performance. The etic view in this instance revealed that many participants were willing to talk about their intimate and emotional illness experiences.

What becomes difficult, as an ethnographer, is to identify ‘When are you an outsider looking in?’ and ‘When are you an insider?’ At one level I am an insider, in that I am a heterosexual Anglo-Australian male studying heterosexual Anglo-Australian men. However, I am an outsider in that I do not have prostate cancer and I am younger than the research participants. Perhaps the emic and etic also oscillates within me as the researcher, dependent on the context. For example, I could relate to some of the historical accounts that participants gave of growing up in Australia. However, I was unable to relate in the same way to their experiences of prostate cancer.

The emic/etic integration is also congruent with the reflexive approach that has been adapted for this study. The term reflexivity refers to self-consciousness on the part of the researcher to reflect back on oneself as a research tool or instrument (Gifford, 1996; Goodrick, 2001). During the 1960s and 1970s, a reflexive turn in ethnographic research occurred (Altheide & Johnson, 1994). The researcher was acknowledged as part and parcel of the setting, context and culture that they were trying to understand and represent (Altheide & Johnson, 1994).

Self-reflexive ethnography incorporates the psychoanalytic aspects of fieldwork, or the extent to which ethnographic writing is informed by and results from the ethnographer’s unconscious desires, thoughts, emotions and experiences (Hunt, 1989). Boyle (1994) argues that the effects of the researcher, and the research strategy on findings, must be acknowledged in the ethnographic account (Boyle, 1994). In such writings, ethnographers are no longer viewed as standing "above and outside what they study" (Ellis & Bochner, 1996, p. 19). There is integration
of data with the researcher’s understandings of how that data was mediated by their role within the setting (Goodrick, 2001).

In subscribing to reflexivity, I acknowledge that ethnography as an interpretive endeavor combines the perspectives of both the researcher and the researched. It follows then, that as the researcher, I need to acknowledge and situate ‘self’ (Davies, 1999; Goodrick, 2001; Hammersley, 1990). To this end, I recognise, reflect upon, assess and make available to the reader, not just ‘what I know’ but ‘how I know it’ (Reinharz, 1992). I have interspersed field notes and reflective thoughts throughout this thesis that provides readers with such information. I acknowledge that I have multiple commitments that affect how the research is done and reported. My background and identity affects what questions I ask, what I learned in the field, and my interactions with participants, as well as my own interpretive lens. There is no one standpoint from which to judge all cultures and ways of being in the world. I am conditioned to see various perspectives; hence the things learned from this research are partial truths (Clifford, 1986).

I have interwoven a reflexive ‘self’ with participants and findings throughout this thesis. Specificities such as access to a setting, personal relations with the members in the setting, how field research data was conceived and recorded, and a number of other pragmatic issues are outlined in Section Two, Research design and processes used in this project. All these processes have important implications for what I report as the findings of the research (Altheide & Johnson, 1994). Davies (1999) notes the inevitability of reflexivity in social research, and argues that reflexivity-informed research produces better, not worse research. However, I have been cautious not to adopt a radical reflexivity that places my experiences, rather than those of the participants purportedly under investigation, at centre stage (Davies, 1999).

This research draws on a number of conceptual frameworks that serve as a roadmap to guide the research process. The practicalities and need to navigate rather than legitimate, inform the adoption of frameworks for this research. Miles and Huberman (1993) remind us that research is primarily about the application of ‘good’ warranted strategies, not about abstract epistemological allegiances to a particular framework. Perhaps Lather articulates it best by explaining when theory
is embedded in everyday life, it “then becomes an expression and elaboration of politically progressive popular feelings rather than an abstract framework imposed by intellectuals on the complexity of lived experience” (1986, p. 67). Lather goes on to suggest:

...reciprocal relationships between data and theory in which data must be allowed to generate propositions in a dialectical manner that permits use of priori theoretical frameworks, but which keeps a particular framework from becoming the container into which data must be poured. (1986, p. 67)

In Table 1, Postpostivist paradigms of inquiry, Lather (1994, p. 105) depicts various paradigms according to purpose. For example, the column ‘Understanding’ is the purpose of interpretive, constructivist and microethnographic research and ‘Deconstruction’ is the aim of poststructural and postmodern paradigms. Lather offers this table to “help distinguish how each paradigm offers a different but not exclusive approach to generating and legitimizing knowledge” (1994, p. 105). As McCotter (2001) has previously discussed, I am also comfortable with the notion of purpose driven theory and acknowledge that different theories guide my research.

Table 1 Postpostivist paradigms of inquiry (Lather, 1994, p. 105)

<table>
<thead>
<tr>
<th>Prediction</th>
<th>Understanding</th>
<th>Emancipation</th>
<th>Deconstruction</th>
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</thead>
<tbody>
<tr>
<td>positivist</td>
<td>interpretive</td>
<td>critical</td>
<td>poststructural</td>
</tr>
<tr>
<td></td>
<td>naturalistic</td>
<td>neo-Marxist</td>
<td>postmodern</td>
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<tr>
<td></td>
<td>constructivist</td>
<td>feminist</td>
<td>postparadigmatic</td>
</tr>
<tr>
<td></td>
<td>phenomenological</td>
<td>race-specific</td>
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<td></td>
<td>hermeneutic</td>
<td>praxis-oriented</td>
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<tr>
<td></td>
<td>symbolic interactionist</td>
<td>Freirean</td>
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<td></td>
<td>microethnographic</td>
<td>participatory</td>
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First, this research has a commitment to deconstruction through a postmodernist framework. Middleton suggests the distinguishing characteristic of postmodernism is:

...disbelief, scepticism, or suspension of belief in universal truth or in the possibility of a totalizing master narrative, and, instead, a focus on the various master narratives, disciplines, or theories as regimes of truth as
Postmodern ethnography has insisted on full acknowledgement of the limitations of the ethnographic process and product, and the intrusive and unequal nature of the ethnographer’s participation in the culture, as well as the distortions and limitations of the textual product (Stacey, 1988). The admission of partial accounts with reflexivity and self critique are integral to the postmodern approach to ethnography (Clifford, 1986).

The deconstruction strategy involves analysis of the social and cultural texts that purport to speak of the experiences of interacting individuals (Dickens & Fontana, 1994). A key part to deconstruction is that, as well as breaking down existing structures, it also reconstructs and creates new structures (McCotter, 2001). Postmodernism and deconstruction provide me with the freedom to search for and present multiple meanings from my data and search for new structures. It also gives me permission to be a writer, participant, interpreter and theorist in this thesis research.

Relativist postmodern ethnography has attracted criticism for abandoning any attempt to represent an independent reality, which leads to a form of relativism where all accounts are equal (Hammersley, 1990). Ellis and Bochner (1996) suggest that the idea of alternative forms of expression within postmodern ethnography does not mean that ethnographers are no longer accountable for what they write. They argue “deliberate, systematic, and careful observation of social life is still crucial; the partial and contestable nature of postmodern ethnography does not give the ethnographer license to lie” (Ellis and Bochner, 1996, pp. 21–22).

Postmodernism provides me with the reminder to reflect on what experiences I bring to this research as an ethnographer and the claims I make in terms of authority and truth. I am, however, somewhere in between the traditional and the postmodern ethnographic approaches. The experiences that inform this thesis have been mediated through various textual and visual devices. However, regardless of my reporting, the relationships and events described herewith actually occurred. I believe this to be the limits of postmodernity. Emotion and relationships are what
connect us. They are ‘real’ in the sense that we can experience emotions from the past that seem real. However, if we are experiencing emotions in real time, they are a truth. I acknowledge that feelings are a reality and important in the analysis of the data. Moreover, as previously acknowledged by Ridge, Hee and Aroni (1999), emotions of both the ethnographer and participants can strengthen qualitative research approaches. This thesis is more than words and pictures; I have written about people and relationships in which and within I was personally involved.

Second, this research also seeks to ‘understand’ participants’ experiences of prostate cancer through an interpretive microethnography. The interpretive paradigm assumes that the social world is produced by human beings (de Laine, 1997). “Reality is considered an intersubjective world of cultural objects, meanings and social institutions derived as a consequence of social interaction” (de Laine, 1997, p. 5). The ‘interpretive’ refers to the researcher moving beyond observing things to interpreting meaning.

Third, this research is also emancipatory, in that it is concerned with social inequities and seeks to affect social change (McCotter, 2001). Some participant experiences of prostate cancer revealed issues of power. Health care services and professionals were perceived by some participants to operate within and sustain an oppressive ‘medical’ system. Apple (1996) labels oppressive systems as hegemony, in which dominant groups organise an assemblage of meanings and practices that can be oppressive to subordinate groups. Some participants actively contested the hegemony of traditional Western medicine and negotiated, struggled and created meanings of their own (McLaren, 1994). Through participants’ disclosures I have been able to act as a conduit and make public their experiences—good, bad and indifferent—of prostate cancer health services.

In conclusion, this research is not a traditional ethnography and by historical definitions I am not a traditional ethnographer. I seek to deconstruct, emancipate, and understand participants’ cultures and experiences of prostate cancer. I also seek to make myself visible, as ‘being there’ in all the research processes. My beliefs about what counts as knowledge and how I can best attain that knowledge influenced my choice of methods and the way I report the findings of this
research. This study is committed to describing in detail the systems of meaning and emotions that make up the culture and that can account for particular actions. The pre-existing understandings, experiences and theoretical traditions that I use are integral to what I am able to analyse and describe.

**Section Two: Research design and processes used in this project**

In Section Two, *Research design and processes used in this project*, a two part discussion explores the specificities of this study. Part A, *Research Design*, reports the present research design—including sampling, participant recruitment, ethical considerations—and introduces the research participants through vignettes. In Part B, *Description of the research processes*, methods, analysis, limitations and strengths, and research closure are discussed. This provides context to the collection and subsequent interpretation of data presented in this thesis. The theoretical assumptions detailed in Section One—Methodology—are clearly linked to the specific methods described in the following text.

**Part A: Research Design**

**Gaining access – negotiating with the gatekeepers**

Access to conduct preliminary fieldwork—attendance at the monthly meetings of two Melbourne-based prostate cancer support groups (PCSGs)—was negotiated with the groups’ secretaries. My initial contact with the PCSGs’ secretaries was by telephone. I introduced myself as a registered nurse and researcher, and explained that I was seeking their permission to attend group meetings so that I could gain an understanding of men’s experiences of living with prostate cancer. I also explained that, after attending monthly meetings for approximately six months, I would like to invite group members to participate in my research. By attending the meetings I was able to observe the men’s interactions and hear about their prostate cancer experiences. There was usually a scheduled break at the PCSG meetings when I was able to have informal discussions and ask questions or comment on men’s earlier talk or action (Schwalbe & Wolkomir, 2001). This fieldwork was integral to getting a “broad focus or holistic view” and “feel” for the culture, as well as refining and developing the specificities of my research design (Patton, 1990, p. 217).
Permission to attend the PCSGs’ meetings and recruit research participants was unproblematic; however negotiation, explanation and self-disclosure were consistent requirements when I entered the ‘field’. The PCSGs’ secretaries were ‘gatekeepers’ and consequently needed to ‘situate me’. Minichiello (1990) defines gatekeepers as individuals that have the power to grant or deny access to people for the purposes of research. One of the PCSG secretaries in particular, needed to define who I was. He asked questions including:

Why are you interested in researching prostate cancer, you work in emergency at Western hospital don’t you?

The inference was that prostate cancer was not relevant to my clinical practice or expertise as a clinician, what therefore prompted me to research a relatively unfamiliar topic? He also asked me privately:

Do you have a girlfriend?

I felt this question was concerned with verifying my sexual orientation. The need to place me as heterosexual may have been a necessary criterion to granting me permission to talk with the group members. During the meetings, he also made reference to me living in a “trendy” suburb and being “so young”. I believed his need to ‘test’ and ‘know’ me was based on a desire to protect men attending the PCSG meetings from any unethical research investigation. Schwalbe and Wolkomir (2001) suggest that such signifying of masculinity occurs when men research men. Specifically, they argue that the prevailing gender order requires that men must “signify possession of an essentially gendered self that makes our placement in a particular category right and proper” (Schwalbe & Wolkomir, 2001, p. 90). I was open and honest, answered his questions and self-disclosed voluntarily, although I sensed that his suspicions or doubts were never totally alleviated.

Whilst I accepted that his initial questioning was part of entering the field, I did experience some disappointment in having to continually justify my interest in researching men’s experiences of living with prostate cancer. During the PCSG meetings, the secretary often expressed dissatisfaction that prostate cancer did not receive research funding equal to that of breast cancer. Yet simultaneously, his interrogation and critique of my self-funded research seemed to contradict his
argument. His reactions may have also been related to the qualitative nature of my research and his belief that relevant prostate cancer research provided quantitative proof capable of informing cause and/or cure. One realisation was that while ‘gatekeepers’ might open the gate, once inside, the endorsement of the research and encouragement of my presence was not necessarily guaranteed. I also learned that it was not possible to conduct such fieldwork in a purely observational capacity. The dynamics of the PCSG meetings demanded interaction.

Neither of the PCSGs’ secretaries had prostate cancer; they facilitated the monthly group meetings in a voluntary capacity and were unpaid. Both secretaries sought clarification from the outset of my fieldwork that neither their facilitation style nor the PCSG’s function were under investigation. I assured them that the PCSG’s dynamics and politics were not the focus of my research. Ultimately, the PCSGs’ secretaries assisted in participant recruitment by providing formal opportunities to invite group members to participate in my research. One secretary introduced and minuted this opportunity at the June 2001 meeting as ‘John Oliffe’s Mystery Talk’. Initially, I wondered if I had not provided enough detail about my intended research during the fieldwork. However, retrospectively, I think that the comment reflected the secretary’s uncertainty about why I would be interested in researching men’s experiences of prostate cancer. The secretaries also coordinated mail-outs to members who were not in attendance during my formal invitations to participate. Unfortunately, the mail-outs did not yield any respondents.

Gaining access involved negotiation with gatekeepers at different levels. One unexpected gatekeeper emerged during my ‘Mystery Talk’ when I was interrupted by an employee of the Anti-Cancer Council of Victoria (a guest speaker for that PCSG meeting) and asked if I had permission from the Anti-Cancer Council of Victoria to gain access to “their” men’s PCSG. Interestingly, it was not the perception of the secretary, nor was it documented, that the Anti-Cancer Council of Victoria had formal affiliation or ownership of the PCSG. I confirmed that I had Deakin University Ethics Committee approval and that the PCSG secretary had seen and approved the written notification. Despite this somewhat public act of gatekeeping, many men in the group volunteered to participate in the research.
Sample selection criteria

Speaker: What would be the difference between a gay man and a heterosexual man’s experience of prostate cancer? Why are you researching only heterosexual men?

John Oliffe: It’s not intended as heterosexism.... I appreciate your comment and I will re-think my position.

Question time at the conclusion of the presentation of my proposed PhD research. Manning the Next Millennium conference, Gold Coast, Queensland, 12/2000

Reflection: I had the answer, but not the words. I backed off on this today. I drowned out there. I was not strong enough in my defence. Sure I was able to say I had narrowed my research, that I was interested in participants’ constructions and practices of heterosexuality. But that did not answer the question. I need to be succinct and articulate in such matters.

Next time: Heterosexual men tend not to acknowledge the prostate gland as a site of sexual pleasure. Heterosexual men’s dominant construction of sex is erection, penetration of the vagina and climax. In which they penetrate rather than are penetrated. I am interested in deconstructing such notions of male heterosex, especially in the context of prostate cancer and its common side effect of impotence.

Coolangatta, Queensland, post conference 12/2000

John Oliffe: The participants in my study are heterosexual Anglo-Australian men.

Speaker: How do you know they [the participants] are heterosexual? Lots of guys have female partners but have sex with men.

John Oliffe: Would you doubt a gay man if he labelled himself gay? Are you suggesting only straight men lie?

Research methods workshop 5/2001, Deakin University

Reflection: Sometimes it is not about the answer; sometimes it is all about the question.

Post workshop 5/2001, Transit by car from Deakin University at Burwood to home at Elwood

The above field notes describe some of the questions that were raised regarding why I would research heterosexual men. Furthermore, how would I know participants were heterosexual? This research is not concerned with fixed sexual identity per se. Rather, sexuality is multi-defined and includes behaviours, identities, culture and fantasy (Weeks, 2003). Participant behaviours with female partners, in particular their intimate relationships and sexuality and the connectedness to prostate cancer are valued in this research. The purposeful
criterion sample for this research facilitated information-rich cases for in-depth study (Patton, 1990). As stated earlier, the participant criteria for this study were:

- Anglo-Australian men (The Anglo-Australian cohort was defined as originating from a Welsh, English, Scottish or Irish background, at least second generation Australian-born).
- born in Australia between 1912 and 1956, currently living in Australia.
- with a current female partner at the time of diagnosis and treatment.
  - I did not interrogate participants’ self-label of heterosexual. Participants identifying as heterosexual were assumed to be undertaking heterosexual sexual relations and behaviours.
- without formal qualifications in health.

The sample size of thirty-five participants facilitated the collection of valuable information rich data for analysis. The criterion sample assisted in the focus of the study and potentially reduced variation within the cohort (Patton, 1990). Although the participants were from similar backgrounds and demographics, and some similar patterns emerged, the findings were not generalisable to the population and men afflicted with prostate cancer. Causal-effect and generalisation were not the outcome of interest in this study. It was the subjectivity and construction of multiple ‘realities’ from participants’ experience of prostate cancer that was valued (de Laine, 1997). The choice to interview a cohort of heterosexual men was in no way intended as heterosexism. As I noted in my journal entries, I “narrowed my research” and was committed to “deconstructing…male heterosex”. This study facilitated the deconstruction of the participants’ dominant masculinist gendered constructs framing heterosexual behaviour and relationships.

**Recruitment of research participants**
I had several different starting points in my interview chains. Eight participants were recruited from two Melbourne-based PCSGs. I contacted the secretaries from Adelaide and Brisbane-based PCSGs and negotiated the distribution of demographic data questionnaires and plain language statements to group members. I recruited two participants from each of the groups through this recruitment strategy. Therefore, a total of twelve participants were recruited
through PCSGs. On commencement of the study, participants were primarily recruited from PCSGs, but many of these men had previously participated in a variety of prostate cancer research projects. I was concerned that this may have contributed to participant saturation, whereby members of the PCSGs would become disinterested or tired of contributing to research about prostate cancer. Another concern was that a core group of men, well versed and rehearsed in discussing ‘their’ prostate cancer, may have become the dominant hegemonic voice. Therefore I was reticent to recruit all the participants from PCSGs as I believed this would narrow the focus of the research prematurely.

For these reasons I was interested in interviewing a broad range of heterosexual men who had not previously had the opportunity, or did not actively seek support group opportunities, to speak about their prostate cancer. Consequently, I recruited participants through advertisements in city and regional newspapers, national prostate cancer newsletters and the Lions prostate cancer website. The advertisements briefly described my research and invited men with prostate cancer who were interested in participating to contact me via telephone or email. When they contacted me, I explained the study and posted out demographic data questionnaires to potential participants. Twenty-three participants were recruited via these means.

**Introduction to the research participants**

In this section, I introduce each of the research participants through vignettes presenting a sociological and biomedical perspective. This allows the reader to refer to, and put in context, the excerpts of participant narratives that I intersperse with my text in the rest of the thesis. The introductory paragraphs I have constructed reflect what was important to participants during our interviews. For example, if a participant did not discuss children or previous relationships, then such detail does not appear in their introductory profile. Similarly, the tables presenting biomedical details are informed by participants’ perceptions and understandings. For instance, if a participant did not know his PSA score then it does not appear in the table. The intention is to reflect the ‘things’ that were important to the participants and introduce them as who they are—or how they see themselves.
The information also provides insight into participants as ‘patients’ through biomedical data and as ‘people’ through background information. The patient/person dualism in the vignettes helps illustrate the context that I introduced in the prologue to this thesis. The participants chose their own pseudonyms. Some participants chose names that would individualise and help them stand out, such as Arsenal, Top Cat and Argonaut. (Although Top Cat was born in New Zealand, he had lived in Australia most of his life and identified as Anglo-Australian. He has therefore been included in the criterion sample for this study.)

Wayne

Wayne left school when he was 12 years old and recalled having a “truant inspector chasing me [him] around the place”. He left regional Victoria when he was 13 and worked as an apprentice jockey until he “got a little too heavy to ride”. He consequently worked many different labouring jobs for thirty years until he was injured at work in 1991 at 50 years of age. He “still enjoys a pint and a punt and a round of golf” and had a “lot of friends…ones you can go up to and have a yarn with”. He lived in a working class area and said that “now it is obvious that there is a really big gap between the working class…everyone is trying to become millionaires in the one year and ripping off their brothers and sisters”.

<table>
<thead>
<tr>
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<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1941</td>
<td>Erectile dysfunction. Prompted by partner to see a doctor</td>
<td>1996</td>
<td>PSA – raised</td>
<td>Radiation therapy</td>
<td>5 years</td>
<td>Impotent, considering Viagra.</td>
</tr>
<tr>
<td></td>
<td>Frequency of urine</td>
<td></td>
<td>Biopsy – two of the eight specimens positive</td>
<td></td>
<td>5.5 years</td>
<td>Incontinent of faeces and urine initially. Resolved 12 months post treatment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>DRE enlarged</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Eddie

Eddie lived south of Melbourne and worked as a plumber his entire life because “back then I [he] wasn’t scholastic….and didn’t want to go to university or anything like that”. He lived with his wife of 42 years, and they made “all [their] decisions together”. One of their four children and her partner lived with them. Eddie, who never drank alcohol or smoked, found it funny that “here’s me with the good message and they [his family] are all drinkers and smokers”.

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<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1938</td>
<td>Asymptomatic increasing PSA over 2 years</td>
<td>2000</td>
<td>PSA–11.4 Biopsy--one positive specimen</td>
<td>Radiation therapy ADT</td>
<td>1.5 years</td>
<td>Impotent More emotional Reduced penis and testes size</td>
</tr>
</tbody>
</table>

John

John was a farmer from rural Victoria. The farm had been in his family for three generations and John “took over” the property when his father was injured more than 50 years ago. He spoke of the highs of the 1950s “wool boom” and the lows of the 1960s when “you could barely give away the wool or the sheep”. He and his wife “battled like hell and raised five little kids until finally putting up a dairy in the 1970s”. He described his wife as a “tower of strength… full of common sense…and supportive”. He was accepting of having to sell his farm “as none of his five daughters will want to take it over”.

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<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1940</td>
<td>Decreasing urine flow from age 50 years</td>
<td>1999</td>
<td>PSA–26 Biopsy unknown</td>
<td>Radiation therapy ADT</td>
<td>1.5 years</td>
<td>Impotent Reduced penis and testes size</td>
</tr>
</tbody>
</table>
Yanni

Yanni was “smarter than the rest” and that attribute was the fundamental reason he went to university to study and later teach science and technology. He loved baseball and travel, and combined these passions with a trip to the USA in the early 1980s. He shared baseball memorabilia from that trip and his “coaching days” during our interview. He “drinks too much” since “I [he] got retired” in 1994 and drinking alcohol was “no longer social” when “you have too much” or “drink by yourself”. He divorced his wife of 20 years in 1986 and “misses” his son who “does not visit very often”. He met his current partner at Alcoholics Anonymous and she was “in rehabilitation for a drug problem” which he “hopes she gets through”.

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<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1946</td>
<td>Left testicular pain</td>
<td>2000</td>
<td>PSA – unknown Biopsy Gleason score 7</td>
<td>Prostatectomy</td>
<td>1 year</td>
<td>Impotent Incontinent of urine for 2 months post surgery, occasional incontinence</td>
</tr>
</tbody>
</table>

Ron

Ron’s mother died when he was seven years old and “there was only dad and I was a bit of an inconvenience to him” so “he was quite happy to see me fly the nest” at 17 to undertake a building apprenticeship in Sydney. Ron was fairly resilient, having been “down…bankrupt…broke …in liquidation…through a divorce but you recover from them, you have to”. He retired five years ago and he and his partner moved to regional Victoria to be closer to his partner’s family. They were hoping to sell up and return to Sydney because the “weather down here [Victoria] in winter is too depressing”.
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</tr>
</thead>
<tbody>
<tr>
<td>1931</td>
<td>Asymptomatic, requested PSA based on wife’s advice.</td>
<td>2000</td>
<td>PSA– 13.5 Biopsy– revealed “aggressive” cancer</td>
<td>Radiation therapy ADT</td>
<td>1.4 years</td>
<td>Impotent loose bowel actions occasional incontinence of faeces, persistent bleeding from bowel</td>
</tr>
</tbody>
</table>

**Unicorn**

Unicorn “worked in the public service for ten years” before working with his father in their Melbourne-based family transport business. He later managed the business that had been in the family for three generations. He was divorced from his partner of twenty-five years and had two teenage children. Their marriage split was “amicable” and he described his new partner as “sensational”. He had “never really had much bad luck…or any money problems” and had “always been pretty positive”. He had “lots of mates…and mucks up with the same guys exactly as I [he] did when we were at university”.

<table>
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<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1953</td>
<td>Asymptomatic, requested PSA because father and friend had prostate cancer</td>
<td>2000</td>
<td>PSA– 3.? Biopsy– very high aggressive</td>
<td>Prostatectomy</td>
<td>1 year</td>
<td>Treatment of impotence with Viagra. Minor occasional incontinence of urine</td>
</tr>
</tbody>
</table>

**James**

James “came off a farm” when he was 18 years old and “did more than 25 years in the navy” and “the way I [he] am is the way I [he] live life…you have to laugh”. His wife of 38 years was “his best mate” and he commented that “we don’t have too many dull moments”. He “has done quite a bit of drinking” and used to “binge drink and then go to sea for six weeks and not have a drink”. He travelled
extensively with the navy and spent 12 years in Sydney before returning to country Victoria to manage a hardware company. He “hates being idle” and “can’t afford to be out of work” because he “has a mortgage to pay”. He has two sons, one of whom lives in Sydney and the other in Ireland.

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<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1943</td>
<td>Decreased urine stream for two or three years</td>
<td>1999</td>
<td>PSA– 14 Biopsy– Gleason score 9 with positive margins</td>
<td>Radiation therapy ADT</td>
<td>1.75 years</td>
<td>Potent (Spontaneous erection, average one a week)</td>
</tr>
</tbody>
</table>

**Nestor**

Nestor was an “outclasser…not a social person…who doesn’t go to the pub for drinks…and socialises only with people at family gatherings or church functions”. His wife of 40 years was “quite a stunner when she was young” and had been a “dutiful coital wife”. He worked many jobs but ultimately saw himself as a “jack of all trades and a master of none” and eventually “ended up on the invalid pension”. He stated that he had a “short fuse temper” and is inclined to “go off the edge”.

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</tr>
</thead>
</table>
Harry

Harry “was born 250 yards from the southern end of Hyde Park in Sydney in a little rooming house”. He “never made it to high school”, and after “working up on the wheat” he joined the army in 1941 and was later discharged in 1945. At the time of the interview he lived on the Sunshine Coast with his wife of 42 years who he described as a “lovely person…fantastic lady” and stated “that I [he] wouldn’t change anything about her”. He grew his own wheat grass, spinach and bananas which gave him great satisfaction knowing “they are wholesome, knowing that they are not covered in chemicals”. He confided that “love is the best thing”.

Arthur

Arthur was “successful at school” and the first in his family to go to university. He began his university course “the year before Whitlam [Prime Minister] made it free” and his father was able to afford to pay for his first year, although “it was a lot of money to find”. Arthur lived in Melbourne his entire life, and taught in the public school education system and as an educational consultant. He lived in the inner east of Melbourne with his wife of 14 years and their two young boys.
<table>
<thead>
<tr>
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<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1954</td>
<td>Asymptomatic requested PSA because father and grandfather had Benign Prostatic Hyperplasia (BPH)</td>
<td>2001</td>
<td>PSA – 6.4 Biopsy – Gleason Score – 6</td>
<td>Prostatectomy</td>
<td>6 months 10 months</td>
<td>Impotent treatments – injections, vacuum erection device and Viagra Reduced penis size</td>
</tr>
<tr>
<td>1934</td>
<td>Asymptomatic GP suggested PSA test</td>
<td>1997</td>
<td>PSA – 6.8 Biopsy – unknown</td>
<td>Radiation therapy</td>
<td>4 years 4.5 years</td>
<td>Reduced potency</td>
</tr>
</tbody>
</table>

Mac grew up in North Queensland and worked in Australia and overseas as an engineer in the mining industry. The “major dimensions of my [his] life are family, church, work and the communities I [he] personally interact with”. He was a “people’s person as opposed to being highly competitive”. He had two sons and “found fatherhood really rewarding”. His relationship with his wife of 39 years was “the last of the stereotypical roles where the bloke earns the money and the wife cooks and keeps the kids clean and that sort of thing”. I interviewed Mac in Brisbane where he worked as a consultant for the manufacturing industry.

Arsenal had hoped to be a professional soccer player before he “got a very bad injury”. He completed undergraduate and honours studies at university and found “there was a joy in learning”. He worked in South Australia and New South Wales as a university administrator and described himself as a “workaholic”. During that “workaholic stage” he was “incredibly competitive” and needed to “come first every time, to beat others”. Since retiring in 1999 he had felt closer to
his wife and three grandchildren and felt that he and his wife were “communicating in a way we didn’t before”.

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</tr>
</thead>
<tbody>
<tr>
<td>1942</td>
<td>Asymptomatic Cousin diagnosed with prostate cancer encouraged Arsenal to be screened</td>
<td>2000</td>
<td>PSA–6.4</td>
<td>ADT Radiation therapy</td>
<td>1 year</td>
<td>Hot flushes and Mood swings, (aggression) during ADT Rectal bleeding and diarrhoea during radiation Erections without sensation, no libido</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>DRE–T1C</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Biopsy Gleason score–6</td>
<td></td>
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</tbody>
</table>

**Berti**

Berti began work at 13 years of age as an “improver to a pastry cook” after being told by his father he “had to leave school because of the Depression and to help finances in the house”. Tensions grew in the family home until a physical altercation occurred in which Berti hit his father and knocked him unconscious. Berti then “rolled up a swag and walked out” of the family home at 15 years of age and “headed for the city”. He worked many different jobs and had a “Masters degree in survival” which he earned the “hard way” from 1930 to 1933 during the Depression. He retired in 1975 after working as a training manager for 20 years. His wife of 59½ years passed away in 1999 and his new relationship was “better” than the one he had because “there is love in it and we touch all the time”.

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<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>1914</td>
<td>Asymptomatic. Medical history prior to Prostate cancer diagnosis— Bowel cancer, Diabetes, Myocardial infarction</td>
<td>1996</td>
<td>PSA–85.7 (1996) Biopsy—Gleason score unknown</td>
<td>ADT</td>
<td>5 years 5.2 years</td>
<td>Hot flushes, reduced muscle tone, mood swings, frequency of urine. Impotent Reduced testes size</td>
</tr>
</tbody>
</table>

Royboy

Royboy had a wonderful wife who he still thinks of “as when I [he] met her, sweet 16, going on 17”. He served in the army in World War II and was a “club man” who liked it when “the schooner’s free”. He lived in Sydney all his life and after the war worked as a “messenger boy” but ended up “clerical” working in maintenance at a large public hospital. He was “sports minded” with motor bikes in his younger years and lawn bowls as he had “gotten older”. Remembrance Day and the Anzac period was when the “Aussie mateship comes out” and “you can sit down and have a yarn with the bloke sitting alongside you”.

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</tr>
</thead>
<tbody>
<tr>
<td>1918</td>
<td>Asymptomatic. Medical history prior to prostate cancer diagnosis— Nephrectomy for kidney cancer, lung cancer, bone cancer (left femur and ribs) Angina pectoris</td>
<td>1998</td>
<td>PSA– 17 Biopsy—Gleason score unknown</td>
<td>ADT Radiation therapy on left hip</td>
<td>3 years</td>
<td>Nocturia Impotent Hot flushes Reduced penis and testes size</td>
</tr>
</tbody>
</table>
Verlow

Verlow lived in the Western suburbs of Melbourne all his life. His father died in a “hiking accident” when Verlow was 12 years old and after that his “mother was virtually responsible” for him. He joined the army at 18 years of age and served from 1942-1946 in an “ordinance unit, not a battle unit, as a labourer on the wharfs and later as a clerk”. He was “demobbed in 1946” because he “was married and had points and could get out earlier than a lot of the other guys”. He “followed in his father’s footsteps” and worked as an accountant from 1969 to 1984 and retired at 60 years of age “to look after his wife who wasn’t particularly well”. He was a “dedicated worker” who had lots of “mates in the army”.

<table>
<thead>
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<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1923</td>
<td>Asymptomatic Reduced urine stream</td>
<td>1994</td>
<td>PSA – 3.1 (2001) post ADT</td>
<td>Biopsy – 3 of the 6 biopsy specimens positive</td>
<td>ADT 7 years</td>
<td>Hot flushes, loss of strength and muscle mass, impotent</td>
</tr>
</tbody>
</table>

Greg

Greg grew up in regional Victoria where he used to “knock around with Italian mates… eat spaghetti at their place and they’d come to our [his] place and do the same”. He said mateship was not like it used to be “everything is rush, rush, rush today”. He “ended up doing a fitting and turning apprenticeship” but “gave it away when he developed dermatitis”. He “had to stick with an office job which I [he] have been doing ever since”. He had one daughter who is “married and sort of leading her own life and we don’t see much of them”. He and his wife “have a great life together” and share lots of walks and conversations. He followed the Australian Rules football and would have “liked to have been a physical education teacher”.

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Vincent

Vincent grew up in the west of Melbourne and was a “home body” who “doesn’t like moving too far away”. He worked the third generation family market garden with his two sons and “still goes to market every morning at 2.30am”. His wife was the “best woman in the world” a “doll, an absolute gem”. They had five children and three grandchildren and were a “very close family” and he encouraged their children to “bring their mates home”. Vincent had worked hard all his life and didn’t care how people got their living “as long as it was honest”. He loved playing golf and was interested in news and current affairs. He said that “women were really the best workers in horticulture”.

Don

Don grew up in country Victoria, he “never had close sorts of Aussie mates” and wasn’t into “pub drinking with the boys”. He was interested in visual arts and his parents were involved in theatre as both actors and directors. Don boarded in Melbourne, completed his secondary schooling and studied arts at University. When he graduated the “opportunities for people my [his] age was incredible”. He was a university lecturer in fine arts at 26 years of age. He experienced the

<table>
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<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1942</td>
<td>Asymptomatic Wife encouraged him to have a PSA test</td>
<td>1998</td>
<td>PSA – 9 Biopsy – 1 of the 6 specimens was positive</td>
<td>Prostatectomy Radiation therapy ADT</td>
<td>3 years</td>
<td>Impotent Occasional urgency with bowel motions Hot flushes</td>
</tr>
<tr>
<td>1943</td>
<td>Asymptomatic Acute kidney pain prompted check up and PSA</td>
<td>2000</td>
<td>PSA – 3790 Biopsy – Gleason Score 6</td>
<td>ADT</td>
<td>1.5 years</td>
<td>Impotent hot flushes fatigue</td>
</tr>
</tbody>
</table>

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“excitement of the 1970s” with “protest movements, hippies, free love and all that sort of stuff” in “cosmopolitan Carlton” and during his world wide travels. He married and had two children and they shared a house in the inner north of Melbourne. He did “most of the cooking for the family” and said “we sit around and have dinner together” and “have always been fairly close”.

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<thead>
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<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1942</td>
<td>Asymptomatic Slower urine stream Don requested a PSA because his father had prostate cancer</td>
<td>1998</td>
<td>PSA – 27 Biopsy – Gleason score unknown</td>
<td>Prostatectomy</td>
<td>3 years 3.4 years</td>
<td>Incontinent Impotent treating with injections</td>
</tr>
</tbody>
</table>

Charles grew up in Geelong and owned and managed an electric floor heating company for “quite some time” before going into real estate sales “for the money”. He had “been married a long time” and “there are a lot of things that don’t get said but they are understood” in his relationship with his wife. He was the “richest man in Geelong, probably the world” because he designed and built the family home, had six children and a project is still in front of him. He recalled the 1960s when “there wasn’t any power steering in motor cars so men drove” and “pubs were for blokes” with “six o’clock closing”. He was “retired rather quickly as a result of the stroke” when he 60 years old.

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</tr>
</thead>
<tbody>
<tr>
<td>1938</td>
<td>Asymptomatic Previous stroke</td>
<td>2000</td>
<td>unknown</td>
<td>Prostatectomy</td>
<td>11 months</td>
<td>Impotent nocturia (1-2 per night)</td>
</tr>
</tbody>
</table>
Argonaut

Argonaut was the son of a “clergyman” and “whilst seen as middle class the description poor as church mice would not have been an exaggeration”. He stated that “we did not have much money but plenty of books”. Argonaut was born in the NSW regional mining town of Broken Hill and lived in various regional and metropolitan locations before completing his tertiary education in Adelaide. He worked as a university lecturer in Organisational Behaviour before retiring in 1997. Once he set his mind to do something he would tackle it with 100% effort and “make sure he succeeded”. He believed successful people “wrote or discovered something” rather than made lots of money. He was married and had a son and daughter. The family resided in Adelaide’s West Croydon.

<table>
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</tr>
</thead>
<tbody>
<tr>
<td>1941</td>
<td>Slower urine stream, nocturia 1–2 per night Requested a PSA, had been having PSA screening for 2.5 years</td>
<td>1999</td>
<td>PSA—4.1 Biopsy—Gleason score 5</td>
<td>Prostatectomy</td>
<td>2 years</td>
<td>Impotent</td>
</tr>
</tbody>
</table>

Bob

Bob grew up on a farm and moved to Melbourne when he was 16 years old. He married his “childhood sweetheart” when he was 20 years old, they had three children and being “young parents they grew up with their kids”. Bob described himself as a “bit of a wild bloke” in the early days of their marriage, but he had a “pretty good lady” who stuck with him. He liked cutting the lawns and getting out in the garden and reckoned “every man has to have a shed” where “he can work things out in his head”. Bob was a “cleaner by trade” and drove cabs for 20 years “which was a great life because every day was different”.

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<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1942</td>
<td>Asymptomatic</td>
<td>2001</td>
<td>PSA – 8 Biopsy – 5 of the 6 specimens positive</td>
<td>Prostatectomy</td>
<td>5 months</td>
<td>Impotent, Incontinence resolved 2 weeks after surgery</td>
</tr>
<tr>
<td>1946</td>
<td>Asymptomatic GP suggested PSA</td>
<td>2001</td>
<td>PSA – 6.37 Biopsy – Gleason score 8 DRE – Enlarged</td>
<td>Prostatectomy</td>
<td>6 months 10 months</td>
<td>Impotent injection treatment caused pain, Regained urinary continence 3 months post operatively</td>
</tr>
</tbody>
</table>

**Patrick**

Patrick grew up in regional Victoria where he went to a Catholic school for all his primary and secondary education. His “experience of the world was pretty limited” and there seemed only a “small number of career paths to go down”. He eliminated the subjects he didn’t like which left him with a choice of “accountancy or law…and I [he] didn’t fancy accountancy”. He graduated from law school in 1971 and had worked as a lawyer ever since. He married and had three children and although he was “never conscious of class in Australia” he noted that “there are pockets where you despair and wonder if their children will have opportunities”.

**Wally**

Wally was “always good at figures” and although he always wanted to be a plumber when he was growing up in Melbourne, he “realised it just wasn’t me [him] because I [he] wasn’t at all handy”. When he left school after year eleven he
joined the bank and worked in country and metropolitan branches for 35 years. Despite being “sick of working in the bank” his “super [superannuation] is worth it”. He liked to be around his mates because “you feel you can unwind a little bit” and “in sport I [he] hate being beaten”. He was married and had four children. He includes two children his wife had from a previous marriage because “they have been with me [him] most of their lives so I [he] have always talked about them as my [his] children”.

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1949</td>
<td>Asymptomatic Wife encouraged check up with GP</td>
<td>2001</td>
<td>PSA– 8.5 Biopsy– Gleason score 6</td>
<td>Prostatectomy</td>
<td>5 months</td>
<td>Impotent Occasional incontinence</td>
</tr>
</tbody>
</table>

**Bill**

Bill was a scout in the “early days” and had been sailing since he was 14, “we would go off down the channel between the island and the mainland and be down there for a couple of weeks”. He lived in Tasmania all his life, was married and had a daughter. He explained “we have a campervan and a yacht…we are not filthy rich…I worked for a hell of a long time…people could say you are lucky but there is no such thing as luck in that sort of stuff you work for it”. Bill was a “cabinet maker by trade” until the last 14 years of his working life when he worked as a “studio attendant for the Tasmanian Symphony Orchestra” which was “a wonderful time… I [he] enjoy that sort of music”.

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1930</td>
<td>Asymptomatic GP suggested PSA</td>
<td>2001</td>
<td>PSA– 10 Biopsy– Gleason score unknown</td>
<td>Radiation therapy</td>
<td>6 months</td>
<td>Impotent Rectal bleeding during Radiation therapy, resolved</td>
</tr>
</tbody>
</table>
Trent

Trent worked on his family’s rural property in South Australia for two years after leaving high school. There were “three generations working the property” and Trent “realised my [his] grandfather was a tyrant” and that “I [he] was being used as a cheap source of labour”. Trent subsequently left the family property and worked as a banker at “various centres around South Australia” for 39 years before retiring in 1991. “It was a time when longevity in a job was a quality” and “the unsuccessful ones [men] seemed to go from job to job”. He was married, had three children and had retired in Adelaide.

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1933</td>
<td>Asymptomatic GP suggested PSA based on swollen prostate identified via X-ray for renal stone</td>
<td>1999</td>
<td>PSA– 26 Biopsy– Gleason score 5</td>
<td>ADT Radiation therapy</td>
<td>2 years</td>
<td>Impotent on ADT Dysuria Rectal bleeding during radiotherapy, resolved Fatigue</td>
</tr>
</tbody>
</table>

Kevin

Kevin attended a “staunch Catholic boarding school at Ballarat” which was financed by a “rich uncle”. He married “early” after his partner “fell pregnant”, they had three children but later divorced. He re-married and had been with his current partner for 28 years and stated that “it’s the only relationship I’ve got and it’s rat shit… I sleep at one end of the house and she sleeps at the other end of the house”. He “went through my [his] whole working life not knowing what I [he] wanted to do”. He worked as an operator for an “oil refinery multi-national company” for 23 years until he took a redundancy since which he had been “as happy as I’ve ever been in my life”.

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<table>
<thead>
<tr>
<th>Year of birth</th>
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<th>Year of prostate cancer diagnosis</th>
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<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1938</td>
<td>Asymptomatic GP suggested PSA test</td>
<td>1998</td>
<td>PSA–41 Biopsy–Gleason score 7</td>
<td>Radiation therapy ADT</td>
<td>2 years 2.2 years</td>
<td>Impotent Hot flushes Decreased muscle tone Reduced penis and testes size</td>
</tr>
<tr>
<td>1946</td>
<td>Asymptomatic requested prostate check from GP</td>
<td>2001</td>
<td>PSA–46 DRE–T3 Biopsy–Gleason score 7</td>
<td>Radiation therapy ADT</td>
<td>3 months 15 months</td>
<td>Fatigue Frequency of urine, Painful defaecation during the radiotherapy Reduced penis and testes size, partial impotence</td>
</tr>
</tbody>
</table>

*William*

William was born and grew up in Adelaide. He went to an “all boys” school, which made him “extremely nervous around females”. He did teaching because he “didn’t know what else to do”. He graduated from teachers’ college and taught in Elizabeth and regional South Australia. He married and had two boys and described his wife as “very caring, considerate, gentle and humorous”. After his treatment William planned to returned to Manila to teach a grade four class and commented that he had seen “terrible poverty over there” and noted the contrast in Australia where “so many people are trying to climb up the class ladder”.
Randwick

Randwick grew up in country Victoria before moving to Melbourne where he served an “eight year apprenticeship as a baker”. He later worked as a builder’s labourer at the Abbotsford brewery and then as a truck driver. He “worked hard…12 to 14 hours a day… because we always seemed to need money”. He and his wife had lived in the same house in Pascoe Vale for 45 years, where they had reared their three children. He had always enjoyed “his glass of beer and never drank spirits” and still had a couple of “great mates” from the “old days”.

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1927</td>
<td>Nocturia, dysuria, frequency GP suggested DRE and PSA</td>
<td>1995</td>
<td>PSA--unknown DRE--enlarged Biopsy--all six specimens positive</td>
<td>Prostatectomy ADT</td>
<td>6 years 6.2 years</td>
<td>Impotent, Incontinent, Gynecomastia Reduced muscle tone Hot flushes, Mood - more sentimental, Weight gain</td>
</tr>
</tbody>
</table>

Top Cat

Top Cat was born in New Zealand but “shot through to Australia” when he was 21 years old, and had “lived most of his life in Australia”. He would have “liked to be an architect or a journalist” but when he “didn’t pass his school certificate exam” his father “organised an apprenticeship” for him as a plasterer. Top Cat “had lots of girlfriends”, was “married twice” and “always enjoyed a drink” because “it was a reward system for a hard day’s work”. He worked many different jobs including “a sales representative”, which he was “bloody good at” and became “national marketing manager of the company” before buying his own business.
<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1942</td>
<td>Nocturia and frequency. GP suggested PSA</td>
<td>1998</td>
<td>PSA– normal, DRE– T3, Biopsy– Gleason score 7</td>
<td>Prostatectomy</td>
<td>3.5 years</td>
<td>Impotent, Incontinence resolved four weeks after surgery</td>
</tr>
</tbody>
</table>

Clark lived in the same street in the Melbourne suburb of Camberwell all his life, with the exception of three years when he “travelled around and worked in Europe”. He was 24 when he returned from “overseas” and he began working with his father and brother selling “hair cosmetics” in the family business. He had “always been a workaholic” and “had to work hard with my [his] head and my [his] hands to make money”. He met his wife on a “blind date” and they had three children. His “folks used to have a few barnies”, but he and his wife had “always been pretty matey” and had had “only two arguments in 28 years”.

<table>
<thead>
<tr>
<th>Year Of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1941</td>
<td>Asymptomatic Requested prostate check from GP because a friend of similar age had been diagnosed with prostate cancer</td>
<td>1997</td>
<td>PSA– 3, DRE– big bump, Biopsy–8 out of 10 specimens positive</td>
<td>Prostatectomy</td>
<td>4 years</td>
<td>Impotent post biopsy. Tried injections discontinued after initial use. Continent 95% of the time</td>
</tr>
</tbody>
</table>

Max’s “whole life at school was sport…which allowed you [him] to build relationships” whilst the “academic side was just a bit of a nuisance in a way”. His parents owned a “rough end business” and his “father’s only advice was to get a
secure job”. When Max left high school he went to university part-time and completed a law and accountancy degree and a postgraduate degree in management. He “gradually hooked into science research and development” and enjoyed the travel and the creativity his current job provided. He was married and had two teenage sons.

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1949</td>
<td>Asymptomatic Prostatitis, groin pain GP suggested PSA test</td>
<td>2000</td>
<td>PSA—slightly raised DRE—Normal Biopsy—Gleason score unknown</td>
<td>Prostatectomy</td>
<td>9 months 12 months</td>
<td>Partial erections penetration not as strong</td>
</tr>
</tbody>
</table>

Steve

Steve “knocked back a carpentry and joinery apprenticeship in his home town to join the railways” in the western suburbs of Melbourne. He knew when he got a railway apprenticeship he was made, “keep your nose clean, head down and you’ve got a job for the rest of your life”. Steve worked for the railways for 43 years. He “was still doing night courses at 55 years of age”, and when he retired he “was the best in the painting field that the railways had”. He married a “local girl” and had two children and “lived in the same house for 40 years”. Being a “teetotaller”, Steve was “little bit out of it” socially and “not always invited to some social areas”.

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1927</td>
<td>Asymptomatic Recent fatigue Wife encouraged GP visit</td>
<td>1999</td>
<td>PSA—unknown Biopsy—unknown</td>
<td>Radiation therapy</td>
<td>2 years</td>
<td>Fatigue during Radiation therapy Impotent</td>
</tr>
</tbody>
</table>
Ben

Ben was born in Toowoomba, Queensland and “went to school in Brisbane”. He had a “standard suburban life” that was “pretty monocultural, at least by today’s standards”. He completed his PhD in electrical engineering at the University of Queensland, moved to Melbourne in 1974 and worked at a research laboratory. He “enjoyed the Whitlam [Government] era because it helped people think about questioning traditional values”. He married in 1973, his partner “already had three children” and “we had another child as our fourth”.

<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of Prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since surgery at interviews</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1949</td>
<td>Asymptomatic Friend of similar age died of prostate cancer. Ben requested prostate check from GP</td>
<td>2000</td>
<td>PSA– 5.5 (2/2000) 7.4 (7/2000) DRE– Normal Biopsy– One of the six specimens positive Repeat Three of the eight specimens positive Gleason score 7</td>
<td>Prostatectomy</td>
<td>5 months 9 months</td>
<td>Incontinence 6-8 absorbent pads per day (1st interview) 2-3 absorbent pads per day (2nd interview) Impotent, unable to achieve erection with the VED</td>
</tr>
</tbody>
</table>

Seagull

Seagull moved from the east to the west of Melbourne “because I [he] worked at Newport in the railways”. He completed a five year apprenticeship as an upholsterer and “started at the bottom and finished at the top” as the foreman before his retirement in 1991. He was married and had two children. He coached junior Australian Rules football and helped the kids “learn the skills first, before they started playing the game”. Despite his love of sports he was concerned that “the divide is getting bigger between the rich and the poor” and that sportsmen and women were paid so much whilst others live in poverty.
<table>
<thead>
<tr>
<th>Year of birth</th>
<th>Symptoms</th>
<th>Year of prostate cancer diagnosis</th>
<th>Diagnostic tests</th>
<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1936</td>
<td>Asymptomatic Annual GP check up. Seagull requested a prostate check after hearing workmates talk about it.</td>
<td>1998</td>
<td>PSA – 30 DRE – “bit firm” Biopsy – 2 of the 6 specimens positive Gleason score unknown</td>
<td>ADT (Drug trial 3 months) Radiation therapy</td>
<td>2.5 years 3 years</td>
<td>Hot flushes Impotent</td>
</tr>
</tbody>
</table>

Sam

Sam believed that “if your mate is in trouble you help him out all you can” because “somebody has to get involved or the problem doesn’t get solved”. He lived in Melbourne all his life and was in the scout movement for many years which “taught him how to mix with different people and how to take on responsibility”. At 18 years of age he was “called up” to serve in World War II but did not have to go because he was in a “protected industry” which was “sort of disappointing in a way”. He was married, had five children and was an engineer most of his “working life”.

<table>
<thead>
<tr>
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<th>Treatment</th>
<th>Time since diagnosis at interview</th>
<th>Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>1925</td>
<td>Asymptomatic GP suggested PSA.</td>
<td>1993</td>
<td>PSA – 140 DRE – swelling noted Biopsy – unknown</td>
<td>ADT</td>
<td>8 years</td>
<td>Impotent</td>
</tr>
</tbody>
</table>
Ethics

I forgot something in my ethics. Where do I go with this information besides the lines that make the chapters? Here I am, visible in the text, reflexive in the process, and an island in the post-participant interviews. I’ve realised during the last four or five interviews I have a bilateral saturation. There is saturation in the data and no new patterns are emerging, and saturation of the self. I am worn out.

Field note, reflection 12/2001 – after the final interview

There were five key ethical issues arising in the conduct of this research. The first to be discussed is adherence to the principles of beneficence and non-maleficence. Participation in this research had the potential to ‘do good’ as it was cathartic for many of the participants to talk about their understandings and experiences of prostate cancer and how it affected them. However, it also had the potential to be stressful. I gave full consideration to stressful outcomes, particularly as men are often stoic, endure illness, and may not have told me it was stressful to discuss their experience of potentially sensitive issues. Four research participants—Ben, Randwick, Steve and Eddie—experienced stress which manifested itself in a few tears during our interviews. I acknowledge that tears do not necessarily always indicate stress. However, the participants’ tears were accompanied by discomfort and uneasiness that I observed in their body language (such as crossing their arms, heads bowed, diverting gaze, avoiding eye contact, wiping eyes and nose) and voice projection (quivered or muffled voice, incomplete or unfinished sentences). The stressful reactions did not occur in response to particular questions, but with the thoughts or feelings that the questions perhaps prompted. I suspended the interviews when I anticipated or observed such stressful reactions until such time as the participants indicated a readiness to resume. The four participants chose to continue our interviews and verbally re-confirmed their willingness to participate in the research.

All participants were provided with contact details of two experienced counsellors (one male and one female), and encouraged to make an appointment if they wanted support to resolve the issue prompting the stress. In the event that a participant had not wished to continue, for any reason whatsoever, they would have been withdrawn from the study without penalty. All negatives and copies of
their photographs would have been returned to them, and data collected up to that point would have been destroyed.

The issue of ethics of “the self” as researcher that I documented in the previous field note reflection is an ethical consideration for my future research and supervision. It occurs to me that, as a registered nurse, I often control the connections I have with patients. However, qualitative research removes those boundaries through dialogue and observations that might not otherwise occur. This is not to deny the cathartic value for me as a researcher, but I suggest that reciprocal considerations and provisions made for the interviewee should be available to the researcher. In particular, the opportunity to debrief with a counsellor would be beneficial.

The second ethical issue related to ownership of intellectual property. I was given permission from the participants to retain and use their photographs. I considered carefully whether I could return the photographs to the participants or enable them to claim authorship of their photographs within my published work. However, claiming authorship would have revealed the true identity of the participants, enabling their photograph(s) to be linked to their story and this eventuality had to be avoided. Within the thesis and publications arising from this work, photographs are identified by the pseudonym selected by each participant with acknowledgment that each photograph is their work. It was explained in my plain language statement and the consent form that I would retain the photographs for possible use within my thesis, any subsequent publications arising from this work, and professional presentations. From the outset it was clear that acceptance of the invitation to participate in this research included giving consent for me to retain and use the photographs.

The third ethical issue to be considered was disclosure of what might ordinarily be regarded as private information to an individual (the researcher) who was a relative stranger to the participant. The questions were not of a particularly invasive type and offered participants the opportunity to reflect on and provide confidential information about their experiences of prostate cancer and its treatments. To facilitate comfort in the disclosure I met or spoke with each of the
participants at least once prior to our interview[s] to establish rapport and familiarity.

The fourth ethical issue was confidentiality. The PCSGs where I completed fieldwork and recruited participants are not named and no details that would enable the organisations to be identified are provided. Every effort has been taken to protect the identity and maintain confidentiality of the participants in this study. Participants provided a pseudonym for themselves and it was completely up to them to whom they disclosed the pseudonym. In reporting the findings of this research all participants are identified by their pseudonym throughout the text, as are all photographs used. When participants did not want me to have or use their photographs they were returned to them along with the negative or destroyed by me.

All participant interviews were audio-taped and the interview audio cassettes, participant photographs and negatives are kept in a locked cabinet, Level 4, Building B, School of Health Sciences, Melbourne Campus, Deakin University, and will remain so for a period of at least 6 years (a 6-year term is the minimum requirement for secure data retention). Participants’ consent forms and any other information that links the pseudonym to the participant’s real name are stored in a separate locked cabinet at the same location for the same duration.

The fifth ethical issue was informed consent. Participants were informed verbally and in writing via the Plain Language Statement of the specificities of the study. They were provided with sufficient information to competently and voluntarily make an informed decision about whether they wished to participate. I stressed that I was only interested in working with men who were keen to freely participate and there would be no disadvantage in non-participation. I explained that I was a registered nurse, but had no clinical experience in urology and nursing men with prostate cancer. I volunteered this information because I did not want to replicate traditional clinical relationships that some of the men may have previously encountered. For example, the clinical nurse ‘expert’ informing the patient ‘novice’ of what their prostate cancer experiences would most likely be. In this way, I minimised the potential for coercion or power relationships in the recruitment process and in subsequent interactions and interviews with
participants. Participants were required to complete a written consent. There was no deception in this project and the participants were informed about the aims and objectives of the project and the analysis undertaken. The five central research questions / themes for participant interviews were included in the Plain Language Statement.

Participants were told that this was a PhD study and on completion of the research I would mail a brief summary report of the findings of the study to all participants. The findings of this study would be accessible as a thesis. There was also a possibility that the findings may be submitted for publication in or as a book. In the event of any publication, participants who indicated they would like a copy of published articles would be mailed a photocopy. Participants also have ongoing access to their individual transcripts, photographs and quotations to be used in publications.

**Part B: Description of research processes**

Potential research participants were invited to complete the demographic data questionnaire (Appendix A) and return it to me in the provided stamped self-addressed envelope. The completed questionnaires provided information that facilitated the identification of research participants based on the criterion sample specifications. The questionnaire included the question “Do you have a female partner?” rather than asking explicitly if potential participants were heterosexual. The rationale was my interest in researching the connections between men’s intimate relationships with female partners, sexuality and prostate cancer. This was a relevant research question given the potentially life threatening nature and high incidence of incontinence and impotence associated with prostate cancer and its treatments. The questionnaire requested contact details from men who were willing to participate in the research. I contacted participants by telephone, mail and email, briefly explained the study and arranged a mutually convenient time and place to meet. During the initial meeting, I provided participants with the Plain Language Statement (Appendix B), explained the research, answered questions and outlined the details of their participation. Those respondents who agreed to take part were asked to complete the participant consent form (Appendix C).
I asked the participants to use a disposable camera with colour film, supplied by me, to take photographs that illustrated their experiences of prostate cancer. Specifically, I asked them to imagine that they were being paid to mount a photographic exhibition entitled “Living with my Prostate Cancer”, an exhibition that would show prostate cancer from their own unique perspective. I asked the participants to take their photographs within two weeks of the date that I gave them the camera. After they had taken their photographs, I met with participants to collect the camera and subsequently develop photographs at my expense.

After the photographs were developed I met with each participant on a mutually convenient date and time in a location that was free from distractions and where we could talk privately. I showed the participants their developed photographs and asked questions about them. These conversations took between 90 and 180 minutes. The conversations during the interviews were recorded on audiotape and transcribed verbatim. Participants were given the opportunity to read and comment, approve or disapprove the transcript (the written record of the taped interview), to make sure it accurately represented what had been said during the interview.

Specificities of each participant’s participation in the research varied, but all participants were interviewed at least once. Some participants also undertook one or more of the following:

- provision of photographs and / or artefacts
- participation with a series of two interviews
- completion of phone interviews

These variations are discussed in this chapter.

**Data Collection**

Gifford (1996) suggests that in qualitative research it is generally agreed that some type of triangulation should be included in order to increase rigor. She states that triangulation “simply means using a number of different approaches to get at the same question” (1996, p. 60). Methods triangulation was used in this study where which a number of different methods were used to investigate men’s
experiences of prostate cancer. Specifically, the methods included preliminary fieldwork, photographic novella, in-depth semi-structured interviews and participant observation. The specificities of each of these methods are discussed in the following section.

**Preliminary fieldwork**

As I drove through the city on the way to my first prostate cancer support group I recalled a scene from the movie “Fight Club”. Jack, who does not have cancer, attends testicular cancer support group meetings because “it is only when you lose all hope that you find freedom”. The group members “share” cancer experiences and hugs are common place. Jack meets Bob who “has tits” because he’s on hormone therapy treatment. They hug and both men weep uncontrollably.

I wonder what it will be like today – I’m not Jack or am I?

*Thought 12/2000 pre first PCSG meeting*

*Answer: No I am not Jack. There were no hugs, at least no physical hugs, after all this is working class Melbourne not Hollywood. Right?*

*Thought post first PCSG meeting 12/2000*

The initial six months of field work at the PCSG meetings facilitated observation of members’ interactions and discussions about various prostate cancer issues. My experiences in the field informed the refinement and development of the research design. Despite my clinical nursing background, I had no prior knowledge of the specificities of prostate cancer. However, I was soon learning about prostate cancer from the men at the PCSGs. This practice is congruent with ethnographic methodological underpinnings that identify ethnography as involving “learning about the culture from the culture” (Spradley, 1980, p.5). I was also learning about biomedical “facts” from “patients” rather than health care professionals. This raised issues of who was expert. Many participants became experts through their research and patient experiences of prostate cancer. The PCSGs provided a safe place where men had the permission of other men to speak about prostate cancer issues and, as a consequence, the dialogue was open and at times emotional. Gibson and Denner (2000) confirm that men speak about health beliefs and concerns when provided with a supportive environment.
Ethnographic methodology encompasses varying degrees of researcher participation. At the PCSG meetings I was a participant observer where I keenly and critically observed the interactions. However, by virtue of being there, I was drawn into the discussions as predicted by Willms & Johnson (1993). I was asked many questions about the medical treatments and biomedical research of prostate cancer. For example, early in the fieldwork I was asked “Why isn’t local anaesthetic used for the diagnostic procedure of trans rectal ultrasound biopsy (TRUS-Bx)?” and “What have the results of the Trinovin drug trial revealed?” At the time I was unable to answer these questions. However, I accessed resources and shared information with the group members at subsequent meetings. My participation in the PCSG meetings provided me with a purpose and credibility that was important to the group members and, as a result, I established rapport and trust with many of the men. These examples illustrate that the men raised issues and shared experiences and concerns about their prostate cancer and treatments during the fieldwork.

Through this initial fieldwork I began to develop an understanding and appreciation of many issues men experienced as a result of living with prostate cancer. I had not anticipated some of the emerging themes in the initial research design; however, as Spradley (1980) states, ethnography provides a way of knowing from the bottom up, a way of knowing in which the study participants inform the research themes. One emergent issue that members of both groups discussed was the pain and discomfort experienced with a particular prostate cancer diagnostic procedure, the TRUS-Bx. The recurrent emotive nature with which many men spoke prompted my interest in understanding the meanings of the TRUS-Bx to the participants. After I completed the field work and initial participant interviews I was interviewed by Melissa Sweet (2002) from The Bulletin national news magazine about my research. This provided a wonderful opportunity to relay what men had been saying about their experiences of the TRUS-Bx. This media release helped to validate participants and confirm the value of speaking about their experiences. A copy of The Bulletin article published 20/8/2002, by Melissa Sweet is included as Appendix D. Detailed discussion of the findings regarding participants’ experiences of TRUS-Bx is
presented in Chapter Five, *Prostate cancer and health services, Section One, moving in.*

I completed detailed field notes that included my reflections and thoughts, drawings, sketches and descriptions of time, day and place, notes about number of attendees, the structure of the meetings and what was said and done by whom. This was helpful because my interpretations changed during the fieldwork. Hence, it was essential that these changes were meticulously recorded and open to interrogation. I kept observations and interpretations separate and it was possible for field notes to be open to the process of rigorous and critical reflection.

For example, one PCSG meeting room was consistently set up in a formal way. The room setting, as illustrated in Diagram D - PCSG 14/5/2001, placed the Treasurer, President and Secretary behind a desk at the front of the room and the attendees in organised rows of chairs facing them. Prostate cancer education resources such as videos and books were displayed on a separate table at the front of the room. Refreshments including tea and coffee were at the back of the room and there was one entry /exit door. The meetings were formal in that an agenda was followed and minutes taken. “Group discussion” was a regular agenda item (usually the sixth or second last starred item) in which men were encouraged to talk about any prostate cancer or group issues.
My initial interpretation was that the room setup and meeting format was hierarchical, business-like and informed by masculine constructions which served to prohibit, rather than welcome, group discussion about how men felt about their prostate cancer.

However, over the six months of fieldwork, my interpretations changed. The chronology of the meeting meant that prostate cancer “business” was discussed first. This included articles tabled (usually by the Secretary) about prostate cancer, strategies to increase community awareness of prostate cancer and initiatives to raise funding for prostate cancer research. This “information” was disseminated by the Treasurer, President and Secretary (the Secretary and President did not have prostate cancer) and dealt exclusively with prostate cancer “disease”. When the agenda item group discussion was tabled, the business discourse of prostate cancer disease often continued. However, when the men broke from the formal meeting for refreshments, they would talk about “their” prostate cancer “illness” in smaller groups or one-on-one. The formal meeting dealt with political and
professional prostate cancer issues, but the men’s support and discussion occurred in relative privacy.

The fieldwork observations and interpretations gave me a sense of prostate cancer cultures that informed my use of, and preparation for formal individual participant interviews. Specifically, I developed awareness that:

- Many men are more comfortable to discuss the politics of prostate cancer disease rather than their prostate cancer illness.

**Strategy** – I started formal participant interviews by asking disease questions, such as whether they had noticed symptoms or what tests they had completed. I would then gradually move to illness questions, such as what feelings and thoughts they had when diagnosed with prostate cancer.

- Men “control” when and who they talk to about their prostate cancer.

**Strategy** – Participant comfort and control was integral to the depth of discussion during the research interviews. Participants had control of the interview location, time and mode. Five participants requested telephone interviews, and whilst this “mode” yielded less data by way of participant observation, the interviews revealed valuable insights.

- Masculine self or legitimacy is significant to men with prostate cancer, i.e. a dynamic relationship existed between “biomedical business” and “sociological feelings” (often interwoven with humour) during many PCSG meetings.

**Strategy** – During the interviews, participants decided when they were ready to talk about sensitive issues such as impotence and incontinence. I provided opportunities with open-ended questions such as “What side effects did you experience?” However, I did not nominate specifics; rather I let participants disclose and then explored the topics with direct questions.

**Photographic novella**

All research participants were offered a disposable camera containing colour film that was supplied by me and asked to imagine that they were being paid to mount
a photographic exhibition entitled *Living with my Prostate Cancer*. Some research participants ticked the “no” option on the demographic data questionnaire (Appendix A) to the question “Are you willing to take photographs of your experience of living with prostate cancer?” This was usually because participants had difficulty conceptualising the request to take photographs that would illustrate their experiences of living with prostate cancer.

Participants’ reasons for not taking photographs included “I can’t see the relevance” (Max), “I’m no good at photography” (Kevin), “I don’t understand what you want me to take photographs of” (Vincent), “I have poor vision and can’t use a camera” (Verlow) and “this seems more suited to a bucks party” (John). Unicorn was also reluctant to take photographs and responded by email:

> John,
> I am happy to talk to you, but I must emphasise that I am not willing to participate in the photographic side of the exercise.

Unicorn later revealed he thought the photographs were meant to be of his body parts, which he was not willing to do. It was difficult to explain the photographic method and concept over the telephone, via email or when meeting potential participants for the first time. Rapport was integral to asking participants to take photographs. There may have also been a “struggle for control” in which participants controlled their level of participation in the research, as previously identified by Schwalbe and Wolkomir (2001). Time restraints were also experienced by participants, in that they could not find the creative time to think about and take photographs. Sam, Steve, Bill, Vincent and Greg agreed to take photographs. However, when I contacted them after two weeks, one month and three months intervals, they had not taken photographs.

Despite not wishing, or not having time, to take photographs, many men were willing to be interviewed about their prostate cancer experiences. Don decided to take photographs after our initial interview during which he conceptualised ideas for photographs and clarified examples as relevant to the research. Unicorn, Vincent, John, Kevin, Yanni and Wayne discussed artefacts, such as poems, medical documents and “word pictures” rather than photographs during the interviews.
Therefore, men who met the participant criteria and were willing to be interviewed, but did not wish to take photographs, were included in the study cohort. Nineteen participants provided between three and 27 photographs each and seven participants provided artefacts. In total, 26 of the 35 participants provided photographs and/or artefacts that were used to generate and inform discussion during the interviews. Artefacts included World Wide Web images, written documents, books, souvenirs and pre-existing photographs. The artefacts were regarded as “personal documents” in the same light as photographs, which should, as Scott suggests, be considered “texts whose meaning must be disclosed like any other” (1990, p. 85).

During the in-depth semi-structured interviews, participants were asked to discuss their photographs and explain the connections with their experiences of living with prostate cancer. As Wang and Burris (1994) predict, while participants describe the photographs that are most important to them and why, concerns about personal health, community and family arise. The photographs helped facilitate discussion during the interviews and empowered the participants to speak about issues that were important to them. I did not instruct participants about what to photograph. The photographs were intended as a means of facilitating photo-elicitation; however, they also provided data that assisted in the discovery of cultural worldviews of the participants. Participants’ photographs revealed rich data that may not have been elicited through traditional fieldwork, and ensured that the participants had control over what I was able to observe.

**In-depth, semi-structured interviews**

*I interview because I am interested in people’s stories. (Seidman, 1991, p.1)*

*Ben is three months post prostatectomy. Things have not gone well, he is incontinent and impotent and questioning the legitimacy and value of his “cure”. He needed to tell someone he was angry. I was the listener. The interview ended after three hours. We were both exhausted.*

*I will never forget the pain I witnessed today. Was the interview therapy? It could not have been therapy, I did not have any answers – in the end I had no questions, I just listened. Hmmm, perhaps it was therapy.*

**Interview number one, Ben 4/2001**
There was something deeply rewarding and satisfying about talking with the research participants in such a way that I could come to understand their experiences of living with prostate cancer. The in-depth interviews were more like conversations, which Taylor and Bogdan argue “is a stark contrast to structured interviews” (1984, p. 8). In-depth interviews draw on an interpretive theoretical framework emphasising that meanings are continually constructed and reconstructed in interaction. The participant interviews were both inductive and deductive—in that all the relevant themes and questions were not known prior to the research interviews.

An interview guide (Appendix E) provided written lists of anticipated themes to be discussed during the interviews. This ensured that I recalled the anticipated themes and was free to concentrate on the ongoing interaction (McCracken, 1988). The theme list did not direct the questions, but reminded me of the topics to be covered. Whilst utilising the guide I was able to follow leads that emerged. I was interested in hearing about what was important to the participants, and encouraged them to “lead” as this facilitated the collection of rich data, and provided opportunities for patterns to emerge from the interviews. I observed in my initial fieldwork at the PCSG meetings, that when men controlled and “owned” their discussions, much more information was shared.

In total, 35 participants were interviewed. Fourteen participants were interviewed through a series of two in-depth interviews. The series approach was a useful strategy, in that it allowed me to refine the interview theme list and undertake preliminary analysis and clarify or check emergent patterns with the participants at their second interviews. This method is advocated by Gifford who states “analysis is not confined to the last phase of the research process: it is concurrent with data collection and can best be characterised as cyclic” (1998a, p. 544).

The initial series approach to in-depth interviews provided me with clarity and confidence about the research design and emergent patterns. I also realised that little new information was being shared during the subsequent second interviews. Hence, the remaining 21 participants were interviewed in a single in-depth interview between 90 and 180 minutes duration. Taylor and Bogdan (1984) explain that in-depth interviews can involve a single half-hour interview with each
participant, or several sessions each of two hours’ duration, up to 25 sessions in some cases. However, most in-depth interview studies consist of single interviews of approximately 90 minutes. Four participants chose to be interviewed in their workplace, five requested phone interviews, two came to my office at Deakin University and 24 invited me to conduct the interviews at their homes.

My responsibility as a researcher was to report the realities of the participants’ experiences of prostate cancer as they perceived them. One deliberate strategy I used to check the transcript’s accuracy and my interpretations of their realities was to present the transcripts and seek clarity about my findings with the study participants. This was facilitated by member-checking, in which all study participants were invited to read and edit their transcript(s), clarify content, and comment on the interpretation of their interview patterns. Thirty-three of the participants acted as co-researchers and served as judges of the reliability and validity of their data. Many participants kept in contact via telephone and email after sending their amended transcript(s) back to me. A few participants initiated subsequent meetings with me. Some discussions have continued and friendships grown since the initial participant interviews. My journal entry about being worn out after the interviews included in the earlier ethics section may seem contradictory. However, I have noted friendships with participants have changed significantly from the interviewee and researcher roles. They have evolved and are based on mutual exchange, interests and sharing, and as a result are not only sustainable but enjoyable.

Participant observation

Mr. Oliffe: Were you upset [at getting a diagnosis of prostate cancer]?

Eddie: I don’t think so. No. Easy going you know. There was nothing much I could do is there. I know some people drop their bundle and that sort of thing you know... didn’t really worry me...

Excerpt from transcript. Interview with Eddie 10/2001

Eddie is crying, tears streaming down both sides of face, muffled voice, arms folded, then wiping eyes, brushing tears away, then reaching to his pockets, head down and to the left, looking at the floor.

Participant observation integrated with retrospective summary observation

Kellehear (1993) suggests one advantage of the observational method is that it illustrates that people’s actions are probably more telling than their verbal accounts and therefore observing participants is valuable. Fundamentally this may be so; however an anecdote from Damien Ridge (personal communication, May 10th, 2002) provides a cautionary note to interpreting participant observations in isolation and / or haste. Ridge relates a story from his youth, when friends of his parents visited their family home. The friends entered the house along with a dog. The friends, seated and enjoying refreshments, began chatting with Damien’s parents. At the same time the dog was “running amuck” ripping the sofa and cushions, leaving a trail of disarray. Finally, as considerable damage accumulated, Damien’s parents’ disbelief turned to displeasure and they suggested that the “friends” remove “their” dog from the house. To which their friends replied “Our dog!? We thought it was your dog”.

Later in the interview I asked Eddie “What is your take on Aussie mateship?” Again, with tears streaming down his face he replied:

\[\text{Aussie mateship – it has gone. I am so different. I like to keep in contact with mates. I do the things I think someone else would do.}\]

At the conclusion of the interview, as we walked from my office to his car, Eddie apologised for “breaking down” but he “had lost a mate to cancer recently” and was “still really sad about it”. Superficially, Eddie looked as though he was saying one thing but feeling another. However, as Eddie suggested, his reaction was about something lost—his mate. The interview questions may have been triggers for recalling that loss. At another level there may have been interconnections with his vulnerability and mortality. Eddie did not perceive his crying as a bad thing. He thanked me for our talk, said he felt much better, and commented “that [the interview] was really good”.

The participant observations during interviews were documented and provided anecdotal, field and self-observation written notes. The data generated via this method was particularly useful as an adjunct to the transcripts. The technique was generally unobtrusive. However, when obtrusive, which was dependent on participants’ “researcher observation”, the effect wore off in a reasonable time. The participant observation method was effective in that it also:
forced me to familiarise myself (emphasis added) with the participant
allowed potentially unnoticed or ignored aspects to be seen

(Kellehear, 1993, p.126)

The combination of data collection techniques provided a tapestry from which I have re-created the interview moments. I can hear the voices, revisit the observations, read the record and in some instances see photographs that illustrate aspects of participants’ lives. These “souvenirs” keep the memories fresh.

Data analysis

Interview data

In ethnographic studies, analysis is acknowledged as a part of the process of the research during the data collection phase, rather than something that occurs exclusively at the end (Gifford, 1998a). Following each interview I read the hard copy transcripts at least six times, as recommended by Spradley (1980). Sandelowski (1995) defines this as part of data preparation. However, as she predicts, by reading the transcripts multiple times, each subsequent interaction with the text yielded new thoughts (Sandelowski, 1995). I highlighted key phrases and made jottings in the columns of the transcripts about my ideas and interpretations. I also proof read each transcript against the interview audiotapes, wrote in excerpts from my field notes and participant observations, and marked where participants were referring to specific photographs. This enabled me to get a sense of the whole interview.

The preliminary analysis of early fieldwork, interviews and observations led me to refine the research questions and expand participant recruitment strategies. As discussed in the earlier section—Preliminary fieldwork—early fieldwork and analysis informed the interview questions about participants’ understandings and experiences of the TRUS-Bx. I also completed less formal analysis of the early interviews and participant observations. Questions arising from reviews of this data were included in later interviews, and emerging findings were introduced for validation.
All the transcripts were managed using NVivo 1.2 which assisted me with sorting the data. I used a system which Sandelowski (1995) describes as extracting the facts to fracture the data and facilitate new insights. The factual information was least subject to errors of inference and closely aligned to the research themes and questions. Initially 27 categories were used to organise and retrieve the coded data. The topic categories were broad and included “health promotion”, “life changes”, “side effects”, “wife relationship” and “mateship”. The categories enabled me to code, organise, retrieve, and complete some preliminary analysis of the data without separating data segments from their context. At this stage, categories overlapped and were often nested within one another. I was able to combine some broad categories and develop subcategories. I wrote descriptive jottings for each of the broad categories and looked for relationships between them.

I was able to search selected subsets of interviews for particular single-coded or multiple-coded segments using NVivo 1.2. I worked with the coded data and categories, thought creatively and ask questions about the data to develop and explore patterns. Questions suggested by Spradley (1980)—such as, is there information derived from the cultural group that appears contradictory? How do participants conduct their interpersonal relationships?—provided a starting point to begin identifying and explaining emerging patterns. As analysis continued, I returned to the related literature and social constructionist gender frameworks to further develop the analysis. The patterns were developed into storylines and the literature was interwoven with the findings as recommended by Morse and Field (1995). I also used Gerschick and Miller’s (1994a,b) reformulation, reliance and rejection framework to think about and present participants’ experiences of specific treatment side effects such as impotence and incontinence. The findings in the present thesis that use this approach are presented in Chapter Six, *Sexuality, Intimate Relationships and Prostate Cancer*.

Towards the end of data collection I wrote a paper that explored men’s experiences of TRUS–Bx. The experience prompted me to code the transcripts in a more analytical way. For example, under the broad category of TRUS-Bx, subcategories *pre TRUS-Bx* and *during TRUS-Bx* were used to organise coded
data from which patterns of anxiety and control, pain performance, penetration and vulnerability, and dual stoicism were identified. This was a useful process where I moved beyond the broad categories, concurrent with writing up results. Gifford (1998a) and Denzin (1994) confirm that writing is a way of knowing, in which “writing up” is interwoven with data analysis rather than being separate processes.

Subsequent revision of my coding schedules, using a similar process to that described for the TRUS-Bx category, led to further development of more analytic categories and sophisticated explanations and descriptions of the cultural patterns and rules.

As my analysis continued, categories and patterns were developed and documented using labels and concept maps as illustrated in Diagram E.

I looked for instances of meaning rather than instances of specific words, phrases, actions or events (Gifford, 1998a). One example, depicted in Diagram E, was participants’ descriptions of being tested or screened for prostate cancer, which was not necessarily inferred by the specific words “test” or “screen”, but rather the context in which they discussed, experienced and constructed being examined for prostate cancer. Participants’ discussions of the events that led to their examination and the experience of being tested were all relevant to the analysis.
and discussion. Therefore, the meanings of prostate cancer screening or testing emerged in the wider context of the interview as Gifford suggests “what came before and what comes after” are integral to ethnographic content analysis (1998a, p. 548). Continuing the example of screening, participant expectations of being screened and their experience of being diagnosed with prostate cancer can be quite different. This is an example of how what comes after (the actual experience of being diagnosed) is analysed contextually.

I acknowledge my own constructs in the entire research process. The research design, decisions about what constitutes data through to the data analysis were influenced and derived from my interpretive position, and I am not espousing pure representation. Furthermore, as Streubert Speziale and Carpenter (2003) assert, culture is ever-changing and dynamic, and therefore the findings from this study are applicable within the context of this research.

Photographic novella

As stated in the earlier section, Data collection, the use of photographic novella was originally intended as a photo-elicitation method in which participant photographs were used as interview stimuli. This process facilitated participants’ active involvement in the interpretation of each of their photographs, and was essentially a device for generating the verbal information from the interview. “What counts as qualitative data relates overwhelmingly to verbal discourse”, therefore, the photographs depended on participants’ “caption and textualisation” (Emmison & Smith, 2000, p.12). This helped to place the photographs in an analytical framework.

The first stage of analysis was “appraisal” (Emmison & Smith, 2000), in which I viewed all the images after the interviews, paying close attention to the interconnections and incongruities between the photographs and the participant’s transcript record. At this level, I was able to establish that the text provided the context and clarity for the photographs. The participant photographs and corresponding captions are integrated throughout the results Chapters Four, Five and Six in the current thesis study.
I have also examined specific photographs in detail as a way of comprehending the texture and nuances of men’s illustrations of living with prostate cancer. At this level of analysis, I “read” and “interpret” individual participant photographs and detail my findings throughout the results chapters (Emmison & Smith, 2000). Sociological research into media effects suggests that people may read the same image in divergent ways, often depending on their identity, their life experiences and the subject positions they adopt. Whilst there may be a “preferred” or “hegemonic” reading which is intended by the author or reinforces a prevailing ideology, “oppositional readings” can be made of the same text (Emmison & Smith, 2000, p.45).

The entire photographic collection was also sorted into themes in a process known as “inquiry” (Emmison & Smith, 2000). I arranged the collection as a whole and began to sift through the photographs and develop categories. Initially, the categories were broad binaries such as inside-outside, people-places, analogy-reality, illness-health. I developed the themes into more analytical categories with repeated exposure and identified three distinct themes: “special places and people”, “transitions”, and “illness narratives”. The photographic themes revealed participants’ cultural views of Living with my prostate cancer. The themes from most common to least common were:

**Special places and people** - These photographs illustrated significant people, places and possessions that participants could see, touch and inhabit. Participants explained philosophical gendered meanings through special places and people, such as work, family, social settings, homes and cars.

McIntyre (2003) previously described special places in a “photovoice” study of working class women living in Belfast, Northern Ireland. In the present research, special places and people were the most common theme of participants’ photographs. One example of a special place was included by Bob who photographed and spoke about his shed (Photograph A). He suggested “every man has to have a shed” and explained that his wife “hates cricket” but in his shed “I can listen to my cricket” on the radio. He had a “work bench out there” as well as his bike. The shed was a special place that Bob could go when he wanted solitude;
it was his special spot, where no one else was allowed, a place where he could work things out in his head.

**Photograph A**

Transitions – This collection of photographs illustrated embodied changes that were experienced as a result of prostate cancer and its treatments. These included physical changes such as incontinence, fatigue and impotence.

Illness narratives - was a subset of photographs that participants used to describe their biomedical experiences of prostate cancer. Included in this theme were photographs of hospitals, treatment areas and test results.

The abovementioned themes are not presented as a collection in this thesis. Instead, detailed analysis of individual photographs and artefacts, accompanied by participant commentary, description and explanation has been included in the results chapters of this thesis. In this way the photographs are contextual and include participant as well as researcher readings.

**Limitations and strengths of the study**

The study's findings are based on the interviews, observations, photographs and artefacts, of the 35 study participants. The participants’ stories reflect their experiences of prostate cancer and are real from their point of view. However, these experiences and accounts may differ from those that would be obtained by interviewing health care professionals or the partners of participants. The realities in this thesis are no more correct or more sophisticated than scientific truth;
however they are participants’ real versions of the situations at a particular context and point of time in their illness experience.

Causal-effect and generalisation are not the outcome of interest in this study. It is the subjectivity and construction of multiple realities from participants who have experienced the impact of a potentially life-threatening illness that is valued. The resultant ethnographically informed social model of prostate cancer does not provide data capable of producing a “one size fits all” template approach to prostate cancer. However, the findings inform an understanding of the participants’ experiences of prostate cancer and the interconnections with dominant social constructions of masculinity.

One of the major strengths of this study is that it makes an original contribution to the literature on prostate cancer. Ethnographic research of Anglo-Australian men with prostate cancer has not previously been reported. The findings from this study contribute new understandings to men’s health research, through social constructionist gendered analysis. This research also offers methodological insight into how photographic novella can be used in men’s health research.

The method of participant photographic novella and artefacts is not hegemonically masculine, nor is the self-disclosure of sensitive issues that occurred in the present thesis study. Therefore the participants and research methods in this study disrupt the very premise upon which men’s health and dominant forms of masculinity are socially constructed. The participants’ preparedness to talk about illness, their lives, sexuality and intimate relationships with someone willing to listen demonstrates the necessity to inform theoretical profiles of men’s health behaviours with empirical data.

In conclusion, this research contributes to discussions about qualitative methodology and methods, and offers understandings of the connections between masculinity and prostate cancer that are relevant to clinical practice. The findings from this study also informs many possibilities for future avenues of prostate cancer research, a discussion of which is included in Chapter Seven, Conclusion and Recommendations.
After the data was collected

There has been some form of closure to this study through death since Royboy and Berti have died since participating in this research. However, I am unsure when, and for that matter if, there will be complete closure to this study. At the beginning of the research, I believed I could distance myself from the participants in much the same way as I have in the clinical setting. However, the professional boundary that legitimises many clinical moments and distance from patients did not suffice in this research. Nor, I would argue, should it. This ethnographic research enabled me to get close enough to see, hear and know the cultures that I was researching. In most instances, it was not a one-way dissemination but rather a dialogue of exchange in which relationships were formed.

After the data was collected, a few participants remained in contact, whilst others connected with me for a brief “in-depth” moment. I have shared the findings from this study with many men from PCSGs, including all the groups from whom I recruited participants. Some participants became friends and our relationships exist outside the confines and context of prostate cancer. For me, these friendships are now about social interaction, not about researching participant experiences of prostate cancer. This is partly because the friendships have grown and are multi-faceted, and perhaps more poignantly, because I do not wish to think of “losing” them to prostate cancer.

Prostate cancer is a culture, community and club. Once “known”, I was included, encouraged and thanked, especially in the formal prostate cancer clubs – the PCSGs. To contribute to the culture is in many ways “golden” the gratitude is genuine and the validation uplifting. One significant event occurred when I was asked to talk at a Brisbane PCSG meeting in July, 2002. I presented the findings from my research to men with prostate cancer. My presentation was followed by new group members sharing their illness experiences. The four men that “shared” their illness experiences that morning were emotive and animated. They talked about their prostate cancer using the same chronology and depth that I had used to present my research findings. For me, it was especially significant in the context of having recently resigned from my lecturing position at Deakin University in order to write up the research findings. I felt that by making the findings
accessible for men at the PCSG that day, empowerment through research was momentarily tangible. This was especially satisfying for me as a researcher, clinician and man. Appendix F is an excerpt from the subsequent PCSG newsletter, August 2002, that provides an outline of my presentation and the participant sharing that followed.

Perhaps the most difficult decision I faced was to take up a teaching and research position in Canada prior to completing my thesis. While the research data had been collected, friendships developed and I was accepted and encouraged by many prostate cancer activists throughout Australia. By leaving, I may have forfeited contact with some participants and future prostate cancer research opportunities in Australia. I wrote to all the participants prior to leaving and provided them with my Canadian contact details. I framed my departure in positive terms, especially in regards to prostate cancer research opportunities that would be available to me in Canada. The letter to participants is included as Appendix G. I have been particularly pleased to hear from six of the participants who wrote to congratulate and encourage me to enjoy Canada and my new job.

In conclusion, men’s health generally, and prostate cancer specifically, are inextricably tied to gender relations and the social constructions of masculinity. The experience of conducting this research, the success and potential applications of ethnographic and social constructionist frameworks have convinced me that ongoing research will help illuminate what are “fluid” rather than “fixed” gender constructions. I will continue to research prostate cancer using social constructionist gender frameworks. From the perspective of the need for ongoing research I therefore argue that this “beginning” research does not need closure, but rather, further exploration.

**A word about style**

**Writing up the data: participants’ quotations and photographs**

To avoid altering participants’ meanings or imposing my grounded meanings, participants are quoted verbatim. My interjections and repetitive speech mannerisms have been left out and this is indicated by means of ellipsis (…). Long pauses are indicated by ----. Quotation marks indicate where participants’ words, phrases and short sentences are incorporated into the text. Participants’
pseudonyms are used to label their quotations, scanned photographs and artefacts. I have also incorporated diagrams, advertisements and images that inform broader discussion of the findings.

Illustrative data is used to help the readers feel as though they are there, in some sense, just as I have been there (Strauss, 1987). These include excerpts from my field notes that provide information to assist readers to understand what is going on at the interview and in the data being analysed. The field notes are presented in *italics* and indented. They are accompanied by **Bold** font beneath that details the date and context, such as “participant interview”, at which the observations were made. I have balanced commentary with data, rather than suggesting that the data speak for itself. The occasional use of present tense in the findings chapters is used to capture and convey the “real live” data and convey a sense of immediacy (Strauss, 1987).

All the research participants contributed to the findings presented in this thesis study, however various participants feature in each of the results chapters. This case based approach facilitated “thick descriptions” as advocated by Geertz (1973). Detailed descriptions provide the reader with context and a sense of “being there” in the research moments. A summary of discussion and findings is included at the end of each section of results. This approach facilitated summation of the present research findings and comparison with specific reviewed literature.
Chapter Four

Research results

Australian Men’s Health Promotion and prostate cancer

In this chapter, Australian Men’s Health Promotion and prostate cancer, I discuss the findings from this study that address the following research questions:

- What roles do health promotion services play in relation to prostate cancer for men in the cohort?
- What recommendations do participants offer for the future role of men’s health promotion services in relation to prostate cancer?

I have presented the findings in two parts. In Section One, Victims or suspects?—Australian men and health promotion, Randwick, Steve and Kevin are re-introduced through historical snapshots that are explored in the context of contemporary health promotion frameworks. In Section Two, Prostate cancer screening and health promotion, Arsenal, James and John feature as they, along with other participants, describe their experiences, practices and recommendations for prostate cancer screening.

Section One: Victims or suspects?—Australian men and health promotion

As stated in Chapter Two, Section One, Part B, Health promotion and prostate cancer, health promotion is a “means of achieving health for all” through “enabling people to increase control over and improve their health” (O’Connor-Fleming & Parker, 2001, p. 7). Most participants in this study were not familiar with the term health promotion or its specificities. Prior to the formal interviews, I outlined the aims of health promotion so that participants would understand the context of my questions. Participants’ responses assisted me to gain an understanding of their experiences of health and illness while growing up in Australia.
With the exception of Arthur, who remembered the 1980s ‘Life be in it’ campaign (a media campaign that used cartoon characters to encourage physical activity rather than sedentary lifestyle) participants did not recall specific health promotion programs or health messages from their formative years. The findings from this study reveal that most participants did not practise health promotion, especially prior to personal experiences of illness. This is not to suggest there were no health promotion messages, as Patrick clarified, “it’s not to say that there weren't any. It may have just been that I wasn't interested”. Some participants, including Seagull, suggested that rather than health promotion messages, “the media advertised everything that was damaging to your health”. Therefore, beyond the historical absence of health promotion messages, some participants reported that they were encouraged to partake in what are now known to be health-risk behaviours while they were growing up. For example, smoking was socially accepted and encouraged through widespread media advertising for many years prior to the reporting of connections between tobacco consumption and illness.

In this section Randwick, Steve and Kevin recall some pre-prostate cancer experiences from their lives while growing up in Australia. Their recollections provide contextual historical insights to consider and interrogate contemporary health promotion frameworks. Through participants’ experiences and constructions of health and illness, we are able to move beyond the current Australian men’s health promotion profile, to meet, know and ultimately understand some of the men that it represents. This strategy is commensurate with recommendations made by many authors (Buchbinder, 1995; Courtenay, 2000; Huggins, 1998; Lambevski et al., 2001; Thorogood, 2002; Watson, 2000; Woods, 2001) that individual men's lives need to be considered in the context of health promotion discourse. A micro life course perspective, as advocated by Lee and Owens (2002), is used in the presentation of the findings in this section.

**Meeting Randwick**

Randwick is immaculately groomed. His full head of white hair combed back and parted on the left hand side, sits neatly sculptured. He wears dark coloured dress trousers with a colour-coordinated shirt, his leather shoes polished, shine bright and reflect the ceiling lights. He is over six feet tall, strongly built, with high cheekbones and a chiselled jaw line. In his left ear,
he wears a hearing aid, it is attached to an arm of his glasses. Occasionally, during the PCSG meetings, the high ceilings and echoing multivocality isolates Randwick audibly to the buzz of the feedback from his ‘hearing aid’. In these moments, he removes his glasses to adjust the hearing aid. Suddenly sight and hearing impaired, it is as if Randwick finds refuge in disability only to later reinstate his senses, and rejoin the discussion.

Observations and interpretations integrated with retrospective summary—

Randwick was six years old when his father died. He was brought up by his grandmother in country Victoria while his mother lived and worked in Melbourne. Randwick’s grandmother discovered his hearing and sight difficulties in 1941, when he was 14 years old. During a Sunday lunch at a hotel, he asked his grandmother what the notice on the table said. She told him to use his eyes to “look at it” and “read it”. Randwick recalled:

I’d squint my eyes, which I found out from school … you could get them to focus...And just through that one particular day, saying that, she [Randwick’s grandmother] suddenly woke up that I couldn’t see properly. Well, I’d gone through umpteen years of school, of getting up and walking down nearer to the board and then back again to do sums and things like that. In the early stages, they said it was me being lazy and the same with hearing. I had the same problem that I wasn’t hearing people and I’d say ‘I didn’t hear’. Well, they said I was imagining it. And, I began to think myself, I must be imagining that I can’t hear properly and I can’t see properly. Well, once it was determined that it wasn’t imagination both things were rectified. I’ve been using glasses and a hearing aid ever since.

“Through that one particular day” Randwick’s grandmother recognised and validated his sensory impairment. She subsequently arranged a consultation for Randwick with a Melbourne-based doctor who “rectified” both his hearing and sight problems. However, for many years prior to being diagnosed and treated, Randwick was uncertain about the legitimacy of his impaired senses. As a result, he harboured increasing self-doubt about his ability to differentiate between imaginary and real symptoms. During this time he minimised the impact of his disabilities through trial and error problem solving that included squinting and moving closer to an object in order to focus on it.

Randwick’s early experience reveals four health care practices. First, he was reliant on a female (his grandmother) to validate his symptoms and coordinate health care. This is a gendered practice, as has been well established (Lee &
Owens, 2002), in which females are responsible for the health of the men in their lives. Second, professional medical help followed the discovery and validation of legitimate medical ‘problems’, which the doctor subsequently treated. This practice is reflective of the ‘therapeutic age’ (O’Connor-Fleming & Parker, 2001) in which health services diagnosed and treated disease rather than having a focus on illness prevention. Third, prior to medical treatment, Randwick endured and adapted to “umpteen years” of disability. This is congruent with Ziguras’ (1998) suggestion that men self-monitor symptoms and seek help (often from females) following extended, increasingly severe symptomatology. Fourth, Randwick’s doubt about his ability to identify real sensory impairment was compounded by suggestions he was “lazy” and “imagining” symptoms. He was encouraged to stoically endure (and forced to privately problem-solve) through shame of poor work ethic or falsification of symptoms. This finding is commensurate with Hayes’ (2001) suggestion that men’s experiences of their bodies are poorly developed and Ziguras’ (1998) assertion that men often ignore, self-diagnose and / or self-treat illness.

Randwick’s experience also illustrates how prescriptive and influential dominant social constructions of gender can be on how men are allowed to live in their bodies. The way “they said” he “must be imagining” impairment reflects dominant cultural and gendered expectations that Randwick was more likely to be an ‘imaginative’ rather than ‘disabled’ young man.

The four characteristics previously described are often commonly listed men’s health behaviours that contribute to men’s poor utilisation of health promotion programs. These are that men rely on women for health advice; they ignore, endure or act ‘late’ on symptoms; and they are more likely to treat medical problems rather than prevent illness or maintain health. However, submerged beneath this common profile of men’s health promotion, are men such as Randwick, who, in the historical context of 1941, established prescribed masculine health care practices reflective of the period. Self-sufficient, he problem solved and endured disability until his grandmother gave him permission “that one particular day” to admit weakness and accept professional medical help. The foundations of Randwick’s health care behaviours were historically informed
by a gendered division of health labour that did not expect men to be expert in health related matters. Randwick’s behaviours resemble current men’s health promotion profiles. However, the historical snapshot provides contextual understandings of the origins and dominant social constructions, which influenced his health care practices.

**Interviewing Randwick**

*Randwick’s wife Bess answers the door. I have met Bess before at the PCSG meetings. She directs me to the right of the passage where I am greeted by Randwick in the living room. In the background, I recognise a table from one of Randwick’s photographs; it has medications and paperwork on it. Bess interrupts our interview twice. Once with refreshments and once to give Randwick his twelve o’clock medications.*

**Observations and interpretations integrated with retrospective summary-Randwick Interview one, field notes 4/2001.**

The table with medications and papers on it that I refer to in the field notes was discussed by Randwick as he pointed out a section of photograph 2.

Please note that photograph 2 is cropped to protect the identity of Bess (who is standing to the side of the table with her hand on the chair). The black and white photograph 3 is a computer-mediated replica of the original photograph 2 that illustrates the centrality of Bess (whilst not revealing her identity) and provides context to Randwick’s commentary.

Randwick explained as he pointed to the medications in photograph 2:

*It’s an area of the table which [Bess] has partitioned off…she laid out all my pills to be taken every day and it was a little bit of a mind-boggling thing for [Bess] to work out when and how for me to take them…I wasn’t any help to her. I just took what she gave me.*
Randwick’s discussion about photograph 1 revealed the integral role Bess played in complex issues of stock control, monitoring and administration of his medications. Bess’ medication performance was symbolic of her health informer, provider and carer roles in their relationship. The “partitioned off” area of the table provided a designated space for Randwick’s medications and reflected the
presence of illness and treatment (and Bess’ contributions to minimise illness through medications) in their lives. Historically, the table was a site of social gatherings and family dinners at which Bess would coordinate the cooking and serve the family meals. Her role in the domestic sphere continued with the health care she provided. Bess’ centrality and proximity to the pills “she laid out” was symbolic of her caregiver role and of the conduit she provided between the doctor’s medication prescriptions and their administration. Bess continued female health care roles similar to those provided by Randwick’s grandmother. After describing the intricacies of Bess’ medication performance, Randwick proudly acknowledged the parallels “when I was growing up my grandmother saw to it that I had medication or whatever”.

Bess interrupted our interviews to give Randwick his twelve o’clock medications. I observed Randwick and Bess smiling at each other as they exchanged the pill cup and glass of water. They were content in their established roles; Randwick the ‘patient’, taking his pills and Bess the ‘caregiver’ administering medications as per the doctor’s instructions. Their ‘medication’ interactions were playful yet symbolic of their commitment to each other and perhaps reflective of their marriage vows ‘in sickness and in health’. Randwick, although cognitively and physically capable of taking his own medications, continued culturally established, negotiated gendered roles developed through more than forty years of marriage.

Many participants reported that females were, and continued to be, integral to their health care. This gendered practice was often established during formative years and continued in heterosexual partnership. Historically, gender roles in Australia were inflexible and prescriptive. Men were encouraged to work through the provision of proportionally higher wages and protection of jobs. Randwick recalled “in special areas…they kept them [women] out of work”, for instance his mother was a schoolteacher, but “they wouldn’t let her teach so she had to wash and iron”. This iniquitous division of labour enforced ‘male breadwinner’ and ‘female housewife’ roles for many participants and their partners. Randwick was the breadwinner, he “always worked 12, 14 hours a day” because he and Bess “sort of married with nothing”. Work took him away from Bess and their children.
Women’s wages were set at 54% of men’s; hence, women were often at home in unpaid ‘support roles’ (Connell et al., 1999).

One common support role for women was to look after the health of their partner and children. Therefore, dominant social constructions of masculinity and economic policy also influenced a gendered division of health labour. Many participants, including Randwick (and Bess), continued established health roles in their relationships. This finding supports Lee and Owens’ (2002) prediction that many older men take health attitudes and expectations into old age. This has implications for the design of health promotion programs intended for an audience of ‘older men’. It is likely that female partners of older men continue to act as conduits between health promotion messages and the men for whom they are intended.

Randwick married Bess in 1948 and they had lived in the same house for “45 years”. They purchased the house in an area that was “just a big block of land with houses built higgledy-piggledy along the way”. There were:

*No roads or footpaths and we were told that a freeway was on the plans, but we wouldn’t see it in our lifetime. Well, apparently we’ve lived too long because in 1969 they put a freeway through (Randwick points to photograph 4)...we’re about five houses from it.*

**Photograph 4**
Originally, the noise of the traffic “jumped over the wooden fence” but in the last few years Citylink [the freeway construction and maintenance company] built a “concrete wall, which…quietened it down”. Randwick walked over the “concrete walkway…it's part of my daily life…it's no good sitting around home. I must try and get out”. Sometimes it was too cold to cross the walkway so he went the “long way around the creek” to get the newspaper. Randwick’s description and explanation of photograph 4 revealed that considerable environmental change had occurred and affected many aspects of his life. The stark iron and concrete walkways had replaced the parks and vacant land where he once walked. The eight-lane freeway connects Melbourne’s major airports to the city centre and carries thousands of vehicles each day. Consequently, Randwick and his family endured noise and air pollution from vehicles that drove by and aircraft that flew over their house. Randwick’s once serene outer suburban home of the 1960s had become a busy, almost inner city suburb as Melbourne had grown in all directions over the last 40 years.

It was not an informed choice to live next to the freeway. However, Randwick was unable to sell their home and purchase in another location after the freeway was built. He and his family had little choice but to adapt to the changing environment. Environmental factors such as air and noise pollution are now known to have detrimental effects on people’s health. Accordingly, more than 30 years later, air and noise pollution levels are monitored in areas surrounding the freeway near Randwick’s home. Historically, knowledge of and empowerment to control environment was not possible for Randwick. Health promotion has been criticised by Watson (2000) amongst others, for its presumption that all people have equal control and knowledge of variables that potentially impact on their health and well-being.

Randwick was proud to have “built the house” himself and “felt lucky” not to “lose their house” when the freeway was constructed. The home, regardless of environmental challenges and potential health implications, was important to Randwick and his family. Symbolically, the house confirmed Randwick’s craftsmanship and breadwinner status. Within the walls, a lifetime of family memories and artefacts resided and responded. Randwick and Bess will never
choose to leave their home, regardless of environmental changes. This contests and challenges the assumption that people will choose to act in a unified rational way and minimise or avoid potential health risks.

Health promotion has previously been criticised (Hindess, 1988; Lambevski et al., 2001) for its construction of men as rational beings, fully capable of making reasonable decisions based on having adequate knowledge. ‘Rationality’ as a unified stable identity is challenged when we consider material conditions, structural constraints and human emotions, both current and historical, on people’s lives. Randwick’s empowerment came through building a family home and providing for his family. Randwick pointed to Photograph 5 and explained:

we had the car on time payment and we sold that to buy the block of land and then we struggled to get the house done and finished...we only had the flooring in one room, and a small fire, we used to sit in that room with an overcoat...one of the kiddies got a bad flu, and the doctor said we had to line a room or she had to go to hospital...I was particularly busy with the truck [working] at the time... Bess got a neighbor over the road...to line it.

Photograph 5

There was a lifetime of work invested in their family home; it symbolised achievement despite economic, environmental and health challenges. Randwick talked about how he got “the house done” and pulled out all “the thin masonite” used by his neighbour to line the room in his absence. Randwick could claim the
building of the family home as a major achievement. The late model Ford Falcon
was protected in the carport. Side by side, Randwick’s two biggest investments,
house and car, signified success through a lifetime of hard work. It would be
disempowering to abandon such achievements in search of a quieter, cleaner
environment. The years of hard work would be negated, the visual representation
would be lost and the history, as well as the future, would be submerged and
perhaps questioned.

Leaving Randwick’s house

As I board the freeway I think about a well-known Australian movie called
‘The Castle’. Central to the plot of the movie is a family home (hence the
title ‘The Castle’). The ‘head’ of the household, played by Michael Caton,
fights to keep their home. Despite increasing pressure to sell the property,
so developers can extend the nearby airport. Caton’s character relentlessly
defends his family’s pride and joy. The Australian notion of owning your
own home is portrayed in a humorous but sensitive way. The philosophical
parallels between the Michael Caton’s character and Randwick are
striking. It is a fine line between parody and reality when it comes to the
great Australian dream – to own your own home.

Observations and interpretations integrated with retrospective summary-
Randwick Interview two, field notes, 6/2001.

Meeting Steve

Steve is tall, and has thinning gray hair. He greets me with a smile as his
eyes take focus above the silver rims of his glasses. His glance is strong but
shifting with bilateral cataracts that shine opaque as they encroach deep
into his pupils. He is amicable, interesting and talkative. We sit in a little
dinette, coffee and biscuits upon a laminex table. Cardboard boxes
surround us because next week Steve and his wife Molly are moving out of
their home of 40 years, to a retirement village. It is the first time I’ve been
here, but I am sad for their impending change. Steve rationalises that their
home has become “too hard to maintain”.

Observations and interpretations integrated with retrospective summary-
Steve Interview, field notes 8/2001.

Steve “married a local girl” and “built locally” in the west of Melbourne. The
family weatherboard home was convenient to the railways where he worked for
43 years. Steve described the work and conditions he experienced as a painter in
the railways:

You were sort of railway fodder…lugging trestles and planks. In painting it
was always full of fumes, oh, bloody turps and thinners…there was no air
extrusion. In a workshop situation you caught everything that was going…hygiene was non-existent in the railway workshops. There’d be ten or a dozen of you…washing with Solvol, hands all in the one bucket. When I went over there [the railway workshop] last time and saw the extruders and extraction fans and water baths…I said to the young people…you people don’t know you’re alive…in that regard.

Steve came from rural Victoria to complete his railway apprenticeship. He knew that as long as he kept his “nose clean” and “head down” he had a “job for life”. Job security was important; Steve was newly married, had two young children, a mortgage and was the sole breadwinner. He “had a lot of bronchial problems through spray painting” and knew the workshop “conditions weren’t good but we did it that way”. Steve suspected, but was not fully aware of, the potential interconnections between his health and workplace environment at the time. He had no proof of the connection between his persistent wheeze and the workplace, or legislation to support the pursuit of improved work conditions. There was a “lot of politicking…like union bashing or union joining” but occupational health and safety was not practiced or monitored systematically during the 1950s, 60s and 70s at his workplace. Indeed Steve felt fortunate to have a “permanent job, superannuation” that would allow him to provide for his family.

Work was important to Steve. He was “blue collar working class…just above the ruck” and took pride in his physical and intellectual abilities. By his mid-40s Steve’s physical prowess at work had begun to deteriorate and he “realised those young blokes are as good, or better than me”. However, he proudly recalled up until then “[I] could do it [physical work]” and “all through I [he] had this sort of claim for respect”. Steve “was still doing night courses at 55 years of age” and when he retired, he “was the best in the painting field that the railways had”.

Work enabled Steve to fulfill a breadwinner role for his family; it also provided opportunities to confirm, construct and compare his masculinity with other men. Despite being “railway fodder”, he developed expertise that was respected by work mates. His work ethic in the workshop and commitment to learning about painting through attending night school resulted in him finishing up “as a manual training instructor” and being “the best” by the time he retired. There was working class pride in Steve’s performance, achievements and self-sacrifice. He acknowledged his poor conditions and compared them to the young people of
today, which reflected his constructions and commitment to working class performances and expectations.

Steve still meets up with “a dozen men” he worked with in the workshop. Five of them have been diagnosed and treated for prostate cancer. He pondered the disproportionately high incidence and tentatively suggested it may have something to do with “all the manual labour”. He did not suggest direct connections between the workshop conditions and prostate cancer but rather, recalled his work achievements and the masculine status it afforded him amongst other men. In contrast to Steve’s experiences, contemporary health promotion informs workplace health and safety based on established connections between environment and health. Today, Australian workers are less likely to be injured at work and employers less likely to risk litigation by providing unsafe work conditions.

When Steve was unwell during his working years, he would go to his local doctor but:

> What bugged me a bit, his [Doctor] actual treating surgery was only [small]...and my problems then were bronchial [breathing]. As soon as you got in to talk to him, he wanted to have a bloody smoke. It was just cough, cough, cough...that was the early 80s.

The scenario Steve related was difficult to imagine in light of current understandings of the connections between tobacco and disease. However, prior to the 1980s little research or public health information was available to inform people that smoking caused health problems. Many participants recalled that smoking tobacco was encouraged when they were growing up. The majority of participants consumed tobacco for varying durations, however only one participant was a ‘smoker’ at the time of our interview. Participants shared their retrospective thoughts on the stimulus, practice and meanings of tobacco consumption when they were growing up:

> When I was a kid if you didn't smoke you weren't fashionable. I think probably it was a guy thing then more than it is now...it was difficult because no one knew anything. It was no big deal then...the smart thing to do. (Bob)
The media advertised everything that was damaging to your health...Victorian Football League players endorsing Turf cigarettes...I don’t remember a lot of women smoking when I was growing up. (Seagull)

It was sold as a macho image...my ex wife for years wouldn’t smoke in front of her father even though she smoked at least a packet a day...I actually used to smoke while I was teaching. (Yanni)

I rolled my own unless you were going to a dance...you went and bought a packet of perfumed satin tips...you used to flash these out...to the girls. (Berti)

It was recreational...have a cigarette and relax...I remember having cigarette holders and all those funny things...probably 90% of the people...smoked at the time. (Don)

I didn’t enjoy tobacco but because my mates were smoking, to be with them...you had it...I would wait for the first opportunity to just drop it behind me. (Randwick)

At smoko...you would gather together to share a smoke and a yarn. (Steve)

Participants’ references to tobacco consumption provided a reminder that many Australians growing up in the 1940s, 50s, 60s and 70s were encouraged to smoke. Gendered marketing strategies prescribed smoking as a masculine performance indicator for some participants. As Bob stated it was “a guy thing”, that Yanni recalled was sold as a “macho image”. Randwick smoked to be with his mates. Similarly, the work break “smoko” connected Steve with his mates. Seagull did not “remember a lot of women smoking” and Yanni smoked in the classroom while teaching but his ex wife “wouldn’t smoke in front of her father”. The connection between tobacco and masculinity was preserved through associations with motor sports, cricket and, as Seagull recalls, Australian rules football. It was “recreational” for Don to “relax” with a cigarette and join the 90% of people smoking, and Berti flashed his “perfumed satin tips...to the girls” at dances.

Health promotion discourages tobacco smoking through smoking cessation advertisements and programs. However, in the past, smoking was marketed in
shrewd, uncensored and gendered ways. Many participants were exposed to marketing campaigns similar to Advertisement 5 that featured in an article entitled “Smoke Screen” by Simone Chapman in the Good Weekend supplement of the Age Newspaper, Melbourne Victoria, July 6th, 2002. The advertisement from 1956 included the following statement:

After all, doctors are humans too. Like you, they smoke for pleasure. Their taste, like yours, enjoys the pleasing flavour of costlier tobaccos. Their throats too appreciate a cool mildness.

This 1956 advertisement makes the abovementioned claims based on the results from a survey in which “three nationally independent research organisations” asked “113,597 doctors from coast to coast …What cigarette do you smoke?” The “answers came in by the thousands. Actual statements from doctors themselves. Figures were checked and re-checked! The results? Camels…Convincingly!” In the background of the advertisement, scientific data collection and analysis is depicted in the images. At the forefront, the assuring facial expression of the doctor, cigarette poised, concurrent with the scientific stethoscope and white coat re-enforced the positivist research results, “This is no casual claim, it’s an actual fact”. It was only as recently as 1998 that the world’s tobacco companies acknowledged that smoking caused disease and that nicotine was addictive. Their litigation defence has since been that adults smoke with informed consent of such dangers.
For most research participants, tobacco consumption was a short-lived practice. However, some participants became addicted to cigarettes. Kevin started smoking at 10 years of age. He recalled that he thought:

*Smoking couldn’t do you harm... in the back of your head it was, ‘One day I'll give these up’ but there was always next week. ‘I'm under too much pressure now to chuck them in. Next week I'll do it’ but next week went on for 40 years.*

Research reveals that tobacco addiction and smoking cessation are complex issues. There is evidence that relapse is higher in people who began smoking during childhood or adolescence (Moffat & Johnson, 2001), which perhaps partly explains the long-term challenges Kevin experienced in smoking cessation. Unfortunately, most participants smoked and few were fully aware of the risks to their health.

**Meeting Kevin**

*Kevin and I met at a PCSG meeting. He is the consummate protagonist at the meetings as well as being incredibly supportive of the other men. The*
competing binaries continue to oscillate. He wears a hegemonic yet marginalised masculinity, is supportive yet argumentative, friendly yet distant. I arrive for our interview and am greeted by a courteous man with long flowing white hair that hides his ears and shirt collar. It is Kevin, morning newspaper in hand, checking his share portfolio, as the early morning sun casts shadows from his manicured garden onto the porch. We walk inside his house and sit in a room that comes off the kitchen. Upon the stove bean soup simmers.

Observations and interpretations integrated with retrospective summary—Kevin Interview one, field notes 4/2001.

Kevin’s father fell off a lamppost in 1943 while he was working for the State Electricity Commission, after which he “went on an invalid pension” and “basically never worked again”. His mother went out to work but the wages she received were “barely enough to keep the family going and what he [Kevin’s father] got went on smokes and booze”. Kevin had “bed wetting” or enuresis (urinary incontinence) for the first 14 years of his life. He recalled that when it was first discovered his mother took him to the doctor:

*I was told [by the doctor] ‘you’ll have to eat mice if you continue wetting the bed, because that’s the treatment’. I didn’t know at the time, but this was basically a threat. Well, I don’t want to eat mice, so I’ll stop wetting the bed, as if I had any control over it.*

The doctor’s suggested treatment, to “eat mice”, inferred Kevin’s bed-wetting was voluntary that he would choose to control with the appropriate stimulus. Despite the treatment “threat”, Kevin was unable to stop wetting the bed, however he could conceal the evidence. This became particularly important when Kevin and his two brothers “were sent to a Catholic boarding school” at Ballarat in country Victoria, after the money “was put up by a rich uncle”. At boarding school, Kevin slept in a dormitory that housed hundreds of other boys. He was wetting the bed each night and concealment became increasingly difficult. He was faced with a choice between the smell and discomfort of his urine soaked mattress or visibility of his soiled bed linen hanging out a window to dry. He initially chose to minimise his “embarrassment about wetting the bed” by attempting to conceal it. He explained:

*I used to just pull the bed up and try and hide it, so that each night I climbed into a wet bed...well, it was either that or have the whole bed stripped and*
Christian Brothers supervised the boys in the boarding school dormitory. When they eventually discovered Kevin’s urine soaked mattress, they gave him “six of the best…for hiding it”. Subsequently his soiled sheets were hung out the window “for the whole school to see” which effectively made his bed wetting public.

Kevin rated the four years at boarding school as the “most miserable time of my [his] life”. He was socially conditioned to control or conceal his bed-wetting, and when unable to do either successfully, he endured a great deal of public and private embarrassment, humiliation and marginalisation.

Kevin also endured a form of ‘victim blaming’ in which he was suspected of deliberately wetting the bed. Recent health sciences research shows that bed-wetting is usually not an emotional, learning or behavioral problem and common causes for enuresis such as decreased urinary bladder size and tone have been identified (National Kidney Foundation, 2003). Furthermore, children who do not get help or who are punished for bed-wetting might develop emotional or behavioral problems according to the National Kidney Foundation (2003). I met up with Kevin again at a PCSG meeting almost twelve months after our interviews. During our conversation he volunteered, “those Christian Brothers should be investigated for what they did to boys at that boarding school”. Kevin’s experiences informed him from an early age that “control” or “concealment” were more acceptable masculine behaviours than the admission of disability.

The happiest day of Kevin’s life is the day he left boarding school. He recalled:

> Here I am at 15 suddenly let loose…I’ve gone from being super disciplined and whacked every day, to now…I’ve got real money in me pocket and these fancy clothes…and women. Smokes, booze. Like the pubs never bothered about under age. They couldn’t give a damn…I was like a dog that was let off the leash. I just went mad. A series of girlfriends, and finished up getting married to this woman that somehow or another fell pregnant.

After enduring years of marginalisation and subordinate masculinity, and physical and emotional punishment for bed-wetting, Kevin established hegemonic masculine performance through “fancy clothes”, “smokes”, “booze”, “women” and “sex”. His self-perception of being “like a dog that was let off the leash”,
suggested his behaviours were reactive, instinctual and essentialist driven. However, it is also likely that other men, including the Christian Brothers, informed his social construction and demonstration of hegemonic masculine performances. Kevin distanced himself from the Christian Brothers who “wore frocks” and “were all hung-up in one way or another”. He did this by modelling himself on men that had “an axe in their hand, and a cross-cut saw” or were “truck drivers”. He also did what ‘real’ Australian men did, which Kevin listed as “he drank in the pub, swapped yarns with his mates, he smoked, talked about sheilas, didn't act on it much, and that was it”.

Kevin grew up with his “old man down the pub” and after he left boarding school he replicated his father’s drinking and smoking because it “was the fast track to being a man”. Kevin reacted to the subordination, control and marginalisation he had endured through hyper masculine hegemonic performances, many of which are now referred to as ‘risk taking’ behaviours in health promotion discourse. Kevin accepted that he was responsible for his health:

*My diet was the pits. Smoking and drinking, which was what you did anyhow, was all part of the deal…no regular exercise. You got exercise when you built something or dug the garden. So, there was me in charge of me health. I made a botch of it.*

Kevin regretted his subscription to “the deal” of what men did to display and confirm their masculinity. He minimised his marginalisation and pursued hegemonic masculinity that had been unobtainable whilst he was wetting the bed. He had little understanding or regard for the health implications. His retrospective summation of making a “botch of it” suggests that Kevin’s understandings of health and risk taking has changed over time.

**Summary of discussion and findings**

The findings from this study illustrate diverse participant experiences of health and illness whilst growing up in Australia. As stated in the introduction to this section, health promotion, as it is now known, was absent from the majority of participants’ lives during their formative years. It is acknowledged that there may have been other constructions of illness prevention during this period. However, the findings from this study provide contextual data that reminds us of the recent
politically motivated and articulated model of health promotion. The absence of health promotion, as it is now constructed, from men’s early lives is an artefact of different concepts of health from the 1930s to 1970s.

The findings from this study revealed that whilst growing up in Australian many participants:

- had little experience of illness prevention or health maintenance
- used health services to diagnose and treat their health problems
- were informed by females, especially mothers and wives, about their health and illness needs
- self-treated health problems as a way of concealing or controlling the visibility of symptoms and illness
- had limited knowledge of potential connections between behaviours, work, environment and health
- were influenced by social class about expectations of physical work performance and sustainable health and well being.

Exploration of the origins and historical health practices of participants is not intended as a strategy to give voice to a chorus of ‘blaming victims’. That is, participants are not espoused as being uniformly unknowing, disadvantaged and therefore not responsible for their health practices and lack of receptiveness to contemporary health promotion messages. Instead, the commitment to contextual understandings of participants’ lives, congruent with recommendations by other researchers (Buchbinder, 1995; Courtenay, 2000; Huggins, 1998; Lambevski et al., 2001; Thorogood, 2002; Watson, 2000; Wood, 2001) is the motivation for the presentation of this finding.

Dominant social constructions of masculinity in Australia were historically prescriptive and breadwinner roles were enforced by patriarchal economic policy that devalued female wages at 54% of men’s (Connell et al., 1999). In this equation the marriage vow “for richer and for poorer” was often exclusively the responsibility of men, many of whom would trade their physical labour for money in order to provide for their family. The marriage vow “in sickness and in health”
was the domain of females, in which women looked after the health of their men and children. When women were unable to treat illness independently, professional medical assistance was sought.

Such practices reflect the ‘therapeutic era’ of public health that was dominant in Australia during the 1940s to 1970s. As previously established by O’Connor-Fleming and Parker (2001) the therapeutic model focused attention on individual pathology and therapies designed to cure disease. This period was marked by a weakening of departments of public health and a shift of power and resources to hospital-based services. The promise of ‘fast cures’ informed Randwick (vision and hearing problems), Steve (bronchial problems) and Kevin’s (bed-wetting) practice of going (or being taken by females) to the doctor for specific health problems.

The therapeutic model traded on the belief “that all social problems were caused by illness and that disease had nothing to do with either working conditions or the health hazards associated with poverty” (O’Connor-Fleming & Parker, 2001, p. 13). Steve provided an interesting example of this assumption, in that his bronchial problems were treated, yet connections between symptoms and work environment (or the smoke in the doctor’s consulting room or at work ‘smoko’) were not necessarily made.

The therapeutic era was challenged during the 1970s when many participants were approaching middle age and had already established certain health care practices (or lack thereof). As predicted by Lee and Owens (2002), some participants continued health care practices that were informed by earlier experiences and historical constructions of health services, illness and masculinity. Subsequently these early dominant social constructions of health have partly reduced the relevance of health promotion for some participants in their later lives and health practices have not altered sequentially with policymakers’ visions of health promotion.

There is a variable time lapse between health policy implementation and men’s health behaviours. Many older participants continued to subscribe to the therapeutic era that offered fast cures, but they were able to differentiate between
predominantly negative historical health messages and the health information available today. This finding suggests that participants’ understandings of health (and health risks) shifted over time and are not fixed, but continually constructed. This is encouraging from a health promotion perspective because it disrupts essentialist notions that men are ‘naturally’ predisposed to ignore health promotion programs. Although health care has been socially constructed as feminine, many participants understand in later life the need to maintain their health.

The current research finding demonstrates how culture, history and class intersect with dominant social constructions of masculinity and inform and affect participants’ health practices. The micro socio-cultures that Randwick, Steve and Kevin inhabited and negotiated reveal valuable insight to their constructions of health and illness. Participants did not grow up with exposure to contemporary health promotion campaigns such as ‘Men’s Health Tune Up’, ‘Drink Drive, Bloody idiot’, ‘No one should die at work’, ‘World No Tobacco day’, ‘Daffodil Day’ (public cancer awareness and cancer research revenue raising campaign) and ‘Quit’ Smoking initiatives.

The findings from this study are consistent with Lambevski et al. (2001) who, following a study of Australian men’s health promotion practices, concluded that there is limited usefulness in the:

- epidemiological approaches to understanding individual men
- presuppositions of a fully rational male group
- espoused unified masculine identity in discussions of men’s lack of responsiveness to health promotion.

From a theoretical perspective, health promotion programs underpinned by the Health Beliefs Model and the Theories of Reasoned Action and Planned Behaviour, previously described by Nutbeam and Harris (1999), may have limited application for many men. The finding from the present thesis supports Pease’s (2002) recommendation that the assumptions of health promotion models that hold individuals fully responsible for ensuring and maintaining their health be critically examined. Furthermore, the Social Learning Theory, a model where
behaviour and social environment are considered dynamic and reciprocal (Nutbeam & Harris, 1999), is strongly recommended based on the findings from this study. Health promotion strategies such as social marketing offered by Blair (1995), Gibbs and Oliffe (in press) that seek to engage men in health promotion programs through understanding common ‘male’ practices would be well informed by contextual gendered understandings of men’s lives. Such detail would inform health promoters how to communicate with older men about their health in meaningful ways.

It is naïve to define certain types of masculinity as pathological. Men need to be aware of health risk in the first place, prior to considering how they could minimise the risks they face. An appropriate beginning point for designing men’s health promotion programs is audience identification. However, rather than being based on profiles of men’s health promotion, it should be informed by talking with men about health. This is especially true when we speak to older men because health is contextual, socially constructed and subject to change over time. The findings from the present study strongly supports Watson’s (2000) suggestion that rather than uphold the general view that men are disadvantaged by their gender roles, exploration and interpretation should be conducted at an individual level.

**Recommendations**

The findings from this study suggest further longitudinal and life course research into men’s constructions of health would inform the development of health promotion programs for middle-aged and older Australian men. Micro life course, as demonstrated in this thesis study, is a particularly effective method to explore men’s health practices over time. This recommendation is developed in Chapter Seven, *Conclusion and Recommendations*.

**Section Two: Prostate cancer screening and health promotion**

As discussed in Chapter Two, Section One, Part B, *Health promotion and prostate cancer*, prostate cancer has been difficult to situate in contemporary health promotion frameworks. Specifically, health promotion programs that seek to empower men to avoid known health risk factors have little direct application
to prostate cancer. Unlike other cancers, such as skin cancer where ultra violet light is known to increase incidence, the cause of prostate cancer is unknown (Kozlowski & Grayhack, 2002). Prostate cancer is also asymptomatic in the early stages and urinary symptoms and musculoskeletal pain can indicate metastasis (Meredith, 2000). This makes self-monitoring for symptoms less effective, as prostate cancer is often advanced by the time symptoms are experienced. Furthermore, the anatomical position of the prostate gland precludes self-examination available for other cancers such as those affecting breast and testes.

Despite the complexities of prostate cancer, “early recognition and treatment is required to control growth, prevent metastases, and preserve quality of life” (Meredith, 2000, p. 563). Early detection is best achieved through prostate cancer screening. However, Lee and Owens (2002) emphasise that men undertake less voluntary medical screening checks than women. Prostate cancer screening is available through two tests, the Digital Rectal Examination (DRE) and the Prostate Specific Antigen (PSA) blood test. Participants’ screening practices, experiences and recommendations are presented in four parts. Part A, Voluntary screening or Symptom testing explores the events that led to participants’ initial prostate cancer screen or test. Arsenal, James and John feature in Part B and C and they, along with other participants, discuss their experiences of the DRE and PSA screening tests. The findings are presented in two sections, Part B, To DRE or not to DRE: Is that a penetrating question? and Part C, To PSA screen or not to screen: Is that a political question? Part D, Spreading the word examines participants’ screening recommendations and practices for prostate cancer.

**Part A—Voluntary screening or Symptom testing**

All participants undertook PSA blood tests and/or DRE examinations, which revealed abnormalities that led to further investigation and, ultimately, a diagnosis of prostate cancer. Most participants were not diagnosed through voluntary routine screening, but rather through a course of events or stimuli resulting in a continuum of tests.

Female partners influenced many participants to consult a general practitioner (GP). Wayne went at the insistence of his partner because he was “having difficulty getting an erection”. Bob was originally “pushed off” by his wife to get
his “sugar checked” because he “wouldn’t have done it”. Ron’s wife told him “to get a PSA check when he got his influenza vaccination” because she had seen a television show that suggested men should be routinely screened for prostate cancer. Steve had a “lack of energy…but Molly [Steve’s wife] said it’s not right”, so he went to his GP. Similarly, Greg was tested after his wife saw a television program that recommended men be screened for prostate cancer. He went two years after she first mentioned it “because I [he] had no symptoms”. Wally had “an irritable bowel and I would go for a walk and…need to go to the loo and my wife was getting sick of it and said…—you should go to the doctor and see if there is anything they can do”. Wally was subsequently screened for prostate cancer at the consultation with his GP.

The findings from this study show that female partners were integral to many participants’ decision to consult a general practitioner. A few participants, such as Ron, were asymptomatic and requested a PSA screening based on their partner’s recommendation. However, many participants, including Steve, Wayne, Bob and Wally consulted a GP (and were subsequently screened for prostate cancer) after their partners encouraged them to act on existing symptoms. These findings are consistent with Volk et al. (1997) who found that men’s decisions to undergo prostate cancer screening often involves spousal opinion. Moreover, spousal influence may directly or indirectly relate to PSA screening.

A few participants recognised and independently initiated medical consultation because of physical symptoms:

- I was getting up more of a night to go to the toilet and mentioned it to my doctor. (Randwick)
- It was taking a bit longer to have a leak. When I finished...there was always a little bit left...I had to clear...so I went to the doctor. (James)
- I had a sore left testicle. So I went to see my GP about it. (Yanni)

This finding supports Ziguras’ (1998) suggestion that men establish ‘reactive’ self-care practices in which they seek medical consultation after experiencing symptoms. Furthermore, Randwick had been getting up during the night for “a few years”, James went to his GP “two or three years” after initially noticing urinary changes, and Yanni had been “sore for a while” before consulting a GP.
The practice to act late on symptoms has also been described by Jones (1996) and Ziguras (1998).

Some participants perceived that they were asymptomatic, but spoke about subtle urinary changes they had experienced retrospectively, prior to diagnosis. For this group of participants, urinary changes were not perceived as symptoms but rationalised as expected aspects of aging or lifestyle. “With hindsight” Ben recalled “I did quite often get up once at night. I thought that this was a reasonable product of my social life, the amount of liquid I was consuming in the evenings and my age and it was not a problem…I could seem to rationalise it”. Don stated “in retrospect I remember sometimes I was a bit slower to urinate, that was about all”. Verlow “didn't have any symptoms whatsoever. The only symptoms I suppose you could say that I had - - my stream was sort of narrowed down a little bit”. William would “get up probably at least once a night to go to the loo, but then we'd drink probably ten times the amount of fluid that we'd drink here…so I wasn't really aware of any symptoms”. Argonaut had “slowing of the urine stream. I'd get up perhaps twice a night but it was not the sort of problem that one would normally equate with prostate cancer…I thought it was probably just part of the growing old syndrome”. Kevin “had no symptoms at all, and I know that one of the symptoms is people getting up frequently during the night to go to the toilet, but since I'm a big boozer, I tended to do that anyhow”. The subtle nature of urinary changes, absence of pain, maintenance of physical performance and social roles contributed to some participants’ rationalisation of ‘changes’ rather than identification of significant symptoms. The findings from this study also showed that these participants socially constructed their bodies as wearing out over time but did not expect to be ill. This in part, supports Corbin (2003), Hayes (2001), Pease (2002), Williams and Bendelow’s (1998) assertions about men’s limited experience and understanding of their bodies.

Some participants requested prostate cancer screens because they were aware of the possible significance of familial history of prostate cancer or through other men’s prostate cancer testimonials. Unicorn had annual prostate checks because his “father had prostate cancer” and he was aware of his predisposition for prostate cancer development. Arthur went to his doctor for a “full pull through”
because “my father and my grandfather both had benign enlargements” [non-cancerous enlargement of the prostate]...I was trusting him [the doctor] to do everything that seemed appropriate”. Arsenal requested a prostate cancer screen after his cousin contacted him to say he had been recently diagnosed. Clark asked his doctor for a prostate check because:

_A business acquaintance, who said that he was selling his business...because he had prostate cancer and they couldn't do anything for him. I just said, 'And, how old are you?' and he said, 'Sixty' and I said, 'Oh, shit'. Umm, I should go and see my doctor for a check-up because I haven't been to him for a while._

Because of increased awareness of prostate cancer, these participants undertook asymptomatic PSA screening. They perceived the major benefit of screening was early detection and treatment, and therefore avoidance of advanced, life-threatening prostate cancer. This finding indicates that contextually, some participants were willing to be screened for prostate cancer in the absence of symptoms.

**Summary of discussion and findings**

The findings from this study are consistent with Ziguras (1998) and Volk et al.’s (1997) predictions that many men seek guidance and/or are prompted by female partners to consult their doctors. As discussed in Chapter Four, Part One: Victims or Suspects? – Australian men and health promotion, many participants continued established gendered health practices in older age and female partners were their primary health informers. The centrality of females to participants’ health care is strongly represented in this study. Media articles and health promotion campaigns, such as Jo Bailey (Barry 2002) and Shari Belafonte (American Cancer Society 2001) (previously discussed in Chapter Two, Section One, Part B, Health promotion and prostate cancer) may be integral to ‘reaching’ men through female partners and encouraging men to be screened for prostate cancer. However, they are also likely to influence and perpetuate dominant social constructions that women are responsible for the health of the men in their lives.

The findings from this study also confirmed that some participants acted on symptoms after extended periods of time—a finding well established by Jones (1996) and Ziguras (1998). However, in the context of prostate cancer, disparity
existed between biomedical definitions and participants’ experiences of physical symptoms. Biomedical research suggests that advanced prostate cancer can produce weak or interrupted urine flow, frequent or difficulty urinating, nocturia and blood in the urine (Kozlowski & Grayhack, 2002). Many participants experienced and interpreted such biomedical symptoms as expected changes related to lifestyle and/or aging. Corbin (2003) has previously argued that disparity exists between definitions of biomedical ‘symptoms’ and the person’s experience of body changes and sensations. Many participants experienced urinary changes as subtle and non acute which did not ordinarily inhibit activities of daily living. The absence of pain also legitimised self-monitoring of urinary changes, rather than influencing participants to consult a doctor.

A number of explanations are offered for men’s common practice to rationalise and act late on symptoms. Williams and Bendelow (1998) suggest a cognitive basis, in that men separate reason and feeling. Hayes (2001) notes that there is a real issue around men’s development of their own embodied experience. Pease (2002) describes a conceptual knowledge deficit, in that many men know very little about their body or what makes it work and why it sometimes does not work. The findings from this study support, at least in part, all of these explanations. However, the aforementioned characteristics of rationalising, not feeling, denying or not knowing about body or health issues are inextricably tied to dominant social constructions of masculinity.

As previously described by Skord and Schumacher (1982), O’Hehir, Scotney and Anderson (1997) and Ziguras (1998), denial or holding on to symptoms is interconnected with masculinity. Weakness is often associated with the admission of symptoms, physical changes and reduced performance or functionality, and uncertainty accompanies the formal investigation of their origins. Both weakness and uncertainty are at odds with dominant constructions of masculinity. Conversely, to be self-reliant, independent and deny symptoms to self and others is congruent with dominant forms of masculinity. Similar connections between masculinity and health behaviours have been reported by Charmaz (1995) and Courtenay (2000). Furthermore, most participants in this study did not expect, anticipate or accept being unwell and rejected, ignored and denied physical
symptoms. In the aftermath of being diagnosed with prostate cancer, many participants continued to dismiss their pre-existing urinary changes as insignificant. The rejection of symptoms continued despite proof to the contrary and demonstrated some participants’ expectation that there was no reasonable way they could interpret and act on such physical changes.

Some participants who undertook voluntary prostate cancer screening were influenced by other men, either through testimonials or family incidence of prostate cancer. As has been established by Lee (2002), perceived benefit is a facilitator of men’s choice to be screened for prostate cancer. The findings from this study indicate that most participants’ perceived benefit of screening related to mortality and the avoidance of premature death—this has previously been described by Chapple et al. (2002). In effect, participants pursued early identification and treatment to reduce the severity and life-threatening potential of prostate cancer. Voluntarily screening was constructed by some participants as pro-active in that they identified and solved prostate cancer problems early, before it was too late. Their awareness of mortality was constructed through other men’s experiences of prostate cancer. This finding suggests that the use of testimonials in mainstream media may encourage some men to be screened for prostate cancer. Testimonials such as Robbie Flower (Sheehan 2001), which described the benefits of early detection may be effective in influencing some men to be screened for prostate cancer. This strategy has previously been described by Nutbeam and Harris (1999) as the communication-behaviour change model, in which the source of the health promotion message is someone respected by the men most at risk.

**Recommendations**

The findings from this study showed the centrality of females as primary health advisors and confirmed that many participants continued to construct health care and expertise as feminine. A salient line for future research is the exploration of how single men construct health and interpret and act on changes to their bodies. This recommendation is developed in Chapter Seven, *Conclusion and Recommendations.*
Part B—To DRE or not to DRE: Is that a penetrating question?

Potential barriers and facilitators to prostate cancer screening also reside in the screening procedures themselves. Part B and C features Arsenal, James and John’s experiences of the DRE and PSA screening tests.

Male taxicab driver (early 30s): What do you do for a job?
Mr. Oliffe: I am researching men’s experiences of prostate cancer.
Male taxicab driver: Oh, bend over and fingers up the arse type thing.

Brisbane in transit (Taxicab) City to Airport, 7/2002 Post presentation International Sociology Conference.

Male Flight Centre consultant (early 50’s): What is your PhD in?
Mr. Oliffe: Prostate cancer
Male Flight Centre consultant: I had a rectal examination once, everything was alright, never again though.

Melbourne 10/2002 Booking a flight.

It is interesting to hear men’s reactions to my prostate cancer research. It seems much of men’s public perception of the prostate gland includes the rectum or anus and its penetration. This perception is most likely related to the traditional prostate cancer screening test, the DRE. In this procedure the doctor inserts a gloved finger into the rectum and palpates the prostate gland through the bowel wall. Tenderness, enlargement or hardening indicative of prostate gland pathology may be identified in this way.

In the initial PCSG fieldwork I noted the DRE was often a source of humour in public. At one PCSG meeting a group member asked attendees Why did the doctor use two fingers for the DRE? He wanted a second opinion! Similarly a PCSG newsletter advertised an art exhibition which included a sculptured pair of 1.2 metre high hands called ‘Chat’ (Advertisement 6). The newsletter commentary accompanied Advertisement 6 suggested to PCSG members “We might have suggested other names and scenarios, at least for the left hand”.

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The left hand shows an extended index finger, a similar anatomical position used by doctors when completing a DRE. Whilst the DRE is often publicly portrayed in a humorous manner, privately participants’ DRE experiences were complex and contextual. Most participants were anxious about having DREs to screen for prostate cancer.

**Meeting Arsenal**

_A plane, train, bus, cab and leisurely walk later I am at Arsenals’ Sydney home. A perspiring man wearing running shoes, shorts and a Nike T-shirt answers the door. He has been out running, completing his morning jog. He invites me in and suggests I “have a seat” while he takes a quick shower. Minutes later his articulate semi hoarse voice re-enters the room before him, as he offers to introduce me to soymilk and decaf coffee prior to our interview. He seems a little unsure of where his prostate journey will take him, but is pleased to talk about the meandering trail upon which he has travelled._

**Observations and interpretations integrated with retrospective summary—Arsenal Interview, field notes 9/2001.**

Arsenal’s cousin had recently been diagnosed with prostate cancer. He rang Arsenal to inform him of the diagnosis and “since our [their] fathers were brothers” encouraged him to be tested for prostate cancer. Arsenal, despite having no symptoms, went to his doctor “looking for the PSA test”. He requested a PSA blood test rather than a DRE because he “always felt reluctant about it [DRE]” and “just wasn’t prepared to be personally invaded”. He explained with the DRE “I had to gear myself up to bend over or lay down, draw my legs up and have someone stick their finger up my bum.”
Arsenal was reluctant and anxious about the passivity and penetration through having a DRE. At Arsenal’s insistence, his doctor completed a PSA blood test rather than a DRE at their first consultation. However, the PSA level was elevated and a DRE is completed at a follow up appointment. Arsenal recalled that the:

*GP made an attempt to give an explanation as to what she was trying to do. I can’t remember because soon after that [the DRE], I was so enraged by the events that my recollection about some of those details is very poor*

During our interview Arsenal stated that he saw “everything as a competition”, liked “to have control” and to “beat the others”. Paradoxically, the DRE, despite the context and the doctors explanation, demanded subordination, passivity and voluntary loss of control that left Arsenal “enraged”. Many participants were reluctant to have DRE screening. Steve recalled his first DRE that was completed by a locum doctor [not his regular doctor]:

*this big bloke --- and I mean, he was a big bloke [Steve’s hands horizontally wide apart] --- he had bloody fingers bigger than me thumb…By hell…it was tough...because of the size of the man’s fingers...the man was so rough, I thought no, I don’t need this sort of thing*

Steve was anxious about the “size” of the doctor’s penetrating finger which he correlated with the subsequent “tough” “rough” procedure. Finger size and anal penetration replaced dominant male heterosex constructions of penis size and vaginal penetration in Steve’s description. He subsequently avoided future DRE screenings for three years until he went to his doctor with a “lack of energy” and a DRE was prescribed and legitimised as a way of identifying the source of his lethargy.

Aside from the physicality, Steve’s earlier DRE experience with the locum was traumatic because he did not know the doctor. Steve met the locum doctor briefly for the first time, prior to the DRE he described. Comparatively, he experienced far less discomfort when his usual doctor who is a “gentleman’s gentleman…very understanding” completed his DRE. Familiarity and trust reduced Steve’s anxiety, although even now he “breathes a sigh of relief” when he doesn’t get a DRE during biannual consultations with his regular doctor.
Kevin had regular DRE’s to monitor his prostate cancer and treatment. He differentiated between his and the doctor’s experience of the DRE:

*He [doctor] digitally examines people...100 times a day, and it’s sort of - - well, it’s scratching his ear to him. But, to me and any other patient, this is invasive.*

A couple of times Kevin had “got a half dry finger…the lubricant hasn’t been completely around the finger and it hurts quite a bit”. Kevin told his Urologist to “make sure you’ve got that lubricant properly on…right around, before you put the finger in”. The Urologist said to Kevin ‘I don’t know why you’re worrying about things’ and Kevin replied “well, I’m sorry, but…I’m on the receiving end…Take it easy, man”. Kevin was troubled by the “invasive” physicality, being on the “receiving end”, and the doctor’s approach. He reclaimed some control and power by expressing his preference for lubricant and a gentler technique from his doctor. However, Kevin’s tension about having DREs was never completely resolved.

Arsenal was enraged through being “personally invaded”, Steve correlated his discomfort to the “size of the man’s [doctor] fingers” and Kevin tried to regain some control despite being on the “receiving end”. Many participants relied, in varying degrees, on dominant social constructions of male heterosex. Which According to Zilbergeld (1992), are based on functional performance aspects of erection, penetration, and climax. This model prescribes that heterosexual men penetrate and female partners are penetrated. There is a binary logic in this model in that the receptive person is passive and feminine, and the insertive person is active and masculine. This finding has previously been established by Kippax & and Smith (2001) in the context of anal intercourse between men. There is also an analogy between the anus and the vagina in which the penetrated anus is viewed as feminine. The DRE includes recipients being penetrated anally with a gloved finger and the prostate gland being palpated through the rectal wall, which creates tension and anxiety for many participants. Furthermore, as Kippax and Smith (2001) have described, part of this receptive experience is the socially structured nature of the act itself, in so far as the anus is stamped as the most private and shameful part of the body.
The reluctance of most participants to have regular DREs for prostate cancer screening has widespread implications for health promotion programs. Although the DRE is a quick and inexpensive examination, few participants underwent DRE without symptoms and/or their doctor’s recommendation.

Arsenal was also uncertain about the accuracy of the DRE. His first doctor could not feel any abnormality during the DRE “which irritated the hell out of me”. Subsequently he was referred to other doctors and went “from one specialist to another…all of them wanted to do a DRE”. Arsenal was “infuriated” because “not one of those bastards [doctors completing a DRE] would tell me what the outcome was”. He was angry that, despite having many doctors perform DREs, their findings were inconclusive. Furthermore, Arsenal’s suspicion about the limited accuracy of DRE screening is confirmed in two studies by Littrup, Lee and Mettlin (1992) and Lee et al. (1998).

The DREs occurred at a time of great uncertainty and stress in which Arsenal was unsure if he had prostate cancer. He was unsure of the diagnosis, as well being anxious about the DRE, both of which were out of his control. He needed a definitive diagnosis, confirmation of a problem, which he could ultimately make decisions about solving.

Participants’ familiarity and relationship with their doctor also impacted on their experiences of DREs. Arsenal was “infuriated” by the non-communicative “bastards”, Steve, as a “person who’s never had one before” preferred his “understanding” regular doctor and Kevin negotiated power differentials by telling his doctor to “take it easy man”. James and John provided further insight to the correlation between their DRE experiences and doctor relationships.

**Phoning James**

*A lively happy voice travels huskily down the phone line from regional Victoria. He jokes and laughs. James is a man of humour, conviction and principle. His prognosis is poor but he celebrates the moments, including the illness moments that make up his life.*

**Phone Interview James 11/2001**

James read about prostate cancer and PSA testing in the “Reader’s Digest and that’s what actually put that flag in my [his] brain that something wasn’t quite
right with the urinating”. He realised that he “did have the early symptoms” which “two or three years” later he mentioned to the doctor. His PSA test was elevated and James was referred to a specialist for consultation and a DRE. James had “always been able to discuss everything” with his specialist doctor who he described as “a character” and “more of a mate….a fair dinkum mate”. He recalled his first DRE, when the specialist stood back, looking at James lying on the examination bench with his knees raised and buttocks exposed. James explained that he has a tattoo on each buttock:

One is two pigs having sex...’True love’, across the top and ’making bacon’ underneath...on the other cheek is a bunch of cherries. ‘Here’s mine, where’s yours’.

James enjoyed the humour and laughter that followed the specialist’s discovery of his “artwork”. He accepted the DRE was necessary, which was validated when the examination revealed his “prostate was rather enlarged”. He trusted the specialist and doctors and was happy to “let them take charge” and to put himself “in their hands because they are the experts”. Although his cancer was advanced and has most likely metastasised outside the prostate gland, James was relieved that he:

Left [him] myself with them [doctors]...because so far I am still here...so that is pretty reassuring at this point in time.

Phoning John

John speaks with me from his Dairy farm in regional Victoria. He is in the living room, his wife sits across from him at the dining room table, listening to her husband’s interview. He is wounded, angry and full of fight. Articulately hostile, he grapples with his poor prognosis as he casts critique and blame on doctors and a health system that has let him down.

Phone interview John 11/2001

John noticed “decreased urine flow” during his late 50s, and mentioned it to his doctor who “didn’t seem at all inclined to discuss it”. He went back to the doctor 18 months later, “mentioned it to him again that I [he] still wasn’t peeing any better than I [he] had before”. A PSA blood test was taken and “came back at 26”. John was referred to a specialist who performed a DRE. John offered a “word picture” to illustrate his experience of waiting for the DRE:
Naked on the table... for twenty minutes... waiting for him [the specialist] while he was on a phone call... having a go at somebody who had done something that morning

John was vulnerable and uncomfortable as he waited for a DRE that would contribute information about a potentially life-threatening disease. He suggested “some of them [doctors] perhaps enjoy the God-like position it gives them if they scare hell out of you”. The DRE itself “does not worry” John. However, the lack of sensitivity and respect he perceived from this “fairly blunt man” (his specialist) exacerbated his frustration at not being ‘tested’ eighteen months earlier, despite reporting urinary symptoms to his general practitioner.

Comparatively, James’ and John’s experiences of DRE illustrate how significant participant’s expectations of, and relationships with, their doctors can be. Therapeutic relationships based on trust and respect are likely to be integral to the success of health promotion programs that seek to encourage men to be screened for prostate cancer through DRE testing. The majority of participants, including James and John, rejected DREs as a legitimate means of screening for prostate cancer. However, many participants rationalised and accepted (to varying degrees) DREs to investigate symptoms and diagnose prostate cancer. Whilst health promotion campaigns such as John Hopoate (Cancer Society, 2001) (discussed in Chapter Two, Section One, Part B Health promotion and prostate cancer) are intended to be humorous, they potentially increase men’s private anxiety about ‘routine’ DRE prostate cancer screening. John doubted anyone was encouraged to be DRE screened through “banter about gloved hands… because the fact is, most… blokes… are pretty damn uncomfortable” about it.

Perhaps John said it best in his prediction of men’s DRE screening practices:

If they pushed the PSA test and you find you have a reading then I mean the digital thing [DRE] is a natural progression after that and it’s not going to worry you one little bit. But if there is a question of whether you will go in there and have a digital rectal [DRE] or whether you will stay away and go fishing, you are going to go fishing aren’t you?

John predicted that without symptoms the DRE was redundant for most men. He also said “the doctors are just as diffident about it [DRE] as patients”. Although an outlier in his suggestion, John raised a pertinent point. If doctor’s discomfort
about performing DRE affects their willingness to suggest or encourage DRE, a potential ‘stand off’ may occur where neither doctor nor patient is willing to comply with DRE screening. The reluctance may also be informed by dominant social constructions of anal penetration between men as homosexual (Wilton 2000). Therefore, homophobia may also prohibit the undertaking of DRE.

**Summary of discussion and findings**

The findings from this study are consistent with Underwood (1991) and Shelton, Weinrich and Reynolds’ (1999) suggestion that negative feelings and embarrassment about the DRE can inhibit men from undertaking screening. Additionally, this study reveals that the following factors underpin many participants’ disinclination to have DRE screening:

- the disruption of dominant constructions of male heterosex in which men are penetrated, passive and feminine rather than penetrating, active and masculine
- lack of legitimacy to voluntarily initiate DRE without physical symptoms or problems
- poorly established patient – doctor relationships
- homophobia and the need to maintain distance from practices historically perceived as homosexual.

The connection between men through mateship is a traditional time-honoured Australian pastime. Activities bring mates together. For example, competitive sport is a signifier of dominant masculinity, although men often hug each other and display emotion during the course of the game and bathe together after the game. The hotels and front bars where men meet with other men to drink beer and discuss ‘men’s business’ are also common place in Australian cultures. However, sport and alcohol consumption confirm and test masculinities through competition and camaraderie between men. There is a code of masculine conduct that prescribes these as appropriate forums and interactions between men. Many authors, including Ward (1958) and Murrie (1998), have previously established that these behaviours are congruent with dominant cultural forms of masculinity.
The DRE is outside these practices and disrupts dominant heteronormative constructions of mateship and masculinity for many participants. It demands passivity that is feminine and anal penetration that is inextricably tied to homosexual masculinities. To voluntarily request regular DRE screening risks subordination within heteronormative masculine hierarchies. Additionally, it raises suspicions about the subscription to hetero-masculinity and potentially subordinates men in homosexual masculinities.

The health promotion framework most likely to encourage DRE is difficult to identify. The John Hopoate advertisement (Cancer Society, 2001), discussed in Chapter 2: Literature Review, Section One, Part B, Health promotion and prostate cancer is likely to further distance men from voluntary DRE. Specifically, the use of a one time hegemonic masculinity, now suspect and marginalised, which Hopoate represents, re-enforces heteronormative distance from DRE. Furthermore DRE humour may inadvertently perpetuate homophobia, rather than encourage men and their doctors to collaboratively negotiate and undertake DRE screening.

The findings from this study are consistent with Courtenay (2000), Gibson and Denner (2000) and Ziguras’ (1998) suggestions that many men are reluctant to regularly visit their GP in the absence of medical problems. Furthermore, unlike many females who regularly attend obstetrics and gynaecology specialists, participants do not ordinarily consult a urologist until genitourinary problems are indicated. As a consequence, most participants have not established relationships with health care professionals. The DRE was invasive and disruptive for many participants and may have been better tolerated through an established relationship with their regular doctor.

**Recommendations**

The findings from the present thesis study indicate that the design of health promotion programs aimed at encouraging men to have DREs need to be presented as valid, rather than perpetuating their incompatibility to dominant forms of masculinity. Perhaps regular DRE is most likely to occur when doctors are those with whom men have an established ongoing relationship. These recommendations are developed in Chapter Seven, Conclusion and Recommendations.
Part C—To PSA screen or not to screen: Is that a political question?

The PSA blood test, which can be used to screen for prostate abnormalities, became available in Australia in the 1990s. As discussed in Chapter Two, Section One, Part B, Health promotion and prostate cancer the PSA blood test provides an alternative and/or complementary prostate cancer screening test to the DRE.

Unlike the DRE, PSA blood tests were requested by some participants as a prostate cancer screening test. Arsenal said the PSA:

*Struck me as something I could handle...analyse the result, get a number. I’m numerate, I understand what numbers mean, so that was no problem*

Arsenal could “handle” his skin being penetrated with a needle. His arm, from which the PSA blood sample was taken, was an enduring site of muscle mass and tone, a signifier of strength and masculinity. The procedure was visible if Arsenal chose to watch and keeping his arm still re-instated his control. There was courage in having blood taken even though he “don’t [doesn’t] like having needles of any sort”. The majority of participants were physically comfortable with PSA blood tests and intellectually satisfied with the standardised PSA quantitative scores. John confirmed “in my [his] experience the PSA test has been spot on…it is as accurate as you can imagine”.

Despite participants’ comfort with PSA screening, controversy about the appropriateness of widespread screening continues in Australia. The Stricker—Hirst public debate (Gardner 2001) discussed in Chapter Two, Section One, Part B, Health promotion and prostate cancer, presented two polarised medical views of PSA screening that did little to clarify public or professional confusion. Most participants were emotive about PSA screening. Arsenal attended the Stricker—Hirst debate less than 12 months after having radiation therapy. His radiation therapy side-effects included bleeding from the gastrointestinal tract and loose, sometimes bloody bowel actions. He hoped he acted wisely in following his cousin’s advice and choosing to be screened for prostate cancer. He said:

*the disruption to my life after I had it [radiotherapy treatment for prostate cancer] was very, very great. I hope to hell it’s not true [Hirst’s advice not*
to be screened]. I would have hated to have gone through all of this for no reason at all.

The newness, severity and uncertainty of the treatment side effects and prostate cancer disease contributed to Arsenal’s tension. There was no way to be sure or to validate his screening and/or treatment decisions. Whilst not convinced, Arsenal avoided decisional regret and asserted that he expected to “live another fifteen years” through being screened and treated. The public uncertainty of professional medical screening guidelines, as illustrated by the Stricker—Hirst debate, informed an uneasiness for a few participants who, without symptoms, chose to be screened, diagnosed and treated for prostate cancer.

John’s advanced, inoperable prostate cancer was diagnosed in 1999. The Stricker—Hirst debate of 2001 evoked anger rather than uncertainty for him:

*There is such a yawning gap between what they are saying. There can’t be that gap. I mean truth…should be scientifically known*

John expected that scientific “truth” should inform PSA screening recommendations. He was dissatisfied that, despite mentioning the “decreased urine flow” to his GP of twenty years, he was not screened for prostate cancer until 18 months later. John believed earlier diagnosis (when he first reported urinary symptoms to his GP) would have facilitated treatment options and a better prognosis. A few months after the Stricker—Hirst debate, John attended a men’s health night in regional Victoria and reported further public confusion about PSA screening:

*he [guest speaker] stands up there and tells everybody...to go and get tested [with a PSA]...then an employee of the Cancer Foundation Victoria says ’we view this as a disease of over 65s. No wide-spread approach to testing or screening has been successful. The PSA test is flawed and unreliable’...So I can’t believe it. I don’t know where they are coming from.*

John was concerned about the inconsistency of screening guidelines. He also personalised the recommendation that widespread screening is not needed. He said:

*People ignore the fact that over 2600 men die of the disease each year...no one took into account the anger and disappointment of the many men*
diagnosed of incurable prostate cancer which may have been avoided by timely PSA tests.

In contrast to Arsenal’s expectation of gaining 15 years of life through screening, early diagnosis and treatment, John predicted that he had “four years to live” and estimated that he “looked like being cut back about fifteen years” through “late diagnosis”.

PSAs and politicians

Some participants were critical of government and health agencies’ lack of sensitivity and policy to encourage men to have PSA screening. One barrier to screening access was the Commonwealth government restriction of indiscriminate use of the PSA test by taking it off the ‘free list’ effective May 1\textsuperscript{st} 2001. As a result, men who request a PSA screen incur the cost ($36.65) of the blood test (Lions Australian Prostate Cancer Website, 2003). Unicorn’s raised PSA level, identified through screening, was the initial clue that he had prostate cancer at age forty-six. He described the government’s PSA screening decision as “unbelievable”. He said:

\begin{quote}
I could be dead. I mean I paid for it [PSA] anyway. Makes no difference to me whether they [government] are going to cover it but for those who require medical benefits to cover it then they won’t do it because it won’t be covered. I reckon it is actually going to lead to deaths. Late diagnosis…won’t help anybody…that government policy is going to preclude people in my bracket from maybe getting an early diagnosis and treatment.
\end{quote}

The “bracket” Unicorn referred to is younger men, less than fifty years, who are usually diagnosed with aggressive prostate cancer. Unicorn was concerned that the government policy would serve as a disincentive, and disadvantage some men who could not afford the PSA screening test. Previous research by Lee (2002) has established cost as a barrier to prostate cancer screening.

Beyond the dissatisfaction about government policy restricting men’s access to screening, Ron had an expectation that his PSA testing would be free:

\begin{quote}
They sent me a bill…to say you owe us this money for PSA. I said ‘what the bloody hell for’. I rang up, Medicare said you are only allowed one every 12 months. That’s crap. The second excuse was now that your PSA is down you have to pay for them. More crap
\end{quote}
Some participants suggested Australian government and politicians also controlled PSA screening through lack of legislature, policy and poor screening guidelines. Steve suggested the reason politicians do not promote prostate cancer screening and awareness through government policy was:

*Our politicians, like all blokes, are reluctant, don't talk about it [prostate cancer], she's right sort of thing.*

Argonaut suggested:

*If you can bring it [prostate cancer] home to them and say 'hey it can happen to you' then they change quite a bit... they are insulated from the real world...I think politicians are dicing with men's health to be quite honest.*

Don predicted that:

*There needs to be a few more politicians who have a bit of prostate cancer in their life and all of a sudden the whole attitude will change.*

John summated:

*It's a terribly negative message [not to be screened] and if they [government and health agencies] are bloody wrong...they will be leaving themselves wide open for the biggest class action in history.*

Masculine hierarchies and marginalisation were embedded in participants’ critique of male politicians who had power to legislate health policy, restrict PSA screening and not contribute to public awareness of prostate cancer. According to Argonaut, politicians were insensitive to the experiences of ordinary subordinate men who had prostate cancer. This trivialised his experience of and expertise in prostate cancer. Despite living with prostate cancer, he was unable to influence PSA screening policy. Some participants were subordinate as a result of not being heard or feeling de-valued by governments and men in power. The findings illustrated Haye’s assertion that “patriarchy for most men is detrimental” and “only of benefit to a very small number of people at the top” (2001, p. 8).

Participants’ criticism of men in power reflected Australia’s egalitarian society. The historical roots of which are typified by images of early settlers and the ‘Aussie battler’, who was usually male and marginalised, fighting against the odds for a ‘fair go’. Furthermore, the lives of ‘workers’, especially those employed in
poorly paid occupations, have been depicted as iniquitous, yet invisible to governments. As Connell et al. (1999) observed class inequities were present in Australia from a remarkably early period. Don and Argonaut claimed that politicians would feel differently if prostate cancer happened to them.

Historically, the provision of public health care in Australia has been an entitlement, available to all, at minimal cost. Governments have absorbed the financial cost of health and, although monies are derived from Australians’ taxes, the actual cost of health has remained invisible to many public health care consumers. John had “just an almighty anger” that “they [government] are only trying to save money” by discouraging men to be screened for prostate cancer. He was also frustrated by what his urologist told him, “if you had come to us earlier we would have had a much better chance of curing you”.

**Prostate versus Breast**

The notion of equitable, free public health is also disrupted when selected health services attract consumer cost, yet similar services are free. Some participants discussed gender inequities between prostate and breast cancer screening. Arsenal compared the cost of prostate and breast cancer screening:

> It’s alleged that screening [PSA] is costly...when a woman has breast screening for cancer, it costs...about $110, whereas the PSA test...is about $14.

Despite the serious nature of both prostate and breast cancer, Arsenal argued the worthiness of prostate cancer screening and comparative inequities with breast cancer. This reflects competing victims discourse, previously described by Cox (1995) as gender-based diseases competing for funds, research and health services.

Competing victims discourse is informed, in part, by populist media coverage of varying diseases. When breast rather than prostate cancer featured, some participants perceived they were proportionately disadvantaged. Steve provided an example of this in deciding not to donate money for breast cancer research:

> I got this letter...last week, and it...had a great spiel about breast cancer...and would I give $50...I got annoyed within meself [sic] and I tore...
it up...I thought what about the bloody prostate?... had they had...breast cancer and prostate cancer... they would have got my money.

For Steve, there was a sense that prostate cancer was not attracting research funds, public awareness and a profile equal to that of breast cancer.

Seagull worked in a voluntary capacity with a state based cancer foundation. He was available to talk (usually by telephone) with men who were diagnosed with prostate cancer. According to Seagull, the cancer foundation did not encourage PSA testing “because it's going to cost a lot of money for very little result”. He attended a cancer foundation workshop:

We brought it up and said...women have these pap smears and the mammogram, what’s wrong with us...having the same screening process?...I think its bullshit myself.

Some participants agreed that men have to lobby for screening services that women already have. John argued that men were not as vocal or resilient as women when confronted with inconsistent or inaccurate information about cancer screening. He explained that this is because men with prostate cancer are marginalised through being “older”, “confused”, “castrated” and eventually “dead”. Therefore, men with prostate cancer were not problematic or able to ‘fight the good fight’ because they did not have the youth, cognition, testosterone and eventually the life to challenge screening inequities:

They are not getting huge results from breast cancer. They are screening like blue blazes. Just try telling this kind of rubbish [not recommending screening] that they are telling us to the ladies and see what the ladies lobby groups would do to you. They would tear you apart. The men are older men, they are confused men. Very shortly after the doctor gets to them they are castrated men and a bit further down the track they are dead men...So they don’t give a hell of a lot of trouble.

John was not used to being powerless, disadvantaged or discriminated against. Dominant forms of Australian masculinity have historically protected and preserved, to varying degrees, patriarchal privilege and power—especially in relation to women. Moreover, women have historically ‘looked after’ men’s health privately as wives and daughters and publicly in female dominated professions such as nursing. However, women are increasingly active in the legislation of health-related matters, particularly women’s health issues. There is
some abandonment in that marginalised men, unable “to tear you [government] apart” like women, were left to fight for equality. There is also the abandonment of patriarchal government and health care, where men in power choose breast cancer above prostate cancer screening. Patriarchy in this instance is eroded and enforced simultaneously. The government preserves patriarchy through subordination of men with prostate cancer but responds to arguments by women for women’s health services.

**Summary of discussion and findings**

Tannock (2002) amongst others, suggests that waiting for symptoms rather than undertaking asymptomatic PSA screening would better serve most men. Ironically, such recommendations prescribe the continuation of three practices that challenge men’s health. First, as has been well established by Courtenay (2000) and Gibson and Denner (2000), most men are poor consumers of health services and avoid doctors in the absence of established health problems. Second, as described by Skord and Schmacher (1995) and Ziguras (1998), most men seek medical consultation for established symptoms after an extended period of time. Third, as suggested by Lee and Owens (2002), many men are poor consumers of medical screening and health promotion programs. At a global level of men’s health, professional health care advice that men are better not to know if they have prostate cancer informs, perpetuates and replicates current commonly cited men’s health behaviours. It is especially concerning that men’s common health care behaviours are condoned, if not prescribed by health care services and professionals. This finding from the present research thesis illustrates suggestions by Woods (2001) and Huggins (1998) that health services themselves affect men’s utilisation.

In the context of prostate cancer, the majority of participants were dissatisfied with suggestions and innuendo that they acted unwisely in choosing to be screened / tested and treated. Participants reacted to government and politicians, compared breast cancer to prostate cancer, and claimed inequities of gender and class. Participants validated and defended their decision to be diagnosed and treated through these strategies. Moreover, they challenged inequities and contested the institutional patriarchal power of medicine and government. The
findings illustrate Hayes’ (2001) claim that patriarchy disadvantages many men, and Courtenay’s (2000) suggestion that medical institutions as well as illness can marginalise men.

There is a strong possibility that the Australian governments’ discouragement of PSA screening (through policy and consumer cost) is related to the limited availability of medical resources. Subsequent treatment of the increased number of prostate cancer cases identified through widespread screening could exceed the supply of available resources. There was a dramatic rise in the number of new cases of prostate cancer between 1990 and 1994, following the introduction of the PSA test (AIHW, 2000). However, following the initial controversy about the appropriateness of PSA screening, fewer PSA screens were completed, and a subsequent fall in the number of prevalent prostate cancer cases was reported (Smith, Armstrong & Saunders, 1998). Similarly, in Canada, widespread PSA screening resulted in the diagnosis of many early stage prostate cancers. The increased number of diagnoses created a demand that exceeded the supply of prostate cancer health care resources (T. Pickles personal communication 25th January 2002). As a result, many patients in Canada were redirected to the United States for treatment. However, in Australia, the demographic isolation and financial cost would inhibit patient redirection for prostate cancer treatment. If cost of treatment is the rationale to discourage PSA screening in Australia, then clearly older men attract less value in terms of health promotion resources. This is another example of patriarchal power and its ability to marginalise subordinate men. It also exemplifies how health promotion is selective in whose health is promoted. The findings from this study illustrate Watson’s (2000) claim that many men’s lives are submerged beneath the profile of men’s health promotion.

Recommendations

The findings from this study showed that PSA screening was advocated by the majority of participants. Ironically it appears to be government and government funded health promoters that are cautious about recommending PSA screening. This brings into question the compatibility of prostate cancer and men’s health, given the common men’s health profile that outlines numerous hypotheses for men’s irreverence towards maintaining their health. Based on the findings from
this study, future research should investigate how PSA screening awareness can be achieved through targeted health promotion programs. This recommendation is developed in Chapter Seven, Conclusion and Recommendations.

**Part D—Spreading the word: Screening advocacy**

As discussed in Chapter 2: Literature Review, Section One, Part b, *Health promotion and prostate cancer*, although prostate health promotion programs have been minimal, media and health agencies sporadically attempt to raise public awareness of prostate cancer. Strategies include testimonials from sporting identities such as Robbie Flower (Sheahan 2001) and Ted Whitten (Hanlon 2002). Some participants recalled seeing such prostate cancer messages—however, no participants requested PSA or DRE screening as a result. Steve, prior to being diagnosed, saw Ted Whittens’ ‘last lap’ of the Melbourne Cricket Ground. He did not undertake PSA screening as a result, but in the aftermath of his prostate cancer diagnosis, Steve said “they did not discover Teddy’s prostate cancer until it was too late”. Steve distanced himself from Ted’s image of finality and their shared diagnosis of prostate cancer. In doing so, he provided an example of how the context of sportsmen’s testimonials is an important consideration for health promotion. This finding supports Watson’s (2000) suggestion that health promotion requires more than dissemination of health information, ultimately, it is what people do with the information that counts.

The majority of participants noticed media-generated prostate cancer information after they were diagnosed. This may reflect the lack of targeted prostate cancer campaigns in Australia, as well as participants’ lack of receptiveness to health promotion programs. Kevin recalled “a year or so back” seeing a television commercial about prostate cancer shortly after he was diagnosed. It was a “statue peeing and that if your stream’s not good…get it checked out”. As Kevin described, the commercial showed an emasculated child statue having difficulty passing urine. The commercial was on low rotation, screened mostly during the day for approximately six months in 1998. The statue did not symbolise masculinity, instead it depicted a marginalised childlike lack of control of troubled “waterworks”. The narrator suggested men seek assistance if they experienced urinary symptoms and provided details of where a monetary donation could be
sent to assist the prostate cancer research funding (“which is drying up”). Kevin recalled the commercial in the context of his diagnosis and said prostate cancer was “a word of mouth thing” and not “worth the big bang on TV and advertising”.

The majority of participants advocated asymptomatic PSA screening for men. Their rationale for screening advocacy was the belief that screening increased the detection of prostate confined cancer and the effectiveness of treatment. Participants varied in the specificities of their screening recommendations. Steve suggested, “the only way we’re going to do it is similar to the mammary tests that the ladies have”. He said “It’s got to be compulsory…that’s the only way we are going to get through to men…they’ve got to be sent a nudge.”

Steve recommended that “all men” be contacted at sixty years of age and told “I want you to come to this place and have this simple test”. His advocacy for compulsory PSA screening was premised on the belief that health professionals best serve expertise and medical surveillance. The compulsory screening model was also influenced by his belief that men would not undertake screening voluntarily.

Most participants were more conservative in their screening recommendations. Arsenal suggested prior to PSA screening, “men need to be aware that prostate cancer is a serious condition…the weaknesses of the PSA test” and “how to deal with a positive result”. Following that information “those people that wish to be tested, should be tested”. Arsenal’s recommendation was congruent with contemporary health promotion philosophy in which men are informed and empowered to choose PSA screening. Argonaut also recommended that information be provided prior to PSA screening. However, he predicted that once men get that information:

> A lot of them don't want to know any more...it is a fear thing...part of the problem is how do you actually get to accept that life is worth living in different ways irrespective of whether you can just go on doing what you have always done in the past...it is a matter of raising options in terms of life.

Many participants agreed with Argonaut that it was unlikely that men would voluntarily undertake prostate cancer screening. This, in part, underpinned
participants’ common practice to promote the health of other men by informing them about the advantages of PSA screening. This practice disrupts some commonly-held beliefs that men do not talk with other men about illness or engage with health promotion.

Some participants were involved in advocacy groups and spoke publicly about prostate cancer issues (including PSA screening). Arsenal learnt from his father that “blokes don’t talk about illness and that with each other” and “usually tough it out”. However, despite his earlier subscription to dominant social constructions of masculinity, in the aftermath of his prostate cancer and its treatment, Arsenal was:

> Actively involved with others in helping...I am doing a weekend course...trying to get media attention for prostate cancer and making myself available to speak publicly at various forums...lobbying politicians.

Arsenal was also on the “working party” for the “support and advocacy committee”. He explained the document in photograph 6:

> I've got this 80 page document here and I was reading this for my first meeting and I thought shit, that's me, that's how I felt, and so I went to this meeting...I joined this incredible group of people...I was accepted very, very well...I found it rewarding reading this because up until then (since being treated for prostate cancer) I hadn't been reading...this is the first coherent document that I read. I haven't been able to concentrate, but this is something I've wanted to concentrate on.
Arsenal’s illness experiences resided in the pages of the *Prostate cancer treatment guidelines for patients* manual. He was anonymous but represented in a document that advised about many issues men face when diagnosed with prostate cancer. It validated what he felt as ‘real’ and was congruent with other men’s experiences. Through the document, Arsenal contributed to prostate cancer awareness and advocacy at a policy level. Although originally “put off by the psychosocial side”, Arsenal utilised generic qualities that he developed as a university administrator. He contributed and critiqued policy documents, collaborated with others, attended meetings and spoke publicly. The subject matter had changed from university budgets to prostate cancer, however work was still a central construction of his involvement. He masculinised talking with other men about prostate cancer and re-established aspects of his “workaholic” years in paid employment through his prostate cancer ‘work’. Furthermore, he was powerful and authoritative in the pursuit of emancipation of self and other men with prostate cancer.

Some participants talked with men in small groups and suggested PSA screening. John took a powerful authoritarian masculine stance and was robust in his approach:

*I talk to them and blow their ears off…some want to hear it and some don’t…there are a lot of people that would rather not know*

Steve usually mentioned his prostate cancer to small groups of men. However, most information was shared one-on-one. He explained:

*You’ll get a guy, he’ll come up to you afterwards and say…what was that you were actually talking about…what did you do…how did you know…I say to them just quietly….start off with your G.P….the PSA test is the thing to have*

Many participants found that their prostate cancer had resulted in changes to how they talked with other men about health. Steve acknowledged, “three years ago I wouldn’t have talked to anyone like I do now”. Max said it was “amazing” that within a month of his diagnosis “every one of my [his] friends had been and had a blood test [PSA]”. He recalled that prior to being diagnosed when he was with his mates:
We would just chat about things, but guys never - - - I would never have chatted like that with these guys before...we'd go and play golf...you'd talk but not talk about anything really.

Most participants informed their sons, brothers and other male relatives that they may have an increased chance of having prostate cancer and should consider being screened. Arsenal said:

I wrote to my son saying if you want to get an understanding...I convinced him to get the PSA test done earlier...I sent him this book...web sites.

Whilst Arsenal was able to convince his son to be screened, other participants had less success. Verlow suggested to his 53 and 40 year old sons that they should be screened:

the older lad, he went to his doctor to have a PSA and the doctor said, 'oh, no, I don't do that...I do the digital rectal examination'. Well, my older fellow shot off like a frightened duck...he hasn't gone back because this doctor doesn't believe in the PSA...my younger fellow...says 'Oh, yeah, dad I'll do it when I'm 40.' So he turned 40 in June just gone. I said...‘Are you going to have that test?’ ‘Oh, I'll leave it until I'm 45, dad.’...you can lead a horse to water, as is the old saying.

Many participants noted similar difficulties in convincing their sons to be screened for prostate cancer. Trent said “indifference” best described his sons’ reactions to his suggestion that they be screened. He summated that their “perception is that they probably think that it could not happen to them”.

Summary of discussion and findings

The findings from this study show that most participants talked about prostate cancer and recommended screening to other men. These findings disrupt three commonly held beliefs about men’s health promotion practices: first, that men are unlikely to take an active interest in maintaining their own and other men’s health; second, that men do not speak publicly about illness; and third, that men are unlikely to engage in health promotion activities. These findings support, in part, Gibson and Denner’s (2000) prediction that men will talk about health and illness if they have the permission of other men. Many participants in this study broke with hegemonic masculine constructions and spoke to other men about prostate cancer, in the context of having prostate cancer.
They informed other men, often through testimonials, that symptoms were not always identifiable and encouraged movement away from symptom recognition and report based health care practices. The practice of some participants to educate and inform male family members about prostate cancer revealed shifting gendered constructions of health. The role of family health informer is traditionally feminine. However, in the context of having prostate cancer most participants provided information about the disease to other men in their family.

Some participants who became prostate cancer activists operated at a community level and contributed to health promotion programs in various capacities. Some participants joined professionally run programs and/or began independently run PCSGs. The independent support groups emphasised the capacity of individuals to act collectively on issues affecting their health and the health of other men. Nutbeam and Harris (1999) have previously identified similar health promotion programs, initiated and maintained by non health care professionals, as community mobilisation.

The findings from this study also illustrate that men with prostate cancer can promote health. Therefore health promotion should be inclusive of men with illness, which supports previous arguments made by Buetow and Kerse (2001) and Morris (1998) that illness and health are interconnected in most people’s lives.

**Recommendations**

Given the lack of intersectorial co-operation in regards to prostate cancer screening, health promotion is most likely to originate and reside with men who have prostate cancer. A salient line of inquiry is to investigate the health promotion roles of prostate cancer support groups. This recommendation is discussed in Chapter Seven, *Conclusion and Recommendations.*
Chapter Five

Research Results

Prostate cancer and health services

In this chapter, Wayne, Top Cat and Ben feature, along with other participants as they experience health care services and interact with health care professionals at different points of their prostate cancer illness trajectory. The findings detail participant informed answers to two research questions:

- What roles do health services play in relation to prostate cancer for men in the cohort?
- What recommendations do the participants offer for the future role of men’s health services in relation to prostate cancer?

The findings are presented in three sections. In Section One, 'Moving in', participants’ experiences leading up to, and including, their prostate cancer diagnosis are presented. Section Two, 'Moving on' provides insight into participants’ treatment decisions and their experiences of medical interventions. In Section Three, 'Moving out', participants share their experiences of recovering from prostate cancer.

The sections Moving in, Moving on and Moving out are used to present participants’ experiences and interactions with health services through diagnosis, treatment and recovery from prostate cancer. Participants’ illness experiences are not unified linear processes, and the repeated use of the word moving is intended to reflect the fluid nature and connectedness of all aspects of prostate cancer illness. Moreover, the terms are commensurate with ethnography and the concept of moving in, on and out of cultures and subcultures. For example, in section one participants are moving into health service cultures and belong to patient subcultures as their diagnosis is confirmed.
Section One: ‘Moving in’

Participants’ prostate cancer experience did not begin at the moment of diagnosis. The discovery of prostate cancer was incremental for most participants. There was a period of ‘moving in’ to the diagnosis, which was often based on a continuum of medical investigations that ultimately proved a diagnosis of prostate cancer. This involved the transition from being a well man to being a man with cancer of the prostate gland. It was a quantitative journey in which up to three scores or numbers were provided for men under investigation for prostate cancer. The first two scores came from the PSA and DRE diagnostic tests (discussed in Chapter Four, Section Two, Health promotion and prostate cancer) which provided preliminary evidence of potential prostate pathology. However, the espoused inaccuracy and unreliability of the PSA and the subjectivity associated with DRE provided hope for some participants that there had been a mistake in the numbers preceding the definitive diagnostic test, the trans rectal ultrasound prostate biopsy (TRUS-Bx).

We join Wayne, Top Cat and Ben as they are ‘moving in’ to their diagnosis of prostate cancer.

Meeting Wayne

I park in a narrow one-way lane where the backs of houses spill out from both sides. Past a high rusty galvanised iron fence, I find a small weatherboard house on a large lot and knock on what I think is the back door. Wayne appears. He is five foot tall, has a shiny red face and wears a smile. Broken capillaries form vascular spiders that break across his nose and spill onto his cheeks. The asymmetrical frozen blood roadways display life stories upon a facial canvas that has been kissed by the sun, alcohol and tobacco. We sit across from each other at the table. It is the only piece of furniture in the large open room that connects the kitchen to the living room. The room looks big because of the lack of furniture. I decide it is small furniture in a medium house on a large block of land. Everything seems ordered and relative, if only for that moment.


Wayne assured me “around here it’s all working class” but he noted that “even” the working class has a “really big gap between it”. He “looked like going up and getting things organised for my [his] future” through a highly paying job “bagging
barley”. However his “turning point” came when “I [he] had this accident” at work. Wayne had been on “Work cover” ever since (10 years). Illness threatened to follow injury as Wayne went to his GP at the insistence of his partner Sophie, who “pinpointed that there was something wrong” because he was “having difficulty getting an erection”. Wayne’s GP completed a DRE and PSA blood test, both of which revealed abnormalities.

Meeting Top Cat

A tree lined street borders Top Cat’s inner east Melbourne home. It is a middle class suburb that realtors describe as a ‘sleeper’ suburb, one which is gradually gaining in value. I am greeted by a bald, tall, heavy set man called Top Cat. As he speaks, an occasional vowel infiltrates the dialogue and reveals his New Zealand origin. He sits across from me on a modular lounge, in a living room busy with ornaments and family portrait photographs. Top Cat is pale with just a bead of sweat above his top lip. He is going to the movies with his wife later this afternoon but I sense he may run late because we are deep in conversation, deep in his life, a life less ordinary.

Observations and interpretations integrated with retrospective summary-
Top Cat Interview 5/2001.

Top Cat recalled his life during 1994:

I’d just come back from a trip overseas, I had money in the bank. I had a good business. I had a future ahead of me. I was going to work until I dropped. I was never going to retire, blah, blah, blah, I was King Dick.

All that changed when Top Cat woke up one morning in 1996 and “just couldn’t move”. An X-ray revealed a fractured vertebra which left him “lying flat on my back” for the remainder of the year. In 1998 he was “granted an invalid pension”. However, his “one-man sub-contracting business” had “virtually disappeared”. During this period his brother was diagnosed with prostate cancer, his mother-in-law passed away with lung cancer and his “knee goes on me [him]”. Top Cat also noticed he was “increasingly getting up during the night and going to the toilet”.

Top Cat went to his GP to get an analgesic prescription because of his painful knee. During the consultation, the GP did a DRE check which revealed Top Cat’s enlarged prostate. Top Cat told his doctor after the DRE “my father had benign prostate hypertrophy…my brother is in remission for prostate cancer and I am going to the toilet six times a night”.

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Meeting Ben

I buzz the security door and a voice directs me to ‘come up’. Ben opens the door. I walk through to a penthouse suite on the twenty-sixth floor. I stand dazed for a moment wondering which of the 270 degree Melbourne city views I will take in first. Invisible speakers pour classical music into the room from all directions; the music is subtle in volume and premium in quality. I am directed through to the sunken lounge that holds the minimalist themes which resonate throughout. Ben wears sports trousers and a polo shirt. He is articulate, well groomed and athletic. He is relatively young, in his early fifties. He has a story to share and during our first interview it is apparent he will tell his story to one person and I have the exclusive rights. It is an emotional three hours that follow.


Ben utilised his engineering skills at work; however people and project management were increasingly becoming a core function of his role, which he enjoyed. He recently applied for an internal promotion, and if successful he will be able to develop managerial skills through leading a team of workers and contributing at a higher level to his current employer. Ben started having regular health checks because he needed a “bi-annual medical before getting my [his] licence [private pilot licence] renewed”. His medical check-up included a “prostate check on two or three occasions”, however, more recently, he was prompted by the death of friend with prostate cancer to request a PSA screen. Ben was “healthy” and “never felt ill” or “in any discomfort” but had “a high PSA reading” and his DRE revealed an enlarged prostate gland.

Participants in this study were from diverse class systems that limited and informed their occupational choices. Wayne was working class and the physical endurance he demonstrated through manual labour was his stock in trade. It was also a signifier of his masculinity and illustrated how gender intersected with class. Unfortunately, when he was injured, Wayne became unemployed in the short term and unemployable in the long term, because without physical endurance he was unable to provide labour. He had little savings and was reliant on “Work cover” compensation provided by the government. Wayne was subordinated by class structures and marginalised within working class hierarchies through injury and inability to work. As Wayne experienced, the working class “has a really big gap between it” through subordination of working
class men who were unable to work. Top Cat was middle class and owned his own home and car. Through injury sustained at work, he lost his plastering business and ability to work. He also lost the potential to earn what had become a substantial income. However, assets along with the “invalid pension”, preserved a comfortable lifestyle and reduced the visibility of Top Cat’s marginalisation. Ben was middle—upper class, had a PhD and pursued a career through employment in a highly paid executive position. Ben’s career continued to gain momentum and was a significant part of his life and masculine identity; it stimulated and mostly satisfied his intellectual, managerial and social appetites. His dedication, long working hours and expertise were rewarded, indeed the ‘fruits of his labours’ surrounded and represented him, just as Wayne and Top Cat were reminded of the limitations eventually imposed through what happened to them while labouring.

As has been well established by Connell (2000) and Donaldson (1991), working and middle class men are more likely to rely on physical labour for paid employment. They are also more likely to encounter hazardous work environments and physical injury that prematurely end their working lives. Physical labour eventually eroded Wayne and Top Cat’s ability to perform physical labour. Physical endurance and paid employment were no longer demonstrable signifiers of their masculinity. They were subordinate by class structures and marginalised through injury prior to being investigated for prostate cancer. In contrast, Ben demonstrated many hegemonic masculine characteristics. He was successful and powerful, at the peak of his working career.

There is mounting evidence that Wayne, Top Cat and Ben will be ‘moving in’ to patient subcultures of men with prostate cancer.

The Trans rectal ultrasound prostate biopsy (TRUS-Bx)

These men are emotive; an underlying whisper of anger raises its audible voice as the group members discuss injustices of pain which accompany their TRUS-Bx. I sense a building momentum in the meeting room that is bound to confront me as the etic. Moments later I am asked directly, ‘Why isn’t a general or local anaesthetic used for the TRUS-Bx?’ I attempt to gather a rational factual biomedical answer but I am drowning in the debris left from the collision of my biomedical and ethnographic worlds. It is an ephemeral emic moment, or is it? After all I cannot defend the indefensible. I resolve the conflict as a research question and assure the group it is one I will address.
Wayne, Top Cat and Ben underwent TRUS-Bx based on their PSA and/or DRE abnormalities, which would confirm or deny a prostate cancer diagnosis. As discussed in Chapter Two, Section One, Part A, *Biomedical prostate cancer research*, the TRUS-Bx is performed by placing a probe in the rectum. A spring-loaded needle attached to the ultrasound probe enters the prostate gland through the rectum. Tiny pieces of tissue, usually between six and 12 samples, are removed from the prostate via the needles. The samples are then examined under a microscope and a definitive prostate cancer diagnosis is made (University of Toronto, 2000). The severity is measured and quantitatively expressed through the Gleason score.

Many participants in this study underwent TRUS-Bx without a local or general anaesthetic and reported pain and anxiety as a result of the procedure. The findings from this thesis study are organised around four concepts: (a) Pre TRUS-Bx: Anxiety, control and hegemonic masculinity, (b) Pain performances and masculinities, (c) Penetrated masculinity, (d) Dual or duelling hegemonic masculinity: Clinician and patient.

**Pre-TRUS-Bx: Anxiety, control and hegemonic masculinity.**

The period preceding the TRUS-Bx procedure was a time of anxiety for many participants. Uncertainty about the invasive nature of the procedure and the impending results of the TRUS-Bx undermined characteristics of hegemonic masculinity—including sexual prowess, self-reliance and independence.

Wayne recalled “the stress…really knocked me about” because his PSA was high, and “they [doctor and friends] were just pushing me straight into the situation [TRUS-Bx]”. Wayne “put it off because he [doctor]…made a real big deal of it”. Wayne was “panicking” because the TRUS-Bx could confirm his suspected prostate cancer. He was also uncertain about the TRUS-Bx itself, especially since his DRE was “embarrassing” and “degrading”. For six months he tried to ignore his raised PSA. However, the anxiety of not knowing for certain resulted in Wayne eventually contacting his doctor and agreeing to have the TRUS-Bx. Underpinning Wayne’s anxiety and avoidance of the TRUS-Bx were concerns
about the effects prostate cancer may have on his relationship with his partner Sophie. Sophie was twenty-six years younger than Wayne; he described her as “a real dasher” and was worried that his already decreasing potency would be further affected by prostate cancer and its treatments.

Top Cat was at the clinic. He lay on a trolley-bed in a corridor adjacent to the procedure room, waiting for his TRUS-Bx. His mind raced, passivity and childlike helplessness confronted him, his “private parts” had already become public and bodily functions had passed inelegantly from his control:

You are sitting there worrying yourself sick, worrying what the hell’s going to happen... You have to get into the foetal position, after, incidentally having an enema, which was an embarrassment for a start, I admit I was very funny about my private parts.

Top Cat’s anxiety extended beyond the trolley-bed and impending TRUS-Bx. He was consumed by images of other people’s cancer whilst waiting to confront his own. His brother had prostate cancer which was treated but not cured or contained by radiation therapy, and he “virtually nursed my [his] mother-in-law through her cancer” until she passed away less than 12 months ago. Top Cat was reminded and confronted by cancer on multiple levels as he lay waiting for his TRUS-Bx.

Ben postponed his TRUS-Bx twice because it was “awkward to fit in” with his interstate work commitments. “It would have spun out to six weeks” before he got “someone else” to go to “another important meeting” so he could have the procedure. Ben was critical of the inflexibility of his urologist offering the TRUS-Bx only once a week:

The system doesn't go out of its way to accommodate the needs of the patient. It's going out of its way to accommodate the surgeon.

Scheduling inflexibility was one of many examples of “medical arrogance” which Ben cited throughout our interviews. Ben’s dissatisfaction with health services was underpinned by his loss of power and control. His work schedule was of little importance to institutions that provided health services. Ben contested the power differential and re-asserted his control, at least in the short term, by postponing his TRUS-Bx and continuing his work commitments. Career was an important masculine signifier for Ben and it provided legitimate sanction for neglecting
health related matters as well as refuge from a potential diagnosis of prostate cancer. The TRUS-Bx appointment time was inconvenient. Moreover, a prostate cancer diagnosis threatened Ben’s career and perhaps jeopardised his internal promotion application.

Wayne and Ben re-established control, in the short term, by asserting if and when they would have their TRUS-Bx. During this time Ben continued his busy work schedule and Wayne continued a sexual relationship with Sophie. However, neither participant was able to go back in the incremental screening/diagnostic continuum. Eventually they were compelled to know if they did or did not have prostate cancer.

Top Cat admitted private anxiety “worrying himself sick”, but without the definitive diagnosis of prostate cancer, he legitimised a stoic public affect prior to the TRUS-Bx. Many participants experienced a private departure from, but public reliance on, stoicism and control in the pre TRUS-Bx period. Max “cried every day. I'd drive to work and I got really upset - especially when I was by myself, thinking of the consequences of all this”. Don worried if he did have prostate cancer “was it going to kill me straight away”. James was “apprehensive” about the procedure and Steve recalled “in coming to it, I was very nervous about it”. Anxiety and self doubt were often submerged beneath a stoic public performance; after all it was premature as well as unmanly to admit weakness and to ‘panic’ without a definitive diagnosis.

**Pain performance and masculinities**

Most participants described pain performance and tolerance during TRUS-Bx. Wayne, James, and Randwick used dominant masculinist responses to describe pain—indicating that they were able to “handle”, “bear”, and “stand” pain. Kevin revealed a relative pain performance in that he had “had much worse” and similarly Ben did not find the TRUS-Bx “terribly painful” compared to his post operative bladder spasms which were the “worst pain”. The pain performance descriptors were contradictory with the participants’ concurrent acknowledgements that the procedure “was traumatic”, “you wouldn’t like to do it every day”, “was on the painful side”, “it hurt” and recollections of “wincing a
There was contradiction between many participants’ reliance on hegemonic masculine pain performance and the experience of their TRUS-Bx.

*The biopsy was, that is a traumatic thing on its own but you can cope with it…. I handled it quite well. You just bear with it. (Wayne)*

*I wouldn’t like to do it every day. It was bearable you put up with it. (James)*

*It was on the painful side. I must admit that I wasn’t climbing up the wall…I can stand pain, it doesn’t worry me, a bit of pain. (Randwick)*

*It hurt, but it wasn’t something that made me go through the roof. Put it this way: I’ve had much worse. (Kevin)*

*I didn’t find it terribly painful. It was certainly uncomfortable---I do recall sort of wincing a few times…when I talk about pain, by far the worst pain I had was bladder spasms. (Ben)*

As White, Young and McTeer (1995) established, one of the ideals of hegemonic masculinity is the suppression of affect, particularly in relation to pain. Participants’ pain performance and tolerance during TRUS-Bx was influenced by dominant social constructions of masculinity that men capable of enduring and overcoming pain are superior, ‘real men’. Dominant cultural constructions that ‘boys don’t cry’ prescribe stoic performance and public denial of pain, both emotional and physical.

There was diversity in pain levels reported by the participants undergoing the TRUS-Bx. Wayne found the TRUS-Bx “painful”, Top Cat had “quite a bit of pain” and Ben “didn’t find it terribly painful”. The following excerpts further illustrate the variation in participants’ experiences of pain during their TRUS-Bx:

*There is no pain. (Royboy)*

*A bit uncomfortable, but not painful. (Clark)*

*It’s a little bit painful….you could feel the needles going in. (Argonaut)*

*Stinging pain…not a terrible pain but enough to wake you up. (James)*

*I hung on like grim death…it was pretty damn painful. (John)*

*They were shooting holes in me, the most uncomfortable half hour I have ever spent. (Ron)*
I’m sure that when they did get the two positive plugs that I nearly levitated off the table. (Top Cat)

That was probably the hardest part…there was pain…more traumatic than facing…the operation. (Yanni)

Participant pain variations are best explained through Connell’s (1995, 1997) work in masculinities that offers diversity, rather than a unified pattern of masculinity. In the context of pain, the plurality of masculinities confirmed that there is no uniform physiological marker of men’s pain experience; specifically, that pain tolerance is not congruent with testosterone levels and real man performance. Participants, although from similar cultures, were diverse in age, class and subscription to hegemonic masculinity and pain performances.

**Penetrated masculinity.**

The TRUS-Bx procedure involved participants being penetrated anally with an ultrasound probe and rectally with biopsy needles. Wayne described how “they go up your backside” which he found “sort of degrading” and Ben summated that “it wasn’t frightfully pleasant”. Top Cat pointed to a photographed bike pump that sat against a brick wall (Photograph 7) in summarising his TRUS-Bx experience:

You have a bloody great rod jammed up your anus…the insertion was bad enough but the worst part is that you could feel it flicking around deep inside you…probing.
Top Cat suggested that he may have been doing a disservice to the bike pump in substituting it, in photograph 7, for the “bloody great rod” that was used during his TRUS-Bx. The photograph and narrative confirmed Top Cat’s tension in being penetrated anally. The experience of anal penetration was new, isolated, unpleasant and not negotiable. The solitary bike pump that stands upright against a brick wall was photographed in a confined private area at the back of Top Cat’s house. He suggested “a more graphic description of what was going to happen” during the TRUS-Bx might have helped, “but, then again, probably if you had known that, it would have made me even more worried”.

Penetrative aspects of the TRUS-Bx procedure disrupted many participants’ dominant constructions of male heterosex performance. Max “was very embarrassed” that “someone was invading my [his] body” and “just lost all that sort of control”. William described being with his partner in the procedure room prior to the biopsy and seeing the equipment that would be used. His concern was “how far…that black bloody thing’s [the ultrasound probe] going up my backside”. Bob said “it’s different on this end…degrading…a dignity sort of thing…basically”. Ron described “an invasion of privacy, my space,
embarrassment…What next?”. Kevin “didn’t enjoy that sort of stuff” and similarly “it wasn’t what I [Arthur] enjoyed”. Arsenal “realised where that [ultrasound probe] had to go and I [he] didn’t feel that good”. Ron “had never had anything like that before”. Bob assured me that there was “no chance of me [him] ever going queer”. After the procedure Eddie asked “how big was it [ultrasound probe]…he [clinician] showed me…it was quite small” and suggested “it cured any of my [his] homosexual tendencies”.

As has been well established by Kippax and Smith (2001), the receptive anal experience is passive and feminine and the anus is stamped as the most private and shameful part of the body. The participant excerpts represented covert codes of heterosexual masculinity in which the silent understandings of heterosexual practices were implicit rather than explicit. Indications of what heterosexual men do not do, rather than what they do, prevailed. Embedded in these explanations is reliance on hegemonic heteronormative masculine non-performances. Specifically, anal penetration is contra-indicated as informed by heteronormative discourses concurrent with some participants’ differentiation, distance, and detachment from homosexuality. This was explicitly expressed as homophobia by a few participants. Furthermore, femiphobia was implicated by some participants’ rejection of the passivity demanded by TRUS-Bx.

Weeks, Holland and Waites (2003), and Jackson (2003) have previously discussed the limitations of fixed sexual identity in heterosex. However, many participants subscribed to dominant forms of male heterosex, which became fragile during the TRUS-Bx and anal penetration. Distance from homosexuality, expressed as homophobia, provided a way for a few participants to reclaim their heterosex masculine identity. Internal examinations are also culturally constructed as feminine, in which females are encouraged and expected to have regular pap smears. Through TRUS-Bx some participants were ‘moving in’ to experiences they used to think only “queers” or women had. The culture of health services prescribed the necessity of TRUS-Bx and the dominant patient culture responded by tolerating, but expressing their displeasure, as a way to preserve their masculine constructions.
Dual or duelling hegemonic masculinity: Clinician and patient

I sit amongst one hundred unfamiliar men in an unfamiliar hall located in an unfamiliar suburb. I am getting unfamiliar looks of sadness and sympathy. It is a public prostate cancer information session. The last speaker is a prominent Melbourne based urologist. The information evening turns into a public consultation in which audience members ask the urologist about the symptoms of anonymous friends. A final question is invited from a withered man who moves in slow exaggerated motion from his seat to a standing position. He deliberately meets the eyes of the urologist, draws his verbal gun from its holster and protests the pain of his recent TRUS-Bx. A hush settles over the crowd, tumbleweed dissects their now connected path, miraculously the urologist disarms the angry-tongued gunslinger. He assures one hundred unfamiliar men that it is the government who is to blame because they don’t refund the cost of an anaesthetic for the TRUS-Bx. Moments later tea, coffee and private TRUS-Bx discussions dominate the intermission.

Questions: Does being denied his marginalisation further marginalise the withered man? Is the urologist more hegemonic by denying his hegemony?
Answer: From the playgrounds of primary school to the board rooms of corporate ‘giants’ to the shared seats on public transport, masculinities are negotiated, relative, contextual and contested. Hegemony today, gone tomorrow.

Observations and interpretations integrated with retrospective summary-
Public prostate cancer information evening Melbourne 4/2001

The above field note was written after attending my first public prostate cancer information evening. It was a powerful event in which a room full of men—many of whom had prostate cancer—contested, competed and in part collaborated. Patient experiences and biomedical expertise sat awkwardly speaking about the same thing, TRUS-Bx, in different ways. One man dared to say how it felt, many men around him nodded and agreed, but the urologist was quick to defend why pain needed to be endured.

In Australia, some TRUS-Bx procedures continue to be administered without a local or general anaesthetic. While the urologist described in the previous field note defended his TRUS-Bx practice on a financial basis, during later field work, two Brisbane-based urologists confirmed that they included a light general or local anaesthetic for all TRUS-Bx patients. I sought clarity from Medicare, the national funding body for health in Australia and they confirmed item “37219”, “TRUS-Bx” attracted an anaesthetic benefit, and had done so since at least 1998; hence, the anaesthetic cost was a claimable rebate for the provider.
Department of Health and Ageing, 2001). This is contradictory to the information provided by the urologist at the information evening in Melbourne (described in the previous field note). However, regardless of the rebate entitlement, the use of a local or general anaesthetic is ultimately at the discretion of the clinician administering the TRUS-Bx, and presumably the decision is based on clinical assessment of the patient.

Some participants suggested disparity in clinicians’ estimations of their pain during the TRUS-Bx. Top Cat “was told there would be some discomfort. Well, in my case, it was a great deal more than discomfort”. Clinicians’ pain predictions are further complicated in that the clinician performing the TRUS-Bx may not have met the patient prior to the procedure, as the clinician is not necessarily the treating urologist. As a consequence, unfamiliarity may have increased participant anxiety. During his TRUS-Bx Randwick said:

‘Oh, God, thank God that’s over’ and he [the clinician] said, ‘No…that’s only three. There’s still three more to go’. He kept going….I don’t think I’ll ever forget it.

Some clinicians’ expectations of men undergoing TRUS-Bx may also influence their decision not to provide local or general anaesthetics. Wayne’s TRUS-Bx pain tolerance and stoicism was validated by his clinician. The clinician assured Wayne that “we have had big blokes here on this table who have cried getting this [TRUS-Bx] done”, but comparatively “with no anaesthetic, you don’t”. I acknowledge that clinicians may offer different insights to the administration of TRUS-Bx procedure. However, it is clear that some participants, such as Wayne, responded to clinicians’ expert advice, as well as their own expectations that the TRUS-Bx would not be painful.

It is likely that participants’ stoicism and reluctance to inform clinicians of their pain, discomfort and anxiety also influenced the continued practice to administer TRUS-Bx without local or general anaesthetic. Many participants were willing to discuss their TRUS-Bx pain with me during interviews or with other men at PCSGs. However, participants did not report discomfort and pain to the clinician administering the TRUS-Bx. Wayne said:
It was painful, but I was just focused on my holiday, regardless of the outcome I was going away, I just wanted it to finish ... I didn’t tell them that it hurt.

Top Cat “did not [tell the doctor about his pain]... because you look at doctors... as authoritarian people... that I [he] was brought up to respect”.

Clark experienced a loss of libido and potency following his TRUS-Bx. He hypothesised that:

The intrusive examination upset something... once they got in and took a biopsy sex just died. Whatever it did, it just affected my sex drive. Maybe it upset a chemical imbalance, there was just no interest any more. I don’t know what it was or why it was, but it was gone. It was hard to get an erection where I didn’t have a problem before.

Despite wondering “what have they bloody done to me now?” Clark did not ask his clinician or doctor about the possible connection between libido, potency and the TRUS-Bx. Clark’s subscription to stoicism and sensitivity about the changes prohibited him from discussing the unexpected outcome.

Most participants sought emancipation for other men by talking about the pain associated with their TRUS-Bx. So although participants subscribed to stoicism during the TRUS-Bx, in the aftermath they described their real experience. This is an example of the power institutions such as medicine and health services can have over some participants. Furthermore it demonstrates the complicity that existed for many participants in their reproduction of hegemonic masculine pain performances. The plethora of participant TRUS-Bx confessionals in the present research thesis suggested many clinicians and participants subscribed to hegemonic pain performance during TRUS-Bx. While dual subscription to stoicism and denial of pain by both clinician and patient prevails, it is unlikely that the provision of TRUS-Bx anaesthetic will become standard clinical practice.

The moment of moving in
Wayne was “a betting man” and he was hoping the numbers would be kind to him today. He waited, again, for his TRUS-Bx results and the Gleason score that would confirm or deny a diagnosis of prostate cancer. The trauma of finding out was exacerbated by the unavailability of the results on two previous occasions:
I went up to my GP to see the results...you build yourself right up...the results weren’t there...said a few prayers type of thing...went a second time they weren’t there again. The third time my doctor had them faxed through. He was reading the sheet out. That was the most traumatic thing because he was reading it out and I am waiting there on the edge of my seat. He said the first one is good. I thought I have only got five to go. And the second one is good. It was all tension stuff. And then he said I think it was number six was cancerous and number eight was cancerous.

The GP that Wayne described maintained his own comfort by imparting a diagnosis of prostate cancer in a nonchalant, informal masculine way. Wayne was unable to enact his scripted, stoic role:

I sort of broke down a bit...he [the GP] said he was quite pleased...He said ‘oh that’s a good reading because you could have had the whole lot cancerous’...when I first heard I had it I thought well that’s the end of it you know, that’s death’s door. See I only live up a couple of doors from the undertaker, and I couldn’t walk past that place for a time.

After the diagnosis Wayne “was just coming home…laying on the floor crying” because of “the thought of dying” and “not functioning properly”. Injury ended his working life and prostate cancer may end his life unless it was treated. However, the treatments would most likely render him impotent and perhaps incontinent.

Every morning after his gym workout, Top Cat went to his regular newsagent (Photograph 8). He bought the newspaper and Tattslotto (lottery) tickets. He was “always looking for a bit of luck…trying to win…big so I [he] can retire comfortably”. Top Cat talked with the owners (whom he knew well) about any number of newsworthy items and told of where his Tattslotto winnings might be spent. Culturally he subscribed to the Australian tradition and national pastime of gambling. After all, he lived in a city that hosts the horse race that stops a nation, the Melbourne Cup. The regular Tattslotto gamble provided him with hope that a bit of luck lay ahead, embedded in the Tattslotto numbers.
Top Cat was workmanlike in adherence to his daily rituals. It helped to fill the void that “not being able to work” created. Although retired, he was not retired comfortably; socially as well as financially he was not ready to retire. Lee and Owens (2002) have previously identified that the circumstances of retirement are important to men’s levels of satisfaction. Top Cat kept busy and hoped for the luck of money and recapturing elements of his 1994 lifestyle. Rather than Tattslotto numbers, Top Cat waited for his TRUS-Bx Gleason number this morning. Although he had urinary symptoms and a family history of prostate cancer his PSA was normal. He hoped that he could avoid ‘moving in’. Again, he was “looking for a bit of luck”:

*He [urologist] called me in, and I must admit he’s an extremely blunt and frank fellow, and he came right to the point. He said ‘there’s no point beating about the bush, you’ve got prostate cancer’.*

Top Cat was devastated by the diagnosis. He contemplated “throwing myself [himself] off the Westgate Bridge” for a brief moment, and explained photograph 9 in the context of his diagnosis:

*That’s the place where you don’t want to go - not yet, anyway. I'm not ready and I cheated the place. Now, I can drive past it instead of being carried in there. So, that's the cemetery…that is my route home from the pool, every day I go past there…I also had a tune that I used to play called One Day at*
a Time by the Hawking Brothers. I'd play that over and over and over and over...just take one day at a time...I don't believe in heaven or hell - I don't think I can...and yet, amazingly enough when I was crook I talked to God a few times. But, whether he's there, I don't know. I had a bit of a chat with him.

Photograph 9

Symbolically, the gates of the cemetery are open as the tombstones sit stark against a cloudy Melbourne sky. Top Cat stands just outside the gates chatting with God. The concrete path represents the continuum of prostate cancer illness, which stretches deep into the distance. Top Cat confronts his mortality, acknowledges the inevitability, bargains with God and resolves to take it one day at a time. An awareness and acceptance of mortality is central to photograph 9, concurrent with distance and relief at being this side of the gates, at the perimeter of the cemetery.

Ben was “pretty good at math” and had a professional understanding of numbers through his expertise in electrical engineering. He was “aware that a lot of people with an elevated PSA do not necessarily have cancer” and did not “particularly expect it [prostate cancer] to happen to me [him]”. Six specimens were taken during his first TRUS-Bx, “five of them were clear” but one had a small amount of carcinoma tissue in it. The urologist suggested, “do another one [TRUS-Bx] to be sure”. Ben recalled:
I said... 'It's either there or it isn't there...you're not going to be a little bit pregnant. If it's got cancerous tissue, it's cancerous tissue isn't it?' He said, 'Oh, yeah. But we need to know how big it is' and so I went back for another biopsy.

Ben constructed health care utilisation as feminine through the use of pregnancy as an analogy for the inconclusiveness of his TRUS-Bx. He also had positivist expectations of science and therefore that the TRUS-Bx would be conclusive and definitive. His anxiety was exacerbated by the uncertainty that prevailed. It was December and Christmas was fast approaching. Ben was notified that his internal promotion application was unsuccessful which he described as “a downer”. He returned to the urologist for the results of his second TRUS-Bx. He was told his Gleason score was 7, “by then I’d [he’d] heard enough”. Ben “couldn't believe it or couldn't believe that it would be difficult to manage”. Ben’s positivist construction of numbers was overwhelmingly significant in the context of his Gleason score, as it not only confirmed the diagnosis, it also distinguished a moderately-severe prostate cancer.

The official moment of ‘moving in’ was a particularly emotive event, and many participants were confronted by illness cultures, subordinate forms of masculinity and mortality. Bill recalled that receiving the diagnosis “was probably the worst part of it”. Bob suggested for a “bloke that has never been sick a day in his life you are going to take it pretty hard”. Charles said “mortality reared its ugly head” and Greg “just couldn't believe it”. Kevin recalled feeling “like you've been hit between the eyes with a sledge hammer and you sort of sit there stunned”. Although the diagnosis was usually based on a continuum of screens and tests, shock and the realisation of mortality were strongly represented in participants’ descriptions of receiving their diagnosis. Similar experiences of chronically ill men have previously been described and labelled by Charmaz (1995) as ‘awakening’ in which men are awakened to death when first confronted by serious illness.

The numbered diagnosis

Many participants relied on numbers or scores to describe their prostate cancer. During the initial fieldwork I noticed that PCSG members spoke in numbers and used them to rationalise treatments and measure recovery. A numbered diagnosis
based on PSA, DRE and Gleason scores signified prostate cancer and quantified its severity. Prostate numbers allowed participants to use traditional masculine biomedical frameworks synonymous with disease, rather than discuss emotive aspects of their prostate cancer illness. The numbers, listed in Table 2, Scores after three tests, were efficient self-explanatory codes that enabled participants to communicate and speak the dominant language of health care cultures. Understanding and using this new language allowed participants to reduce potential hierarchies that might exist between patient and doctor, and to become expert in their prostate cancer and its treatments. The numbered diagnosis for Wayne, Top Cat and Ben was as follows:

<table>
<thead>
<tr>
<th></th>
<th>PSA</th>
<th>DRE</th>
<th>TRUS Gleason score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wayne</td>
<td>Raised</td>
<td>enlarged</td>
<td>2 of eight cancerous</td>
</tr>
<tr>
<td>Top Cat</td>
<td>Normal</td>
<td>T3</td>
<td>7</td>
</tr>
<tr>
<td>Ben</td>
<td>2/2000</td>
<td>2B</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>5.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7/2000</td>
<td></td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>7.4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Some participants, such as Wayne and Top Cat, had previous experiences of health services through injury and/or illness. The findings from this study show that, compared with previously well participants, less disparity existed between expectations and health care service provision in this group of participants. Previous exposure to health service cultures orientated many participants to the rules, regulations and resources in health care institutions. For previously well participants with little prior exposure to health services, such as Ben, the newness of the environment and interactions, as well as prostate cancer, undermined many aspects of dominant masculinity, often for the first time.

Summary of findings and discussion

The findings from this study showed that participants’ anticipation of illness when prostate cancer was suspected but not diagnosed was a significant period, when
many aspects of dominant masculinity were undermined. It is important to note that most participants’ illness experience began prior to their formal diagnosis of prostate cancer. Health services and professionals were encountered during this time and screening and diagnostic tests were experienced when participant uncertainty and anxiety were heightened. Although many participants subscribed to public stoicism during this period, private anxiety disrupted masculine ideals of control, independence and self-reliance.

The findings from this study support Charmaz’ (1995) suggestion that illness can alter or end men’s participation in work and sexual activities, thereby reducing status in masculine hierarchies and raising self-doubts about masculinity. Furthermore, in the context of prostate cancer, many participants anticipated and experienced aspects of the aforementioned changes leading up to diagnosis. The suspicion of illness and cumulative biomedical evidence resulted in uncertainty for many participants. Moreover, there were usually no visible or recognised signs of illness, and mind-body rationality was disrupted when participants who perceived themselves as asymptomatic and healthy were diagnosed with prostate cancer.

Some participants asserted their control, at least in the short term, by postponing their TRUS-Bx, and their definitive prostate cancer diagnosis. This finding is consistent with Courtenay (2000) who suggests men’s avoidance of health services provides a way of establishing and expressing hegemonic masculinity. Some participants took refuge from a potential diagnosis of prostate cancer through relying on hegemonic masculine ideals such as career and penetrative sex. In this way, they were momentarily able to resist moving in to illness cultures.

Ambiguities about the appropriateness of screening and debates about men’s ‘need to know’ if they have prostate cancer may have legitimised and perhaps influenced some participants’ preference to delay the definitive diagnostic TRUS-Bx. Drummond, Laws and Polijak-Fligics’ (2001) suggestion that men were unlikely to make informed decisions about being screened for prostate cancer are also strongly represented in this study. In effect, by agreeing to be screened through DRE and PSA, most participants unwittingly committed to the TRUS-Bx should any abnormality be detected. The majority of participants responded to the
demands of hegemonic masculinity by confronting and confirming their prostate
cancer through TRUS-Bx in order to treat it. So, although some participants
slowed the continuum of screening and diagnostic tests, the majority were unable
to disregard the preliminary evidence and suspicion of illness.

The TRUS-Bx was a significant event for many participants when moving in to a
diagnosis of prostate cancer. The findings from this study are consistent with
previous research by Zisman et al. (1999, 2001) and Kim (2000) that pain and
anxiety are common patient experiences when undergoing TRUS-Bx in the
conventional way—without anaesthetic. The findings from this study also
provided new insights to how gender, culture and TRUS-Bx connect.

Specifically, most participants when undergoing TRUS-Bx without anaesthetic
responded to dominant masculine ideals of pain tolerance and stoicism. Pain
tolerance has previously been explained by White et al. (1995) and Young et al.
(1994) as a socially constructed masculine ideal in competitive sport, and is
reported by Ziguras (1998) as common male health behaviour. Dominant social
constructions of Australian masculinity idealise the tolerance of pain, stoicism and
the denial of weakness. The historical source of these constructions, according to
Conway (1985), is the symbolic images of Ned Kelly, the Anzac Digger and the
bushman. Participants were reluctant to admit pain to clinicians, which
demonstrated the power of dominant forms of masculinity. Moreover, clinicians’
expectations of participants’ pain tolerance during TRUS-Bx may also have been
influenced by dominant forms of masculinity. In these interactions participants’
denial of pain, and clinicians’ expectation of pain tolerance were complicit in
sustaining hegemonic forms of masculinity.

Moynihan (1998) has previously discussed masculinity as a floating signifier and
a puzzling concept for medical professionals. The results from this study illustrate
diversity between and within participant subscription to hegemonic masculinity
that partly explains Moynihans’ (1998) finding. For example, during TRUS-Bx
potential masculine hierarchies exist. The clinician demonstrated precision and
expertise whilst the patient was passive, anxious and uncertain. One way in which
participants can minimise their potential subordination is to be brave, stoic and
deny pain and weakness. Following TRUS-Bx many participants talked about
their real TRUS-Bx experience, reported moderately high levels of pain and recounted how they survived the procedure. Participants were able to align with masculine ideals despite breaking with stoicism by reporting their pain tolerance and pursuing emancipation for other men who would undergo TRUS-Bx in the future. This finding illustrates how masculinity is contextual and continually constructed. During the TRUS-Bx idealised forms of masculinity were relied on. Yet, following the procedure, in the context of telling others about the TRUS-Bx a different ‘story’ and masculinity was often presented. This finding also demonstrates Connell’s prediction that “masculinity is never fixed; there is room for manoeuvre” (1994:6).

The findings from this study show that participants’ TRUS-Bx pain is inextricably linked to anxiety and is more than a single sensation caused by a specific stimulus. These characteristics of pain have previously been described by McCaffery and Pasero (1999), Merskey (1996) and Neff and Stinson Kidd (1993). Most participants’ anxiety related to the penetrative aspects of TRUS-Bx as well as the significance of the impending results. Dominant social constructions of male heterosex performance, previously described by Zilbergeld (1992) as erection, penetration, and climax were dislocated during TRUS-Bx. Participants were receptive and therefore passive and feminine through the anal penetration that occurred with TRUS-Bx. The analogy between the anus and the vagina in which the penetrated anus is viewed as feminine has previously been discussed by Kippax and Smith (2001). Furthermore, as also detailed by Kippax and Smith (2001) the anus is stamped the most private and shameful part of the body.

The findings from the present thesis study showed a heteronormative social discourse that was implied, but not informed, known but not challenged, existed for many participants. Such ambiguity made it difficult to admit vulnerability around the anus due to dominant notions of heterosexuality as well as homophobic fears. This finding is consistent with Smart’s (1996) description of heterosex as a silent signifier and Kilmartin’s (2000) assertion that the institution of heterosex rests upon specific forms of sexual relations.

Participant anxiety about TRUS-Bx also occurred due to the significance of the impending results. Cancer is synonymous with debilitating illness and strongly
associated with death. Therefore, the TRUS-Bx was a defining moment which would confirm or deny the presence of cancer. During the continuum of screening and diagnostic tests many participants conceptualised the need to know if they had prostate cancer using dominant masculine constructions—including rationality and problem solving. Paradoxically, many characteristics of hegemonic masculinity such as career and sexual prowess, became fragile in the moments and months of moving in to illness cultures. The tension and contradictions between and within hegemonic masculine ideals was especially evident at the moment of diagnosis. The problem of prostate cancer was confirmed and most participants experienced a loss of control and were confronted by their mortality. 

The findings from this study support Williams and Bendelow’s (1998) assertion that pain is located at the intersection of mind, body, culture and gender. Furthermore, participant’s pain performances during TRUS-Bx were located at the same intersection, negotiated in relation to dominant social constructions of masculinity by both patient and clinician. The experience of pain was contextually bound and potentially gagged by reliance on stoicism and hegemonic masculinity. The findings from this study support Helman’s anthropological proposition that:

- Not all social or cultural groups respond to pain in the same way;
- How people perceive and respond to pain, both in themselves and others, can be largely influenced by their cultural background;
- How, and whether, people communicate their pain to health professionals and to others, can be influenced by cultural factors. (1990:158)

A complex interaction needs to occur in which health care professionals are willing to listen, and men are willing and able to speak about their TRUS-Bx experiences. It is not the responsibility of men to prove that they are in pain. However, clinicians cannot be charged with the responsibility to provide TRUS-Bx anaesthetics unless men speak up. The conundrum remains that poor health literacy levels inhibit many men from speaking up in audible tones.

In summary, moving in to illness cultures and the experience of health services disrupted the foundations of masculinity for most participants. Hegemonic ideals of independence, self reliance and control were compromised and the possibility
of long term dependence and death unfolded through the continuum of screening tests and diagnosis.

**Recommendations**

The findings from this study show the significance of participants’ experiences of health services leading up to diagnosis. Further research of TRUS-Bx from both the clinician and patient perspectives would contribute to the development of best practice guidelines. This recommendation is developed in Chapter Seven, *Conclusion and Recommendations*.

**Section Two: Moving on**

In her breast cancer study, Emery (2002) used the term ‘moving on’ to discuss patients’ experiences of breast cancer in the first six months following treatment. The term ‘moving on’ enabled Emery (2002) to present a segment of participants’ illness experiences. I use the term ‘moving on’ in this section and acknowledge its origins. However, it is used in a different context in this study. Specifically, by definition, ‘moving on’ refers to the period after diagnosis during which participants decide upon and undertake, or choose not to undertake, prostate cancer treatment[s]. During this time participants move on from diagnosis and experience ‘patient’ and ‘illness’ cultures.

**Treatment decision making**

Wayne had made quite a few big decisions in his life and had “been close to the other side”. He did not choose between specific prostate cancer treatments. Rather, Wayne agonised over an underpinning dilemma that affected his decision to be treated at all. He understood there were side effects, including impotence and incontinence, with all prostate cancer treatments and he was already having difficulty getting an erection, which had “wore me [him] down a fair bit”. Wayne’s mortality and dominant construction of male heterosex, erection, penetration and climax were threatened by prostate cancer and its treatments:

*The thought of dying upset me, that was an important thing...not functioning properly would be the second thing...I had the choice not to get done...like radiation or to carry on with my relationship, that was the important part of it. I thought if I get treated bingo it zaps everything, my relationship is gone and that was important to me...you couldn’t imagine a woman staying.*
Wayne was deciding between quantity and quality of life. He faced the choice to be treated and live longer or not to be treated and continue a sexual relationship with Sophie. Eventually, Wayne decided not to choose between the two. Instead, he undertook radiation therapy and continued his relationship with Sophie. The majority of participants rationalised that treatment was the priority and resolved to deal with side effects, should they occur, at a later stage. This finding has previously been reported Yong (1998). Detailed discussion of participants’ experiences of treatment side effects is included in Chapter Six, *Sexuality, intimacy and prostate cancer*.

Wayne did not make a treatment choice; he was guided exclusively by the treatment recommendations of his doctor and had radiation therapy. Many participants followed doctor recommendations. The urologist asked James “what are you going to do?...I [James] said what do you reckon I should do”. Kevin’s urologist was “confident in the treatment that he [urologist] was prescribing. What do you do but go along with it? Who am I to argue?” Ron assumed “it's like if you take your car along to the motor mechanic you expect him to know all the detail and all the answers”. Steve asked his doctor, ”What would you be telling your father?”...he said, ‘I'd go for the radiotherapy’...I said, right, I'm in your hands”. Wally “just asked him [urologist] things like, well if it was you what would you do?...He said I would probably have the operation”. These participants relied on traditional hierarchical medical models in which they sought and followed expert advice. Many younger participants and participants with localised prostate cancer (cancer confined to the prostate gland) did not perceive that there was a treatment choice to be made. Their preference for surgery followed dominant biomedical treatment recommendations for localised prostate cancer—to remove the prostate gland and therefore the cancer from the body.

Moments after being told he had prostate cancer Top Cat’s urologist recommended and prescribed treatment with a radical prostatectomy. He advised Top Cat to “go away and think about it and come back in a fortnight's time… bring your wife, and we will chat about it”. During the two weeks Top Cat discussed the treatment options with his brother (who had had radiation therapy for prostate cancer), his wife Jenny and his GP. He also bought “the best
book…on the subject”. After much discussion and research Top Cat and Jenny returned to the urologist, who explained exactly what would be done during the surgery. Top Cat had an “eight out of ten chance of being incontinent” which “really worried” him because he used the swimming pool at the gym every morning. The possibility of impotence “didn't worry me [him] because my [his] wife had had a hysterectomy some three years before and isn't interested in sex, so that didn't matter, and life was the better option”. Top Cat asked questions from a pre-prepared list during the consultation with the urologist:

> I started going through and I’d done about three and he says, ‘hang on, is that all the questions there’ and I said ‘yes’, and he grabbed it off me and he put them down in front of me and he started ticking and he said, “Yes, no, yes, no, not relevant, a line through that one”. He said, ‘There you go. That's short-circuited all that, hasn't it.’

Top Cat did not contest or attempt to clarify the abrupt answers to his questions. He accepted “that he [urologist] recommended surgery mainly [sic] as the only thing to do”. Some participants reported that they were actively involved, although their treatment decisions were influenced by their doctors’ recommendations. For example, Bill’s wife had a stroke and she was dependent on him for assistance with her mobility. He chose radiation therapy because “I would be lesser of a burden on my wife by having it this way”. Bill was also influenced by the incongruence of a traditional male job and child-like image put forth by his doctor’s “final words…‘you don't want to be walking around mowing the lawn in a wet nappy do you?…well my suggestion is that you have the radiotherapy treatment’. Similarly, Charles “didn't get the sense that I was being led but I did what he [urologist] wanted me to do. I made the decision he [urologist] wanted”.

Ben was sceptical that “the surgeon recommended surgery” because “most surgeons would”. After the initial consultation Ben researched various treatments and sought a second medical opinion:

> He was a surgeon too…his mission in life was to make sure that I understood that it was serious and that…surgery was required…He confirmed the interpretation of the pathology…and that surgery would almost certainly be the best bet in my case.
Surgery was Ben’s “best bet”, however he was not a betting man. One “useful document” that Ben used was the Epidemiology of Cancer (Photograph 10):

_The data is interesting but what they don't say is [the life expectancy]...if you have a prostatectomy...or radiation...or if you had nothing?_

**Photograph 10**

Ben expected the epidemiological prostate cancer data would enable him to make an informed and correct treatment decision. However, rather than definitive answers, he found diversity and uncertainty in the document. Despite two similar medical opinions and independent research Ben was uncertain about surgery. He wondered, “if it is possible to postpone things a couple of years” in the hope of some “new medical technique that can in fact deal with it”. He eventually dismissed this thought as “wishful thinking” but acknowledged it was the kind of thing you “go through in your mind when you are trying to rationalise it”. Reluctantly Ben agreed to surgery, however emotionally he was unable to reconcile his diagnosis of prostate cancer let alone the potential incontinence and impotence that may accompany treatment.
Some participants sought a second medical opinion from other prostate cancer specialists prior to deciding which treatment to use. Metcalf (R. Metcalf, personal communication, 20th July 2001) suggested that many men diagnosed with cancer seek second opinions because they have to hear their cancer diagnosis more than once in order to believe it. In the context of prostate cancer the findings from this research indicated that the complexity and ambiguity of treatment options, as well as the shock of diagnosis, underpinned participants’ pursuit of a second opinion. Two predominant treatments for localised prostate cancer were available, surgery provided by urologists and radiation therapy prescribed by radiation oncologists. In order to fully explore both treatment options some participants consulted a surgeon and a radiation oncologist. These participants re-assumed some control and researched what treatment would be best for them.

Participant – doctor relationship

Participant – doctor relationships were integral to participants’ satisfaction with health services. The foundations of these relationships were often established during diagnosis and subsequent treatment decisions. The majority of participants were particularly sensitive and vulnerable during the pre-treatment period, while they attempted to understand medical information as well as come to terms with their diagnosis.

As stated in Section One, Moving in, previous exposure to health care services, and the hierarchies they can impose, influenced participants’ reactions. Ben encountered doctors and health care systems that dislocated his customer constructions and ignored his purchasing power. He was rendered classless and powerlessness by the institutions that provided health services. Ben also aligned strongly with hegemonic masculine ideals of independence, self-reliance and breadwinner roles, all of which were undermined by prostate cancer.

Some participants’ contested moving in and on through illness and health service cultures, especially when they were overwhelmed by diagnosis and treatment information, and perceived pressure to make decisions quickly. Trent was “absolutely reeling from…the diagnosis and the information he [urologist] was
trying to hammer into me”. Arsenal was told of his diagnosis and referred for treatment during the same consultation. He described the urologist as:

...an emotional cripple...his performance to me suggests a total inability and insensitivity to other people...he mumbled something about positive margins without explaining and said that I'd better go to a radiation oncologist...it happened just like that, in a flash...I didn't know what a positive margin meant.

Participants and doctors constructed gendered performances with each other. Potential hierarchies existed through contested roles of hegemonic masculine healer and subordinate, marginalised patient. Integral to the functionality of the relationship between participants and their doctors was the avoidance of explicit hierarchical relationships. Some participants perceived that their subordination was enforced and contested moving on through illness cultures by expressing anger and criticism of doctors. These participants defined therapeutic relationships on their own gendered terms which facilitated some control of how and when they would proceed.

The majority of participants’ reported therapeutic relationships with their doctor, as illustrated by the following excerpts.

I was emotionally fragile...like when you are a kid and things are out of control and you need a parent to be perfect and there was a lot of that involved...the qualities I appreciated were the attention to detail in the interview and the patience with which he allowed me to ask the same question twice. (Arthur)

He seemed extremely thorough...he is a bit of mover and groover [sic] sort of guy. He has got a sense of humour...he is matter of fact. (Don)

My urologist seemed to me to be the kind of bloke that knew what he was about. He was quite confident...in the treatment that he was prescribing...he sells himself well...as far as I know I'm getting as good a treatment as Rupert Murdoch. (Kevin)

He rang when he knew a phone call might be appropriate just to say the right thing...I just liked his style. I liked his professionalism...his human side...he treats me with respect...there was the right relationship...I don't think I could have gone through all this if I didn't. (Max)

Fine man...we would talk through what was going on...I was at all stages aware of what was going on...very capable, very skilful. (Patrick)
He is a first class diagnostician. He doesn't deal in bullshit. He knows his limitations. (Argonaut)

He’s easy-going and didn't seem to think anything was a problem...he was great...I had so much trust. (Clark)

I had no doubt from the start that he was at the top of his field so I felt I was dealing with the best. He’s casual...I always remember his statement, ‘we'll fix it, we'll get it, we'll cut it out’...He was always just positive. (Unicorn)

Very easy guy to talk to...made me feel at ease which I think is important because I was going through a lot of stress. He was very reassuring...He came across as a very caring person. A genuine sort of person. (Wally)

Many participants listed hegemonic masculine characteristics—such as expertise and confidence—as integral qualities of their doctor. However, participants also valued more traditionally feminine characteristics of communication, caring and reassurance in their interaction with doctors. Non-competitive nurturing relationships between men were often new and fragile arrangements for participants. They needed permission to be vulnerable in the company of other men and move on in a meaningful way through patient cultures. In these interactions trust and respect were pivotal to participants comfort in being treated.

Treatment experiences

The radiation therapy waiting room was crowded with people. Wayne was “the fittest one there…the healthiest”. He predicted that a lot of the other patients in the waiting room were “gone for all money” whereas he could “be fixed”. Arsenal consciously decided he would “not talk to anyone, so I [he] sat there content to be by myself”. However in the last week he “did relent and actually say something” to another patient in the waiting room. Arsenal found out:

That poor bastard three years ago was diagnosed and had a prostatectomy...his PSA went up to 9 which showed that he had metastases and so he was there for radiation therapy...I felt so sorry for that poor thing.

John said, “it scares the living hell out of you to see people who are terminally ill…coming in there for the same treatment that you are getting”. Bill remarked that the waiting room allowed you to see “there is always someone worse off than you are” and Mac became “aware of just how bad some cases could be”. Many
participants were confronted by other people’s cancer in the waiting room as they
waited for their radiation therapy. Their mortality was realised. However, distance
from death was negotiated through differentiation and distance from relatively ill
‘dying’ patients. A hierarchy of cancer was constructed that enabled some
participants’ to distance themselves from their cancer.

During the 34 daily radiation therapy treatments, Wayne was generally “on a
high” despite the confronting aspects of the waiting room. He enjoyed the
interactions with staff:

The way they get you set up and mark your belly…then they say we are
going to take you down and they race each other out the door…They were
fantastic those people down there. That makes it easier on you…when you
have got good people trying to help you get back into business.

Wayne suggested, “you see a lot of those expert cancer people…they don’t get
very close to the patients…but patients want to have a little knock around talk
with them”. Wayne was grateful that staff cared and took an interest in him
beyond the provision of treatment. The majority of participants were
complimentary of the staff that prescribed and administered their radiation
therapy. The treatment was painless and minimally disruptive. James was able to
combine radiation therapy with work. He did “more than my 8 hours at
work…every single day” before he left in the afternoon to “be radiated”. Seagull
was able to “come in and go home by train” and after treatment, which “was never
a problem”, he “plays bowls”. Bill combined treatment with “looking after his
wife” (who has a stroke) and Mac “finish[s] work about ¼ to 5…have my [his]
treatment about 6 pm…go[es] home and have[has] a couple of scotches”. In these
ways work commitments and leisure were maintained and organised around
treatments.

Top Cat was admitted to hospital the day before his prostatectomy and fasted
from midnight. He was anxious but hopeful that the surgeon would “get it all [the
cancer]”. The tension lifted from Top Cat’s body following the pre anaesthetic
injection, and he “got to seven” after being asked to count backwards from ten as
the general anaesthetic was administered in the operating room. However the
removal of the cancer was not the only concern once Top Cat was anaesthetised.
He “stopped breathing when my [his] heart stopped during the operation and I woke up in…intensive care”. He pointed to Photograph 11:

_Hospitals are for people that are crook and I get really annoyed with people that bag them...I found the staff were just incredible. That is the main gates of the Repatriation Hospital...I was very pleased to see the last of that, and at the same time, that's the place where my life was saved, so that's important._

**Photograph 11**

Top Cat’s life was saved twice, through both the removal of the cancer and the subsequent post-operative resuscitation he required. The hospital, in both time and space, was distanced. Symbolically, the boom gate, which separated the sick from the healthy, was down. This was the view as Top Cat left the hospital following vulnerable moments and miraculous recovery. It was the place where he, with the help of others, won two battles to stay alive.

Participants undertaking surgery were treated as in patients and usually stayed in hospital for up to one week. Participants related various experiences of their surgery and hospitalisation. Bob had a “big bleed” and was back in the operating theatre “in the afternoon”. Ben was “concerned about the bladder spasm and I couldn't get a clear answer on what the problem was”. Clark cried with relief when his surgeon told him “Oh, by the way, we got it all.” Don had to “learn to
walk again” following surgery and Max “just kept getting…angry that I was there, because everybody seemed, in my eyes, as if they were twenty years older than me”. The majority of participants recalled events and cultures that were removed from their everyday lives, but were extremely grateful and complimentary about the care provided during their admission. They were also relieved to leave hospital and formal health care cultures. Most participants were unable to work for six weeks following surgery and the side effects of impotence and incontinence were more acute than radiation therapy.

Top Cat wore “napkins for approximately a month” for urinary incontinence following his prostatectomy. He re-established urinary continence quickly, because he “adhered to the rules” and did his Kegel (pelvic floor exercises) exercises. Top Cat was also impotent but rationalised that he had “been married twice…had lots of girlfriends…sown a lot of wild oats” and had “a lot of fun in my [his] time”. Urinary incontinence and impotence were common side effects of prostatectomy, although the severity and longevity were variable. Detailed discussion of the findings related to participants’ urinary incontinence and impotence and the effects on sexuality and intimate relationships is included in Chapter Six, Sexuality, intimacy and prostate cancer.

Ben tried to find out “where's the best place in Australia to do this sort of operation?”. He was unable to get an answer because “unlike AFL [Australian Football League] footballers, they [surgeons] don't publish their scores, their quality outcomes”. He discussed photograph 12 “what you have there are three tea bags of a superior quality versus six of an inferior or modest quality”. There was a guarantee that Ben was getting a superior quality in choosing the brand name tea but unfortunately, in the health system, there was “no way I could have known that”. He suggested:

*The whole system doesn't really allow us to work with it because ultimately we're just cannon fodder, grist for the mill, we're not actually customers. But we should be seen as customers.*
Ben wondered “did I go to the best surgeon in Melbourne, or is he one of the second-rung surgeons?”. He was “amazed how little my [his] operation cost…the net cost to me [him] was less than $2,000…that is hospitalisation, surgery, pathology, the lot”. He suggested “if I could have spent another $10,000 to have got a surgeon who was only 1% better, I mean, thank you, I would have paid it”.

Ben was a consumer and furthermore he ordinarily had purchasing power. Despite career success, wealth and education, he was unable to purchase a cure and manage his prostate cancer. His money could not buy superior quality in health services because the ‘name brands’ were not identifiable. His control, independence and problem solving ability were dislocated in the short term and endangered in the long term. Ben was affluent but unable to purchase.

Following surgery, Ben experienced incontinence and impotence “far worse than he expected”. He discussed photograph 13 in detail and explained it was:

...a billboard...a series of slogans or bumper stickers, that would just describe particular feelings that I’ve had, or particular opinions that I hold that I think are relevant to this whole topic.
Ben made his billboard using a computer and gave me an A4 hard copy because the photographs he took of it were not fully legible. The words that appeared on Ben’s billboard resonated throughout our interviews. He experienced grief and loss and was critical of health services and research. The words that Ben used to describe his experience of health services were false expectations, misleading statistics, inadequate information, medical arrogance, poor communication, funding inequity, government neglect and dishonesty. These phrases were placed at the top of his billboard. Symbolically, the personal effects he experienced as a consequence of these inadequacies were listed underneath. Top-down effects and hierarchical relationships were explicit throughout Ben’s discussion of: frustration, anger, depression, regret, irretrievable loss and quality versus quantity. In separate boxes in the billboard were the words Medical arrogance and quality versus quantity. They were two unresolved issues and major causes of Ben’s discontent:
I certainly thought the incontinence would be a matter of weeks and the impotence a matter of months...I discovered that was all wrong, so I feel quite depressed, somewhat deceived and misinformed, and certainly disappointed.

Ben mourned the loss of his quality of life and presented a rational, articulate, informed and educated synopsis of the inadequacies of health services and research. However, beneath Ben’s hegemonic masculine subscription, an emotive man looked up in response to an interview question I asked about telling work colleagues of his prostate cancer. Eyes about to overflow with tears he said, “You can’t keep secrets”. Perhaps, therein lays the tension. Ben refused to show weakness, but the energy involved in concealing his losses and the anger directed at medical services was exhausting him. Anger, commensurate with hegemonic masculinity was expressed, rather than the admission of weakness synonymous with subordinate forms of masculinity.

**After sales service or self treatment**

Most of the participants’ recommendations for prostate cancer health services pertained to practicalities around the ongoing care and support once the cancer had been treated. Ben “found out most of what I [he] know [s]” about “buying the right kind of incontinent pad” through his own efforts. He suggested that health services aren’t “really geared up to deal with this side”. Similarly, Randwick was discharged from hospital following his prostatectomy without a supply of incontinence pads or advice on where he might purchase them. Ron experienced rectal bleeding following radiation therapy and asserted, “so far as he [radiation oncologist] is concerned his job is done”. Top Cat would “like more communication from the specialist” following surgery.

The lack of after care created dissatisfaction and some participants invested considerable time and effort establishing how best to minimise their treatment side effects. Many participants were aware that their vulnerability was visible, and in many cases nurtured by health care professionals through diagnosis and treatment. However, once the treatment was completed, nurturing relationships, especially those with their doctor, reverted to traditional masculinist consultations. The subsequent treatment side effects, especially incontinence and impotence,
were often treated by other health care professionals including nurses and physiotherapists.

**Summary of discussion and findings**

The findings from this study show that moving in and on through prostate cancer situated many participants in new, unknown health service cultures. Furthermore the environment, interactions, people and language in health services were unfamiliar to many participants. Approximately one third of the participants in this study had pre-existing illness or injury prior to being investigated for prostate cancer. The findings from this study show that repeated exposure to health services influenced participants’ interactions with health care services and personnel. Participants with no prior illness, and closer association with hegemonic masculinity were more likely to contest the marginalisation they perceived as a result of illness and health services. This is not to suggest that all illnesses are experienced as equal nor was it exclusively mutual that previous exposure necessarily prepared participants for the specific challenges associated with prostate cancer. Rather, it reduced the newness of the illness experience as well as health service and patient cultures.

All but one participant in this study was treated by a male physician, and the communication and interactions between patient and doctor were strongly influenced by gendered constructions. In effect, the relationships between participants and their doctors disrupted as well as relied on dominant constructions of masculinity. In particular, moving in and on through diagnosis, treatment decisions and medical interventions demanded different types of relationships and communication for many participants. The complexity of these relationships and interactions was demonstrated by participants’ experiences of treatment decision making.

Many participants’ defined, negotiated and enacted ‘active’ or ‘collaborative’ involvement in treatment decision-making based on the relationship with their doctor, and their reliance on hegemonic masculinity. The findings from the present thesis study show that participants’ relationship with their doctor strongly influenced their treatment decision making. This finding supports Fowler et al. (2000) and Donovan’s et al. (1999) assertion that specialists overwhelmingly
recommended the treatment they themselves deliver—urologists recommend prostatectomy and radiation oncologists recommended radiation therapy. This finding from the present thesis research provides insight to how men construct collaborative treatment decision making, which Davison and Degner (1997), Davison, Gleave et al. (2002), and Davison, Degner and Morgan (1995) have previously suggested is men’s preferred role.

Many participants perceived that they were encouraged to be active and collaborative in treatment decision making. This was particularly important because it helped participants re-establish control and independence and demonstrated respect between men. Furthermore discussion about treatment options reduced participant subordination that accompanied illness. Therefore, trust and respect rather than treatment impartiality was integral to the functionality of participants’ relationships with their doctor. After all, there was no ‘right’ treatment choice, as survival rates and side effects were common to all treatments.

It was also important for participants to understand their diagnosis, have time to process treatment information and re-establish various levels of control before committing to treatment. Information overload and time pressure to make treatment decisions were poorly tolerated by some participants, especially those who strongly aligned with dominant forms of masculinity.

The findings from this study also provide insight to why men are typically poor consumers of health care services. Consultations with doctors are potentially hierarchical in which men admit vulnerability and weakness and ask for help. Therefore subordinate forms of masculinity can result by virtue of men not being able to solve or endure their medical problems. An atypical relationship occurs in which men receive help from other men. This can be a particularly fragile arrangement which disrupts dominant constructions of Australian masculinity that premise male-male relationships on competitive endeavors, taboo of introspection and self-disclosure, as has previously been described by Edgar (1997) and Webb (1997). Moreover the emotive nature of prostate cancer and dependence on doctors dislocates dominant male heterosex practices of reliance on female partners for providing men’s emotional needs, as previously established by Kilmartin (2000). The findings from this study show that participants constructed
their gendered self in response to health service and patient cultures, often in
direct consultation with the personnel they encounter.

Dominant forms of masculinity are socially constructed as incompatible with
illness, as established by numerous researchers including Charmaz (1995),
Gordon (1995) Martino and Pallotta-Chiarolli (2003), and Skord and Schumacher
(1982). Prostate cancer and its treatments affected participants in deeply gendered
ways. Approximately half of the participants continued paid employment, the
majority in white-collar executive positions. They had reached or were
approaching their career peak in terms of financial reward and seniority during
their 50s and 60s. Many participants in this group reported long working hours in
order to achieve and maintain their work performance. Paid employment enabled
many participants to be breadwinners within their families and situated them as
‘useful’, successful men in society. Prostate cancer adversely affected some
participants’ dominant ideals of being working men. Independence and self
reliance were also undermined by prostate cancer and social and physical
freedoms were often adversely affected. Traditional masculine roles of protector
within the family, and husband and lover became fragile when prostate cancer and
its treatments were experienced. Subordinate illness and patient cultures were
experienced, and the uncertainty of maintaining or re-establishing associations
with dominant forms of masculinity disrupted many participants’ gendered
constructions.

**Recommendations**
The findings from this study show complex connections between masculinity,
ilness and health care services. Further research into prostate cancer
communication from both the patient and health care professional perspective
would provide contextual understandings of the interactions that occur. This
recommendation is developed in Chapter Seven, *Conclusion and
Recommendations.*
Section Three: Moving Out

‘Moving out’ refers to the recovery period after acute treatment in which participants distanced themselves from patient cultures and its framing cultures of health services. Some participants had ongoing long term or lifelong medical treatments and ‘moving out’ related to the time and temporal distance from diagnosis and initial treatment.

Wayne had an accident on a horse years ago, “I got dragged on my head by a horse with my foot in the stirrup and I thought that could have been the end of it”. He said:

I had a few chances and now I have another...Life has been pretty good...I am not going to let it get me beaten [sic]. I have really enjoyed life. I have really had another go at it.

Wayne “was angry and sad for a little while” but had “overcome it alright” and was considering the use of Viagra for his impotence. Wayne’s recovery was conditional, the “cancer could come back”. However, he “got over the first big shock” and predicted he “will be able to cope and face up to things, if it is a bad one” next time. Wayne still “enjoys a pint and a punt and a round of golf”. He had regular PSA blood tests to monitor his prostate cancer recovery. He appreciated the support of friends and had a lot of good mates who helped him during his illness:

A couple of guys that have the garage...come and do my car and when I get a few bob together I ...buy them a couple of dozen stubbies. I have had a lot of mates who have had cancer and been sick...they just really appreciate you being there with them and carting them...backwards and forwards...You try and help each other.

A few participants, including Wayne, subscribed to dominant cultural ideals of Australian mateship as described by Ward (1958) and Murrie (1998) and suggested that it extends to illness. Top Cat was less convinced of the compatibility of mateship and illness. He was with “a group of guys, having a beer at the RSL [Returned Servicemen’s League]” after his operation:

One of them turned around and said, ‘Well, what does it feel like not to be a real man any more?’...I just laughed it off and didn’t think of it until I got home, and it just stuck in my mind, and it really got to me...Now, whether he
was trying to be a smart arse, I don’t know...I never brought it up with him again...You are sensitive at that time.

Top Cat suggested that the competitiveness and put-down jokes were commonplace between ‘mates’ rather than genuine friendship, (this has previously been described by Edgar, [1997]). Top Cat explained “a lot of men lie about their sexual prowess” and his ‘mate’ who made the comment “had to reassure himself a little bit” because “his marriage had split up some time before”. Top Cat did not confront his mate, but assured me “it’s in the memory bank”. The competitiveness of their mateship was not overt for the moment but it remained integral to the relationship. The older men at the RSL approached Top Cat privately to ask about symptoms of prostate cancer. However, they “wait until there was no one else around and obviously they didn’t want to be…heard talking about it in front of their mates…it’s a man thing”. Top Cat’s mate severed public discussion about prostate cancer. However, other men in the group initiated private one to one discussions with Top Cat. Gibson and Denner (2000) previously suggested that men require permission from other men to speak about health and illness. At the RSL there was private rather than public permission to speak about prostate cancer. In this way the “man thing” of not admitting weakness or vulnerability was preserved and the informal inquiries that followed situated Top Cat as a survivor and informer.

Ben had mates when he was at university but when “we got married, of course, the family issue took over”. Ben did not talk with other men about his prostate cancer. Furthermore, he rejected historical images of Australian mateship:

*The rugged bushman, that isn’t the way we live. The Digger, Anzac...that’s not the typical Aussie. I know it’s the myth, I know it’s something people like to revere from time to time...but I don’t see much of that when I walk down the street.*

Ben distanced himself from the historical origins of Australian masculinity and mateship. Most participants suggested that mateship was an institution for younger single men and, as predicted by Edgar (1997), Kilmartin (2000), and Tschann (1988), most married men relied on their female partners for social and emotional support.
This sporting life

After Top Cat was treated for prostate cancer he was diagnosed with a heart problem:

*Fuck it, I don't care...I've beaten cancer...that's more important than a bloody heart complaint. If I'm going to die of my heart, it should be quick and painless...not painful like cancer.*

Top Cat did not have “a prostate any more to worry about” and had won his battle with cancer. He rated heart disease less fearsome than the cancer culture he had recently moved out from. Furthermore, he was “doing something with himself”…going to the gym”, his “fitness level is higher”, and he had “got more mobility” than when he initially injured his back and knee.

Top Cat, used physical performance as an indicator of their recovery and determinant of well being. Clark had played golf at “the same club since I [he] was nineteen years old”. After his prostatectomy, golf became a metaphor for his recovery from prostate cancer in which his physical performance, competitiveness and mental health were intrinsically linked. Clark told a story that demonstrated the analogy:

*A veteran...who was in solitary confinement in Vietnam...he was off a handicap of 3 or 4 when he went to jail and he came out and he played to a handicap of 3 after being...locked up for three years. He had played every golf shot in his brain. I said, well if he can do that, ‘so can I’... We'll just do it easily. That was part of the healing that I will be out there [playing golf].*

Clark was a long time member of the golf club at which he socialised, competed and demonstrated physical prowess and skill amongst other men. His return to the golf course and match play following surgery were significant milestones in his recovery from prostate cancer. He was free from the physical and social restrictions inherent to illness cultures. Many participants continued a long association between physical activity, sport and masculinity. Mac attended the gym each morning, Seagull would ride his bike every day, Argonaut ran on his home treadmill, Max returned to competitive running and golf and Vincent resumed fishing and hunting. As has been well established by Drummond (2002), Edgar (1997), Pease (2002) and Sabo (1985), sports are regarded as a site for the development of masculine behaviours. The findings from this study show that
physical performance and competitiveness provided many participants with reassurance of well-being, achievement and recovery from prostate cancer.

Ben’s recovery was inhibited by impotence and incontinence that were constant reminders of his prostate cancer. He also harboured internal conflict that he explained through photograph 14, which presented two images of Ben using the bathroom mirror:

>This is to represent the fact there’s a real me and there’s an image of me… I give out two stories… there’s a degree of falseness… For most people, certainly at work…’How are you [Ben]?’ ‘I’m great.’ ‘Fine’. How was the operation?’ ‘Really good.’ ‘What was the outcome?’ ‘Excellent.’ ‘…now that is story number one, but story number two… there is incontinence… far worse than I expected… I didn’t understand it would be like that… I’m extremely disappointed… and the impotence is worse than I expected, and they are not trivial matters. They are not going away. They are permanent life long problems. They are irreversible. So, there are two really different stories here.

Photograph 14 (black and white application to protect identity)

One image represented Ben’s public hegemonic masculine self which stoicism preserved at work. The other private identity was marginalised and wanted to speak out and seek emancipation. The reflection and the real, the public and private, the hegemonic and marginalised co-existed in perpetual awkwardness and conflict. Ben was powerful yet powerless, in control yet out of control, wealthy yet poor. By not speaking up about his dissatisfaction, “the public probably
sees…no problems with this health system”. Ben wanted other “men to have better choices” but “there is a privacy issue, and also I don't want to be a perpetual moaner”. The stoicism to which Ben subscribed precluded him from helping men facing prostate cancer and prohibited his acceptance of help from other men. He was both rich and poor through his reliance on hegemonic masculinity.

The newness of Ben’s prostate cancer made our discussions immediate, almost in the treatment moment. Charmaz (1995) has previously suggested ‘time distance’ from diagnosis and treatment often correlates with the level and visibility of men’s grief and loss when confronted by illness. She suggested that as time passes, loss is accepted and memories of illness are hazed. Perhaps her findings, in part, provided insight to my last meeting with Ben four months after our first interview.

Men at work

Ben was dressed in a black suit and yellow tie, a spry affect was visible on his face and he greeted me enthusiastically. There was a change since our last interview, an air of optimism. I was eager to talk with him, hopeful, as if Ben was about to tell me that he was continent and potent. Instead he told me he had been promoted by his employer and was moving interstate. We talked about the concept of “ceilings” in organisations, where employees often reach their potential as judged by management at one organisation and have to move to another for promotion. Ben smiled and suggested:

I [he] might have just reached it [the ceiling], but it wasn’t where I’d been sitting for the last ten years…there’s still plenty of exciting things to do, so I won’t be worrying about ‘ceilings’ for a little while.

Ben had prepared a presentation to introduce himself to his new staff and explain how “they fit and what we might do together”:

However, when I talk about myself, I talk about my career, my family, but I’m not going to tell them that I'm incontinent and impotent...You just don't make such public statements.

The hegemonic masculine Ben was reaffirmed by undertaking his new job. A promotion, interstate location and new staff provided him with the opportunity to re-invent his hegemonic masculine self. Furthermore perhaps this opportunity
allowed him to resolve the internal disputation that existed between his hegemonic yet marginalised masculinity. Ben’s work promotion confirmed his achievements, validated his expertise and acknowledged his work performance. It was also a significant moment in his recovery from prostate cancer and moving out from illness cultures. Our interviews had finished, Ben’s statements about his prostate cancer were complete, he had returned to work.

Many participants constructed their return or continuation of paid employment as a significant indicator of their well-being and recovery from prostate cancer. Max returned to work after surgery and suggested that prostate cancer “didn’t impact on my productivity”. Vincent was “able to get back and do almost anything I did before” at his market garden business. Wally could have gone back to work part-time but he “wanted to go back to a full days work” following surgery. Bob returned to work “early” after surgery because “some people can retire and some can’t”. Through paid employment participants were able to move out from illness cultures and reclaim traditional breadwinner roles.

Diversity in moving out

There was diversity in how participants distanced themselves and framed their recovery from prostate cancer. John suggested:

*We all believe we are going to be cured but unless somebody comes along with the right vaccine the bloody plague comes through and you die like bloody rabbits in heaps.*

Ron had recurrent bleeding from his bowel following radiation therapy. He suggested, “it is like going bald. You have to live with it”. Following his prostatectomy, Charles was told “you need to have your kidneys looked at”. The subsequent tests revealed his “left kidney is on long service leave” and he was diagnosed with early kidney failure. This diagnosis followed a previous brain haemorrhage and recent prostate cancer. For some participants, illness was clearly cyclic and chronic rather than episodic, and moving out from illness cultures was tentative and conditional.

Perhaps the saddest contravention of cyclic and chronic illness was death. Royboy knew he had a short time to live. He had cancer of the lung, ribs and kidneys as
well as the prostate. During our conversation he spoke with a shortness of breath and audible wheeze, as he explained his acceptance of impending death:

*I say to the family I’ve got a lot of things to tell mum and dad, and my two brothers and my sisters when I get there [heaven] . . . of course the general knowledge is that’s not possible, but I say it must be a good place. I’ve never heard of anybody coming back.*

Royboy left for the “good place” on the 6th of January 2003, aged 84. His daughter sent me an email and clarified that prostate cancer was not the direct cause of his departure.

**Summary of discussion and findings**

Many participants monitored and contributed to their recovery from prostate cancer through demonstrating characteristics of hegemonic masculinity—such as physical endurance, competitiveness and/or by reclaiming signifiers such as work and career. In these ways participants were able to move out of patient cultures and back to the lives that were interrupted by prostate cancer. The findings from this study are consistent with Gordon (1995) who previously described beneficial aspects of hegemonic masculinity in the conceptualisation and recovery from testicular cancer. Frank’s (1991) assertion that people with other diseases are sick but those with cancer “fight it” is also strongly represented in this study. Many participants expressed their recovery from prostate cancer in language and concepts commensurate with characteristics and philosophical underpinnings of hegemonic masculinity. Conceptually, prostate cancer was something to be beaten, to establish power and control over, which was synonymous with patriarchal masculinity. However, instead of patriarchal power over other men and women, prostate cancer was controlled, subordinated and ideally eradicated.

Hegemonic masculine constructions are often used by media when reporting cancer testimonials. Scale (2001) has previously reported the use of “struggle language” that accompanied cancer testimonials and reflected hegemonic masculine ideals of competitiveness and aggression. Media representation also embodied hegemonic masculinity through depictions of how men cope with and manage their illness. For example, media coverage of Ted Whitten’s (Hanlon, 2002) courageous last lap and Robbie Flower’s (Sheahan, 2001) survivorship
provided templates for how men can construct prostate cancer and masculinity on their own gendered terms. Although marginalised through prostate cancer, many characteristics of hegemonic masculinity were self-evident in how these men spoke about their experiences and coped with illness. Similarly, many participants in this study demonstrated courage, rationality, fighting spirit and problem solving in their management and recovery from prostate cancer.

Survivorship and recovery from illness is increasingly being socially constructed as compatible with dominant forms of masculinity. For example, Kirk Douglas’ book entitled *My Stroke of Luck* offers stroke recovery advice. The Michael J Fox Foundation for Parkinson’s Research and the *Lucky Man* memoir about his ongoing battle with Parkinson’s describes the management and search for a cure. Christopher Reeves’ autobiography *Still Me* assures readers that he has never been disabled in his dreams despite being confined to a wheelchair since breaking his neck in 1995. These men demonstrate courage, power and the willingness to problem-solve despite illness and disability, which is publicly applauded. The management and spiritual, if not physical recovery from illness facilitates the demonstration and preservation of many masculine ideals.

Charmaz (1995) warns that men often revert to masculine practices that risk their health once they perceive they are recovered from illness. It is a difficult level of abstraction to attempt to categorise good from bad aspects of masculinity in the context of prostate cancer. The findings from this study show most participants continued health care practices including regular consultations with GPs or specialists following prostate cancer and its treatment. Participants’ testing of performance aspects of their masculinity through the resumption of paid employment and/or physical performances to confirm their recovery does not necessarily constitute health risk. Moreover, many of the gendered practices described by participants were integral to moving out from patient cultures and back to their previous lives.

In conclusion, the findings from this study support Nicholas’ (2000) suggestion that differentiation between harmful and beneficial aspects of hegemonic masculinity should be explored. Specifically, the context of how hegemonic masculinity was framed and enacted, especially in the recovery from prostate
cancer provided understanding of how aspects of hegemonic masculinity might be advantageous to men. Many philosophical underpinnings and characteristics of hegemonic masculinity contributed in positive ways to participants’ recovery.

**Recommendations**

The findings from this study support future longitudinal research to investigate the compatibility of dominant forms of masculinity, recovery and health maintenance over time. This would provide information about the sustainability of dominant forms of masculinity and health maintenance beyond acute recovery and/or in the presence of illness. This recommendation is developed in Chapter Seven, *Conclusion and Recommendations.*
Chapter Six

Research results

Sexuality, intimacy and prostate cancer

As discussed in Chapter Two, Section One, Part A, *Biomedical prostate cancer research*, all contemporary prostate cancer treatments can result in side effects including impotence and voiding problems. The specificities, as well as the severity and duration, of the side effects vary between and within treatment modalities. However, it is clear that prostate cancer, its treatments and side effects, impacted on participants’ sexuality and intimate relationships. In this chapter, the following research question is addressed:

- How does prostate cancer and its treatments affect the sexuality and intimate relationships of the men in the cohort?

The findings are presented in two sections, based on treatment modalities. In section one, ‘Two new I’s – Impotence and Incontinence following prostatectomy’ Arthur, Patrick and Clark feature, as they, along with other participants, share their experiences leading up to and following prostatectomy. The findings are presented in two parts, part A, *impotence* and part B, *urinary incontinence*.

Trent and Randwick feature in section Two, ‘Lost testosterone and radiated masculinities: Androgen deprivation therapy (ADT) and radiation therapy’, as they, along with other participants, share their experiences of Androgen deprivation therapy (ADT) and/or radiation therapy.

As discussed in Chapter Two, Section Three, Part B, *Male heterosexuality: relationships, sexuality and social constructions*, Gerschick and Miller’s (1994a,b) framework of reformulation, reliance and rejection is used in the analysis and presentation of findings in this chapter.

Gerschick and Miller (1994a,b) originally developed the reformulation, reliance and rejection framework to investigate the tensions between physical disability
and hegemonic masculinity. In this chapter, Gerschick and Miller’s (1994a,b) framework is used to assess how participants adjusted to the discrepancy between their masculinity following prostate cancer and its treatment[s], and dominant social constructions of masculinity. Participants’ treatment side effects such as impotence, diminished libido, urinary incontinence, and loss of muscle mass were assessed against characteristics of hegemonic masculinity. Specifically, hegemonic masculine characteristics including frequent sexual impulses (Kilmartin 2000), sexual performance reliant on erection, penetration and climax (Flood, 2002; Metcalf, 1985; Tiefer, 1987; Zilbergeld, 1992) and embodied control and muscularity (Cheng, 2000; Evans, 2001; Loeser, 2002; Morgan, 1993). Participants responded to the discrepancies between their masculine performance and dominant social constructions of masculinity by reformulating, relying or rejecting characteristics of hegemonic masculinity.

It is important to stress that participants in the current thesis study were not simply and neatly incorporated into Gerschick and Miller’s (1994a,b) framework. There were contradictions, tensions and diversity within and between participants’ responses and no participant exhibited one pattern exclusively. The framework enabled me to develop the analysis and present the findings in an inductive contextually sensitive way and, as Gerschick and Miller (1994a,b) predicted, one pattern often dominated while the other two were presented to a lesser degree.

**Section One: Two new I’s – Impotence and Incontinence following prostatectomy**

Prostatectomy, the surgical removal of the prostate gland, is a common treatment for localised prostate cancer that is confined to the prostate gland and has not spread to other parts of the body. As a by-product of prostatectomy, acute urinary incontinence and impotence occur. However, the duration and severity of these side effects varied greatly between the fifteen participants in this study that were treated with prostatectomy. We join Arthur, Patrick and Clark in the moments leading up to their prostatectomy and follow their post-operative recoveries.
Part A: Impotence

The anticipation of impotence

Meeting Arthur

*I am lost and late for my interview with Arthur. I phone to let him know I will be another ten minutes. I sense his appreciation and frustration through the audible ‘blacksops’ inherent to two mobile phones connecting. He is working to a schedule. In spite of my inability to read maps, moments later his street and house appear like a suburban oasis. I scale three steps at a time to the front door when suddenly I am greeted by a well-looking young man. Unsure if I am in the right place, I reach down to my backpack to retrieve the piece of paper with the address written on it. Before I can check it, he says ‘John?!’ Moments later Arthur and I are having coffee in a nearby cafe before picking up his youngest son from ‘day care’. We talk informally. I feel like he could be an old school friend – there is such little distance between our ages and interests.*

Observations and interpretations integrated with retrospective summary-

Arthur and his wife, Vera, “didn't talk about the sex, the sexual side of it” prior to treatment because “at that stage it was about survival, it was about paying for it and dealing with it and it was all future focused”. Arthur watched television the night before his surgery. Down the hall in an adjacent room, Vera lay in bed. It was a difficult time; tomorrow Arthur would have a prostatectomy that will render him impotent and incontinent in the short term and perhaps in the longer term. Arthur wanted to make love, however in the “cruelest blow”, Vera, who “doesn't like having sexual relations when she was having her period”, was menstruating. Arthur eventually went to bed, Vera “fondled me [him] and I [he] actually had a very pleasant ejaculation and sort of said farewell to it. I knew that was going to be the end of it”. There was awkwardness in the climatic moments, “love was there…but you just didn't know how to react”.

Meeting Patrick

*I drive into Melbourne’s central business district (CBD) midway through Friday afternoon and search for a parking space near a multi story office block that is home to many law firms. I take the elevator to the thirtieth floor and confirm with the secretary that I have an appointment with Patrick. I sit waiting, poised over a Business Review Weekly (BRW) magazine, pondering my choice of casual attire. My suspicion is confirmed as an impeccably dressed man in a black suit and neutral tone tie makes his way over to me.*
He introduces himself, hands me his business card, and invites me to a private interview office. The classic mahogany table reflects the tradition and power synonymous (at least to my mind) with what ‘Law’ represents. Patrick, the solicitor, sits adjacent. I can’t help but ponder the irony of me being in this office and conducting this interview. My feelings of self-doubt are heightened as I consider how much Patrick’s time would ordinarily cost me.


Patrick and his wife Victoria did not have sex as often as they used to because “both of us [them] working long hours” which resulted in them being “busy” and “tired” with “never enough hours in the day”. There was also a loss of communication in that “each of us perhaps mistakenly believing that the other wasn’t [isn’t] interested”; this reduced the sexual activity they once had. Patrick returned to work the day he was diagnosed with prostate cancer and “broke into tears” as he talked with a work colleague about the likely impotence that would accompany his treatment. The colleague “summed it up well by saying” ‘you are stiff all over when you are dead’. Patrick adapted his colleague’s philosophy and rationalised that “if you are alive you can do whatever you can do, if you are dead then you can't do anything. So the first objective is to be alive”. Patrick was “able to get myself [himself] back together again”, although “the rest of that day I [he] was a bit down”.

Meeting Clark

A rich baritone voice resonates and echoes in the high ceilings. Scotch on the rocks in hand, sentiment and sadness visible. Clark is visiting an old friend, a previous reincarnation, that was caught in a battle with an opponent of unknown ability. He describes a previous life, one which existed for a short time but left an indelible but victorious memory. Golf and football trophies surround us and are cited as analogous to ‘beating’ cancer. We are retrospectively exploring the life of a man who once had prostate cancer –his name was / is Clark. We are also celebrating the life of a man who continues to win many golfing battles.

Observations and interpretations integrated with retrospective summary- Clark post interview one and two, field notes 7/2001.

As the scheduled date for his prostatectomy approached, Clark and his wife Rose were consumed with the uncertainty of what lay ahead. They “have a cuddle…and all of a sudden I find that she's howling and all of a sudden I'm howling”. He said
to Rose “if I've only got a short time left, let's make the most of it”. Clark had been impotent since his TRUS-Bx a month ago, but had not discussed it with Rose. He privately hypothesised that his impotence and sudden loss of desire was due to a “chemical imbalance” triggered by the TRUS-Bx. Rose interpreted their recent lack of sexual activity as Clark withdrawing from her prior to his surgery.

As illustrated by these three relationships, the majority of participants shared long-term intimate relationships with their female partners. Most participants, including Arthur, Patrick and Clark, had been with their current partner for more than 20 years. Their relationships were at diverse points but enacted in traditional ways. Most participants formalised their union with partners through marriage, purchased a home and raised a family. Arthur and Vera both worked, were in their mid forties and had three young children under ten years of age. They managed a busy household and had an active sex life. Patrick and Victoria’s children were grown up and had left home. Their working lives were busy and fatigue infiltrated and affected their communication and sexual activity. Clark and Rose were both self-employed but considered retirement as they approached their sixties. Two of their children, in their early twenties, lived at home with them. Clark and Rose had “always been pretty matey…joke and laugh” together and, prior to the TRUS-Bx, shared penetrative sex for more that 30 years.

Most participants and their partners were consumed by issues of mortality, and impotence was often dismissed in the context of managing a life threatening disease. Some participants discussed the potential for impotence with their partners prior to surgery and rationalised that cancer treatment was more important than their potency. Bob’s main concern was how his wife Gwen “feels” about his impending impotence. Gwen assured Bob, ‘it is not important anymore’ and suggested they should ‘just have a cuddle’. When first diagnosed with prostate cancer, Bob was reluctant to have surgery but Gwen asserted, “never worry about the stupid male thing, you get it done…I would sooner have you alive.” Greg and his wife Kathy “talked about that [impotence]…we discussed that. We thought my health was more important than the sexual side of life…so it didn't worry us. We went through that pretty thoroughly”. Collaborative reformulation between participants and their partners differed from Gerschick and
Miller’s (1994a,b) descriptions of disabled men. The findings from the current thesis study showed how some participants reformulated hegemonic masculinity in direct consultation with femininities. This finding illustrates Connell’s (2000) prediction that masculinity is constructed in relation to femininity as well as other masculinities. It also demonstrated the power of hegemonic masculinity, whereby some participants required support from their partners to consciously break with its ideals.

Many participants also premised their willingness to accept impotence on their advanced age. They perceived their sexual prowess was already partially eroded through ageing and predicted that if they became impotent following surgery, it would have little effect. Bob said “sex is not as important as when you are a young bloke”. Argonaut believed “when you are much younger you are much more gung ho about sex and it takes on a much greater significance in your life”. Many participants accepted that their sexual performance naturally declined with age based on essentialist constructions, in which virility was synonymous with male youth and titrated with testosterone levels. Similar essentialist explanations of male sexuality are presented by many researchers including Archer (1996), Buss (1995), Phillips (2001) and Van Den Wijngaard (1997).

Dominant social constructions that prescribe and presume ‘old’ men as asexual, and only ‘dirty old men’ as sexually active, were also likely to influence participant’s expectations and expressions of their ‘older’ sexualities. Many participants complied with masculine hierarchies in which young men’s virility is overt and older men are expected to place less emphasis on sexual prowess. Potency was legitimately reformulated through these constructions. This is not to suggest that participants gave up masculinist power through impotence, rather alternative expressions through other aspects of their life such as family, social status, accumulation of wealth and consumerism were demonstrable. This finding is consistent with Buchbinder’s (2002) predictions of how older men express their masculinity.

Many participants also constructed sexual performance and sexuality as identical in their anticipatory acceptance of impotence prior to surgery. They relied on penetrative sex to express their sexuality; and sexuality was constructed as an
instinctual reflexive physical performance rather than being explicitly connected with desire and emotion. This construction of sex, based on erection, penetration and climax is synonymous with hegemonic masculinity—as has been well established by Connell (1983, 1995, 2000), Cheng (1999), Edgar (1997), Metcalf (1985) and Zilbergeld (1992). However, following prostatectomy, some participants experienced a discordant relationship between libido which remained intact, and erectile function that was lost. Connell (1983) has previously labelled and critically assessed this construction of sex as phallocentric, a model in which the erect penis is the overriding principle in sex, which serves to separate men from their sexuality.

In the time leading up to prostatectomy factors including the recent diagnosis of a potentially life-threatening illness, age, functionality and longevity of intimate relationships influenced participants’ willingness to forgo their potency. However, many emotive challenges can accompany impotence when it does occur. Gradual decline in sexual performance and libido was different to the experience of impotence for some participants. In the moments, months and years following prostatectomy, the re-establishment of potency was a significant aspect of many participants’ recoveries.

We now join Arthur, Patrick and Clark as they recover from their prostatectomies. Arthur woke up after his surgery and looked down:

> I had no penis at all, it had retracted right inside the body and that was very depressing. I could see the scrotum, I could see the [urinary] catheter tube going into my body and there was nothing, it had just retracted so much.

Arthur explained “it is not as if your penis gets shortened it is just how much is exposed, it gets repositioned” during surgery. In the first few weeks following discharge from hospital, Arthur sometimes “look[s] when it is flaccid and it looks like it used to and sometimes it's barely there…I haven't actually had a full erection to know whether it can get back to what it was like”. Vera “tells me she thinks it is smaller but I haven't been able to get the glans of my penis to…swell so maybe that might fix things up”. Arthur said, “not knowing beforehand [about the penis shortening] is a definite issue and a lot of men didn't seem to know”.

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Victoria took a series of seven photographs (1/3 of their total number of photographs), all of which were similar to photograph 15. They featured Patrick’s penis and surgical scar following prostatectomy. During our interview, Patrick looked at the photographs and explained:

*There are two reasons for having those photos, one is to show the scar which effectively runs from the naval right down to as far as you can go without doing some other damage. And the other one is…to show that the penis, I believe, is shorter than it was.*

Patrick explained that “in the course of the operation in taking out the prostate gland they had to cut off the urethra just where it enters the bladder…the hole has been created and that pulls it up and to my un-medically educated mind appears to shorten it”. Patrick “wasn’t aware of that [penis shortening] in advance” of the surgery and “asked the Urologist about it…he said ‘yes it sometimes happens like that’. Patrick did not “have any problem about that”:

*It is no real concern. It is just the way it is. I am told if and when it does become erect it would be the same size as it would have been anyway so that doesn’t, that is not an issue.*

**Photograph 15**
Patrick’s face was not visible in any of the photographs that included his genitals (although his face was included in two photographs when he was dressed). The photographs were dominant in the collection; however during our interview Patrick spoke intellectually about the physical changes and dismissed them emotionally. A reduction in penile erection size would affect his sexual performance and was more significant than reduced flaccid penis size. Patrick compared his current body to the past and although his “first objective is to be alive”, loss and changed identity were present as a result of the unexpected “damage” he perceived.

Arthur and Patrick rationalised their penis size reduction through the mechanics of surgery. However, it was an unexpected by-product of their treatment. Unlike other surgeries, aesthetic changes to external genitalia were not necessarily anticipated because the prostate gland resides inside the body and is not directly linked to the penis. The penis biologically and socially differentiates men from women, and Martino and Pallotta-Chiarolli (2003) have previously established that this differentiation is known and understood by boys from a very early age. Moreover penis size, as Edgar (1997) discussed, informs masculine hierarchies in which the large penis is socially constructed as superior and commensurate with characteristics of hegemonic masculinity including sexual prowess. Although Arthur and Patrick rationalised the treatment side effect they may have been emasculated by reduced penis size as well as impotence.

The lack of information about the possibility of reduced penis size prior to surgery was a significant issue. The taken for granted acceptance and explanations extracted by participants from medical staff following surgery showed the power and contradictory nature of hegemonic masculinity. Penis size was constructed as an ideal of hegemonic masculinity, yet stoicism, which is also a characteristic of hegemonic masculinity, precluded pre-emptive discussions about reduced penis size. Whilst not suggesting a competing victim scenario, there is a marked contrast with how breast cancer and the loss of a breast is discussed with patients prior to mastectomy when compared to prostatectomy. The lack of information given about the potential for penis shortening provided insight to the expectations of men undergoing prostatectomy by health services and professionals.
The loss of potency

Arthur lay in his hospital bed “on about day 2” after the operation and read the newspaper. He began a crossword, which he explained was represented by photograph 16, “there was a clue there for 23 across and the clue was impotence, it had 13 letters and it was powerlessness”. Arthur was sensitive to the suggestion that impotence made him powerless and also rejected the binary that an erect penis was a symbol of power. He was in the in-between spaces of both rejecting and relying on hegemonic masculinity.

Photograph 16

The media ordinarily reported other people’s lives. However, news about impotence infiltrated and commented but was not representative of Arthur’s experiences. Arthur cited numerous examples from talk back radio, television and print media that presented male impotence humorously and insensitively. The media influences social constructions of male impotence and, in part, informs masculine hierarchies in which impotent men are marginalised and subordinate. Although Arthur rejected the media’s portrayal of impotence, he was committed to re-establishing his potency. In effect, Arthur rejected the media’s method but was reliant on implicit messages that impotence was congruent with subordinate rather than hegemonic masculinity.
Arthur’s reliance on penetrative sex was not constructed in isolation. Rather, at a macro level, he was influenced by society’s dominant cultural expectations that are partly informed by the media. At a micro level, Arthur negotiated his masculine constructions with numerous people, including, but not exclusively, Vera.

Arthur spoke with his urology nurse about his impotence a few weeks after the surgery. She was “real feisty…very sexy sort of woman” and was “very confident of me actually gaining potency again”:

She could talk about sex from the point of view of a woman and she was the first person who said to me how deflating it is for a woman when a man does not become erect and that was very powerful. You worry that is the case and to hear someone say ‘yes it is a fact’, it is deflating.

Dominant constructions of heteronormative and gendernormative female sexuality and expectations became visible through the nurse’s testimonial. She confirmed the “fact” that women rely on an erect penis for sexual pleasure. Arthur was concerned about Vera because “even though she will say ‘I can be pleased in other ways’…there is no doubt about it, she likes the penis penetration”. When Arthur was touching Vera “in other ways”, he wondered “is this really me engaged here” because his “penis is completely slack”. He was “scared” because “a lot of relationships have broken down it seems when the sex stops”.

Arthur’s personal computer was “a life line in terms of communication about the disease and the side effects and treatment”. He joined a listserv and was “cheered up by the communication with other people who have had it [prostate cancer]”. Broom (2002) has previously reported that men with prostate cancer often discuss ordinarily private sexual matters with ‘virtual strangers’ through listserv discussions. It was “an eye opener” speaking with older men and their partners who are in their late 60s and 70s because, “I don’t know that I ever thought about them [older couples] as being sexual people or not”. He recalled they “really helped me realise that ‘hang on’ sexuality is just not for someone in their younger years”. The listserv chats ensured anonymity and provided information that “you probably wouldn’t share…if you met at a social situation”. Arthur found it:
Fascinating about the number of women who write on this and talking very bluntly about their sexual preferences...people in their 60s into anal sex...and bemoaning the loss of erection of their husband.

Arthur’s listserv discussions provided further evidence of female preferences for penetrative sex. Furthermore, the information disrupted his constructions of the exclusivity of vaginal penetration in heterosex and that older couples do not desire penetrative sex. Diversity of sexual preferences and longevity of female sexualities were substantiated at a global level via the internet. If the anonymity of the listserv allowed people to tell the truth about their sexuality, it was unlikely that Vera or Arthur would eventually accept his impotence.

Arthur defended his reliance on a penetrative model of sex and rejected the “feminist notion that penetrative sex...rests with the male” and that “you shouldn't have Viagra available because they [men] should find other ways to enjoy their sexuality”. He re-iterated that there were “a lot of women who like penetrative sex” and was critical that “people who haven't got the problem [impotence] make judgments about other people's sexuality”:

Anyone can close their eyes and put a blind fold on for 24 hrs and get some appreciation of what it's like to be blind. Not of the permanent loss but some appreciation of the hassles. If you were potent you can't be impotent. You can't experience it.

In the first five weeks following the prostatectomy, Arthur noted a loss of “that sense of potency...which would not rely on one being erect, it was a sense of being a man”. He was having “very black experiences”, felt old, “like a 90 yr old man”, “worthless”, and kept himself “invisible”. Furthermore, Arthur was reliant on the procreation imperative encouraged in hegemonic masculinity, previously described by Gerschick and Miller (1994a,b), “when I walk[s] past a pregnant woman...it reminds you what you can't do any more”.

Although momentarily blinded by what he labelled a “black abyss”, Arthur was committed to regaining his and perhaps Vera’s potency. Therefore, his reliance on penetrative sex responded to external and internal pressures to perform sexually in the way he and dominant culture was accustomed. However, he was in the precarious position of not performing sexually to his own expectations, denying Vera her preference for penetrative sex, and not fulfilling dominant social
constructions of masculine heterosex performance. Vera’s sexuality had become especially visible through Arthur’s inability to perform. Arthur was marginalised through impotence which rendered him subordinate in masculine hierarchies. Moreover, he was unable to meet Vera’s sexual ‘needs’ which were reliant on penetrative sex.

Many participants, including Patrick and Clark were less explicit than Arthur, in their reliance on penetrative sex, but nonetheless they were committed to re-establishing potency following surgery. “In the last few years”, Patrick and Victoria “haven’t been particularly sexually active anyway, but I would like to think that is something that you don't close the book on”. Patrick suggested “that even without being sexually potent there would still be some opportunity to have a sexual relationship” possibly through the use of medications. Likewise, Clark hoped the impotence would “settle itself down”. However, his libido was also low. Prior to his TRUS-Bx and prostatectomy, Clark would “see a bird [female] walking past” and think “that's not bad”, but now it was “no interest to me [him] at all”. Despite his lack of sexual desire, six months after surgery Clark also explored ways of regaining potency.

**Initial reliance on penetration**

Arthur’s urologist gave him “this totally anonymous, completely unsexy brown paper bag” (see Photograph 17). Initially the bag contained “pads” for urinary incontinence. However, today Arthur carried his “vacuum erection device” (VED) in it. Vera “saw it [the bag] as a symbol of being sick”. Arthur “found it amusing”, although his reason for including photograph 17, the “dreaded paper bag”, was “part annoyance and part embarrassment”. The white sticker on the bag was “a computer print out of my name which gets stuck on it”.

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Arthur suggested the bag implied “this problem [impotence] is to be hushed up”. However, rather than provide anonymity, it actually identified him:

> Like policeman in plain clothes stand out...it's like here's a brown paper bag 'you can't get it up' that's what this bag says to you and as you walk out through the waiting room there are half a dozen other men...sometimes with their partners or younger children and they all look at you and see you walk out with a brown paper bag and even though it is meant to be anonymous it is...definitely a sign you are in the club.

The paper bag identified Arthur as impotent, through its appearance and the attached ‘patient’ label. Moreover, it situated him in a “club” of subordinate, impotent men who resided in the urologist’s waiting room, identifiable by possession of brown paper bags waiting to see their urologist. Arthur wanted to move out of this subordinate club and culture which he had been forced to join. He demanded distance from his own impotence and detachment from the marginalised collective of men that were afflicted.
Paradoxically, the intent of anonymity through the use of a brown paper actually identified the owner as impotent. In Australian cultures, the brown paper bag has been used in this way for many years. Social images of popular culture which prescribe putting a bag over an ugly person’s head during sex and the alcoholics’ cheap wine encased in brown paper bags have acted as identifiers of the anonymous and symbols of marginality and subordination. In this way, Arthur contested his anonymity as well as his identification through the brown paper bag.

Arthur described the VED as “unpleasant”:

*It made my penis get fat at the base but not exactly grow. Had these inch notches marked on it...and there was still a good two inches of space for me to grow into which was very deflating...they call it an esteem, how hysterical...I could get an erection out of it but not like I used to get...it was just really painful...it [Arthur’s penis] was pushing right against the tube you could see the skin pushing up like someone’s face against a window.*

The mechanics and artificial nature of the VED resulted in pain rather than the pleasure Arthur previously associated with having an erection. The erection was mechanically produced and confined to a plastic tube; his penis was different in size, form, sensation, colour and movement to how it used to be. The practicalities and loss of spontaneity also detracted from the VED ‘treatment’:

*It is hard to do it in a house like this with young kids who run around the place saying ‘hi dad let’s go and play footy’. ‘Sorry I am pumping my dick at the moment I can’t’.*

Arthur stopped using the VED and tried Viagra. He found “buying it [Viagra] at the chemist is so hard when you go up to the 18 year old girl with your packet of Viagra to pay for it”. He tried Viagra but it did not “always work” and he got side effects of “headaches … sinus …indigestion” and “could not sleep after using it”.

Arthur was reliant on hegemonic masculine ideals of potency and penetrative sex, yet he was consistently reminded of his inability to meet those ideals. He was marginalised through impotence as well as the purchase and possession of products to treat it. Despite this, as our first interview came to an end, Arthur revealed he was “trying the injection” that afternoon, which his doctor would administer at the surgery.
Patrick began “investigating that issue [potency]…not long after I got the [urinary] catheter out…but that…hasn't been present and forthcoming”. He went to a “Chinese herbal medicine type person” who gave him “a concoction of herbs” to “repair the [erectile] nerves” and “get some function back”. Patrick set up a workshop in his shed (photograph 18) and methodically prepared an organic herbal remedy to restore his potency. Each week he got “a number of packets of weird and wonderful herbs which I would take home and boil up with 2 litres of water”. He boiled it “down to 4 cups worth and drink[s] two cups each night and 2 cups each morning”. The shed provided a private place where Patrick could problem solve his impotence without the risk of public identification. However, after “about 6 months…I [he] came to the conclusion it wasn't doing any good”.

Photograph 18

Eventually he discussed potency treatment options with the urologist and was told his best option “is injections” which Patrick suggested “is not necessarily the best thought either” because “I don't suffer a lot of distress about it [impotence]. I am happy to be alive and feeling well and living life”. Despite Patrick’s disclaimers about his interest in regaining potency, he and Victoria investigated the use of the injections:
We bought home a video to watch how you do it...it makes you...cringe a bit when you see the penis being injected...it is stated that where it is injected it isn't painful. I understand that intellectually.

Clark described his libido, “sometimes there's an urge like…it would be good and then…it's gone”. He suggested it was like giving up smoking; eventually “you don't worry about it for three or four days…a week, two weeks”. Despite a lack of desire, Clark decided to try “the injection” to restore his potency because “it’s…a masculine thing that you expect to be able to do”. In this way, Clark responded to dominant social constructions rather than his own desire to continue penetrative sex.

Both Patrick and Clark dismissed the importance of being potent and rationalised the mechanics of treatment. They also consistently denied any emotive or intimate need to regain potency. Therefore, some participants—including Patrick and Clark—pursued ways to re-establish potency but simultaneously disclaimed their reliance on penetrative sex. In this way, they protected themselves from another point of failure that occurs if treatments do not restore potency. After all, if the medically proven treatments worked for other men, participants may have perceived themselves to have failed the treatment, rather than the treatment failing to re-instate their potency. Participants also protected themselves from potential ridicule associated with being older men trying to gain erections artificially rather than stoically enduring impotence as a by-product of age and illness. This is informed by some treatments, such as Viagra, that are often socially constructed as recreational, rather than legitimately therapeutic. All these factors contributed to some participants being uncertain about the appropriateness of treating their impotence.

The injected penis

Arthur got an erection following the injection and “that weight of blood in your penis was terrific”. He quickly made his way home from the surgery but “unfortunately I couldn't use it [the erection] because [Vera] wasn't around”. She “had an appointment in the afternoon and…I had to go to a meeting that night”. A few days later, Arthur had an erotic dream and was “able to achieve an erection on my [his] own which was capable of penetration”. He made love to Vera but it was “extraordinary worrisome and I didn't enjoy it and it was all over very quickly”.

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He found it ironic that he was unable to “produce ejaculate” but “still prematurely ejaculate[s]”. The next day he got an erection again, and “this time a lot more control” in delaying his ejaculation. Arthur tried the injections twice more but experienced “extreme pain…in the head of my [his] penis. The pain was murder and lasted for as long as the erection. Nearly 4 hours”. Ineffectiveness, side effects and loss of spontaneity accompanied Arthur’s three treatments and dislocated a lifetime of erectile experiences and sexual practices. Penetrative sex felt, looked and was enacted differently. Arthur demonstrated the separateness of his sexual performance and sexuality. He did not mention the intimacy of re-establishing penetrative sex with Vera. Instead, he critiqued his performance and evaluated his climax control. He constantly, consciously monitored his penis and sexual performance.

**Reformulation**

Patrick administered the injection to himself at home. His “erect penis is the same size as prior to surgery” but “the experience was very painful”. Patrick was unable to have penetrative sex because of the pain and it “took two hours to get rid of it [his erection]”. He asserted that he would not try the injections again and had “explored successfully other ways” including “more touch” to be intimate with Victoria. Patrick concluded that “the relationship is actually better” and he and Victoria were “a little closer” than prior to his prostate cancer diagnosis. Although “a little sad for not having sex” when he was potent, Patrick was “still glad to be alive”. After all, there was “not much point worrying about the past”. Patrick reformulated how he was intimate with Victoria and was physical through touch rather than penetration.

The injections worked “about seventy percent as it should” for Clark. However, they were “just a disaster…how can you sit there on the side of the bed with a bloody needle into your old fellow?” He decided that he was “better [to] have something else to occupy my [his] mind”. He advised that “if someone said to me ‘should I have ‘em?’ [injections] I’d say unless you’re a real…sex maniac, don’t worry about it”. In retrospect, “we didn't know how difficult the alternatives were going to be” and “the artificial…just wasn’t worth it…it had to be natural or not at all”. Clark accepted that penetrative sex was no longer a part of his and Rose’s
relationship, “we are probably better mates than lovers…we enjoy each other's company…and do a lot of stuff together”. They went out to restaurants, “just the two of us” and “sit and talk” and “get on really well together”.

Many participants initially used treatments to restore their potency but eventually abandoned them due to the artificial nature, ineffectiveness and lack of spontaneity in achieving and maintaining their erection. This finding may offer some contextual insight to Meuleman and Mulder’s (2003) meta-analysis finding that a mismatch exists between the high rate of erectile dysfunction and low impact on sexual quality of life following prostatectomy. Many participants found a gap between the mythological ease and the real difficulty of achieving potency though the use of medical treatments. The findings from this study support Basson’s (1998) assertion that misunderstanding, misinformation and miscommunication are major contributing factors to men’s non adoption of medical treatments for impotence. Specifically, the findings from this study show that many participants expected treatment[s] would provide quick fixes and the concept of rehabilitation and gradual recovery of potency was poorly understood.

Some participants accepted impotence without trying mechanical or chemical treatments. Greg “just thought let nature take its course” when confronted by impotence. He and his wife Sharon “have a great life together” and “there's more to life than just sex”. They “still have our [their] cuddles” and “put our arms around one another and say we love one another”. Greg had “had wonderful help from [Sharon]”, she had “been the backbone”. Being together was important, especially given Greg’s advanced prostate cancer and poor prognosis:

> She [Sharon] doesn’t show it but I know that she’s had to deal with a lot...we hung on together, battled on through it together, which we still do.

Contextually, as some participants grew older, their long term relationships were less reliant on penetrative sex. When these participants became impotent, their expressions of sexuality, love and intimacy were reformulated, and alternative, less hegemonic masculine sexual performances were enacted through shared activities, physical closeness and touch. This finding from the present thesis is consistent with previous studies by Gordon (1995), Gritz et al. (1989) and Fergus et al. (2002a,b) of men with testicular and prostate cancers.
Some participants experienced alteration to specific erectile, penetrative and climactic sexual functions following prostatectomy and various functional aspects were demonstrable without mechanical or chemical treatments. Variations included climax without an erection, partial erections, and climax without ejaculate. Yanni was “having sexual relations…in so far as I could without getting an erection” through “a lot of oral sex from both perspectives” and “caressing”. It was “a fairly satisfying sex life” but “different in the fact that you can't penetrate”. He and his partner Mandi called it “proxy sex”, and explained “you are having sex when you are not having sex”. Yanni said “it’s more about intimacy than penetration but I think from both points of view it is quite enjoyable”. Yanni was unable to obtain an erection and climaxed without ejaculate. He and Mandi did not share penetrative sex but enjoyed intimacy and a loving relationship.

Reliance

Arthur’s reliance on penetrative sex continued but “the idea of a mechanical/chemical erection lost its appeal”. Arthur sent me an email update in November 2002:

> While I have been able to have orgasms since early after recovery from the surgery and these are often accompanied by partial erections, I have had a few nocturnal erections that have woken me up! I have been able to have erections rigid enough to achieve "natural un-assisted" penetration on Dec 6&7 2001, May 18, 2002, May 26, 2002, August 29, 2002 and November 10, 2002. (Yes, I note the dates! Wouldn't you?) But these events are not yet as they were due to reduced sensitivity, stress (Will it stay up?) and consequently premature (dry) orgasm. But as Woody says, ‘even bad sex is great!’

Arthur’s sexual performance was improving, he “no longer feel[s] like a failure in bed” and “our love life is getting better at being inventive”. That said, Arthur confirmed “if I don't continue to improve I will go back to them [injections]”. He remained committed to resolving, by whatever means he could, two discordant relationships between his (a) libido and erectile function, and (b) sexual ‘dysfunction’ and hegemonic masculine ideals of erection, penetration and climax.

Unicorn was also reliant on hegemonic ideals of penetrative sex. He explained that sexually, he was “getting towards normal”, but in the interim he used Viagra
which was “a bloody ripper”. Using Viagra had altered some aspects of his sexual performance, “you have to have a couple of hours up your sleeve” and “you can't…get onto somebody out in the car” because “you need to plan”. Unicorn was also unable to drink alcohol when he used Viagra because “it really kills it [his erection] off”. However, one major advantage of Viagra was that “12 hours later, good as gold, works again” and you can “still make use of it”. Overall, “the end result is really as good as it was” which “makes you feel like a man to be just about performing like the old days”. Unicorn referred to his youthful days when he lived up to the culturally dominant masculinity that placed sexual conquest as the patriarchal right of young men. His halcyon hegemonic youth was reclaimed as Unicorn distanced himself from impotence, middle age and prostate cancer.

The two youngest participants in this study, Arthur and Unicorn, were reliant on many characteristics of hegemonic masculinity. Just as masculinity is socially constructed, so too, are prescribed hegemonic masculine performances related to age. Arthur and Unicorn were both in their 40’s and had current relationships to gender that many older participants did not have. They were relatively young, previously healthy and virile and in the prime of their careers prior to being diagnosed with prostate cancer. Furthermore, I interviewed both participants within twelve months of their surgery and impotence, and many of their experiences were still unfolding at the time of our interviews. These factors are likely to have contributed to their explicit reliance on penetrative ideals of hegemonic masculinity.

**Rejection**

Rejection of penetrative sex was the least well represented category in this study. Two participants renounced penetrative sex as a social construction to which they were not aligned. They created alternate masculine identities and emphasised their status as people.

Argonaut did not see impotence “as a problem in terms of my [his] sexuality” and suggested:

> Being a man is not necessarily being able to get an erection as far as I am concerned. So there is no problem. Let's put it crudely. My identity didn't reside in my dick.
Argonaut rejected the idealised form of hegemonic masculinity that prescribed erection, penetration and climax as society’s construction of how a real man’s sexuality should be enacted. Moreover, his personhood and masculinity were constructed outside the parameters of dominant heterosex constructions prior to being impotent rather, than in response to losing potency.

Harry was not treated for prostate cancer but asserted that penetrative sex was “not important in life”:

*It [penetrative sex] is only a product of your conditioned mind. ‘I like that experience and I want to repeat it again and again’...I really don’t care...sex is just...hype.*

Harry explained “my friend…done [sic] those injections. Boasting that he could do it for an hour. Who wants to have sex for an hour? not me”. Harry rejected sexual prowess and hegemonic ideals of ‘staying up all night’. He situated the “conditioned mind” as being influenced by dominant social constructions which were “hype” rather than reality. Therefore, he rejected penetrative sex, as belonging to dominant cultures rather than reflecting his own gendered constructions.

**Summary of findings and discussion**

The findings from this thesis study support previous suggestions by Charmaz (1995), Farrell (1986), and Skord and Schumacher (1982) that illness can threaten many aspects of masculinity—including sexual prowess. Moreover, in the context of prostatectomy, the treatment as well as the disease directly impacted on participants’ masculinity, sexuality and intimate relationships. Participants’ penis aesthetics and functionality were directly affected by prostatectomy. The smaller, impotent penis signified being at odds with ideals of hegemonic masculinity, as has previously been discussed by Edgar (1997), Flood (2002), Kimmel (1987, 1990), Martino and Pallotta-Chiarolli (2003), Potts (2000) and Tiefer (1987).

Most participants were prepared to accept impotence as a by-product of living longer. This finding has previously been established by Yong (1998). Participants’ willingness to give up potency was at odds with dominant social constructions of male heterosex based on erection, penetration and climax, previously described by
numerous authors including Lee and Owens (2002), Metcalf (1985) and Zilbergeld (1992). However, in the context of having a potentially life-threatening illness that was treatable, participants chose impotence as a way of avoiding death. Many participants were philosophically commensurate with the Queensland Cancer Fund advertisement (2002) featuring Peter Dornan, which predicted “after cancer there are some things you just have to give up”.

The anticipatory acceptance of impotence was also influenced by participants’ constructions of age, and dominant social constructions of masculinity that older men should ‘grow old gracefully’ and be ‘well respected’ for their achievements rather than sexual prowess. Fleming (1999) and Thompson (1994) have previously suggested that older men are socially constructed as asexual, and Buchbinder (2002) has identified culturally acceptable masculine expressions for older men that exclude sexual prowess. By responding to the masculine hierarchies implicit to the subordination of older men, participants avoided emulating a caricature or parody, rather than a living example of hegemonic masculinity based on sexual prowess.

Prior to prostatectomy most participants’ long-term relationships were based on shared activities and emotional connectedness as well as penetrative sex. Therefore, alternate expressions of intimacy had been established by many participants, and the centrality of penetrative sex synonymous with hegemonic masculine ideals had, in part, been reformulated. The findings from this thesis study are commensurate with Edgar (1997) and Kilmartin’s (2000) prediction that intimacy and sex are not necessarily the same thing, and supports Weeks, Holland and Waites’ (2003) prediction that sexuality shifts over time and life course. Furthermore it demonstrates the limitations of conceptualising sexuality as a fixed identity, which has previously been critically assessed by Weeks (2003).

Although participants constructed an anticipatory preparedness to accept impotence, when it occurred many participants investigated how they might re-establish potency. Many participants’ did not expect to be reliant on penetrative sex, however a discordant relationship between in tact libido and impotence, and the desire to re-establish sexual practices that had been part of their long-term intimate relationships influenced decisions to seek medical treatments. This group
of participants underestimated the complexity of their sexuality and reliance on penetrative ideals of hegemonic masculinity. This illustrates Connell’s (1994) prediction of the tensions within a given pattern of masculinity and the contextual manoeuvring rather than fixed state of gender. It also supports Jackson’s (2003) suggestion that for those who identify as heterosexual (as well as those who do not) heterosexuality is a site of struggle and contested meanings.

Many participants initially responded to strong cultural assumptions that men initiate sexual activity, previously described by Lee and Owens (2002), and that the ability to initiate sex was reliant on being able to obtain and maintain an erection. This dominant construction of male sexuality has been described by numerous authors including Flood (2002), Kimmell (1987, 1990), Lee and Owens (2002), Metcalf (1985), Tiefer (1987) and Zilbergeld (1992). Medical treatments enabled some participants to obtain an erection, which chronologically facilitated the beginning point and foundation of penetrative sex. However, the findings from this thesis study show that the means by which an erection was achieved, maintained and controlled were also integral components of the phallocentric model of sex. Frequent, spontaneous, natural, rigid erections reflect the virility, desire and manliness tantamount to hegemonic masculinity and these sexual performance indicators were rarely met through medical treatments.

In summary, most participants reformulated penetrative ideals of hegemonic masculinity. This finding from the present thesis study is consistent with Fergus, Gray and Fitch (2002b) who similarly noted that men with prostate cancer redefined phallocentric models of sex. Fergus, Gray and Fitch’s (2002b) description of redefined sexuality is consistent with the reformulation pattern used in the present thesis research. Furthermore specificities of reformulated activities such as shared activities and more touch, as previously reported by Gordon (1995), Gritz et al. (1989) and Fergus et al. (2002a,b), are strongly represented in the present thesis study.

A few participants continued to respond to dominant social norms of masculinity, and were reliant on how society expected them to perform sexually. They were concerned with how others viewed their masculinity. These characteristics of reliance have previously been described by Gerschick and Miller (1994a,b).
Participants perceived impotence to be located within themselves, rather than within a social structure. The findings from this thesis study showed that the two youngest participants strongly relied on dominant ideals of penetrative sex.

The least-represented pattern in this study was rejection, which reflects the power of hegemonic masculinity, in that few participants were willing to explicitly break with its ideals. Two participants challenged the cultural fiction previously described by Potts (2000) that impotence produces a dysfunctional male heterosexuality. Furthermore, their rejection of potency as society’s dominant construction of how masculinity was enacted allowed them to define masculinity on their own gendered terms.

In conclusion the findings from this study show diverse constructions of male heterosex, and this illustrates Jackson (2003), Kitzinger & Wilkinson (1994), Pease (2002) and Smart’s (1996) prediction of the plurality of heterosexualities. The patterns of reformulation, reliance and rejection facilitated the description and presentation of participants’ relationship to hegemonic masculinity at a specific time and context. However, these patterns are subject to change and contradiction as evidenced by the results from the present thesis study.

**Recommendations**

Future research to investigate the effects of impotence on the female partners of men following prostatectomy would provide valuable contextual insight to how reformulation, reliance and rejection are constructed by women and men in heterosexual relationships. This recommendation is developed in Chapter Seven, Conclusion and Recommendations.

**Part B: Urinary Incontinence**

Prior to surgery, Arthur was “concerned” about the potential for incontinence but “pretty confident” it would “not be a great problem…because of my youth”. Post-operatively, he used “pads for a couple of days” to absorb the small amounts of leaking urine he was unable to control, but regained urinary continence in less than a week. Arthur was comforted by the outcome and suggested “if I did have incontinence that would be a terrible burden to live with”.
Some participants predicted that urinary incontinence would be relatively more debilitating than impotence, should it occur, post surgery. Argonaut “really did fear incontinence” prior to his prostatectomy because he “saw this as a demeaning sort of situation”. Trent found it “very difficult to come to terms with” the possibility that he could “be stricken with a social condition” like incontinence, and Top Cat was concerned that it would preclude him from using the swimming pool at the gym. The majority of participants’ concerns about urinary incontinence related to quality of life issues such as social and physical restrictions rather than direct health concerns. This finding has previously been established by Pinnock, O’Brien and Marshall (1998). Urinary incontinence could result in visible losses of bodily control that would socially isolate participants and restrict their physical activities. In contrast to impotence, which could be kept private, urinary incontinence threatened to publicly reveal marginalised and subordinate forms of masculinity. An uncontrolled leaking body is child-like or feminine, whereas the masculine body is controlled. Cultural expectations of men’s bodies have previously been described by Morgan (1993) who suggested that the male body is socially constructed as strong, enduring and self-reliant, and Loeser (2002) predicted that the disabling of these qualities subjugated men to the realm of the “abnormal”, the “feminine” and the “not male”.

Patrick was incontinent of urine following his prostatectomy but remained optimistic and “look[s] for improvement every day”. For “3 months after the surgery” he wore absorbent urinary pads. He pointed to photograph 19 and explained the intricacies of “what they [absorbent pads] are like”:

_I started off with a bigger one than that... It was more like a nappy but after a while I got to those and they were fine, just a little pouch and I was able to use these for another month or so after I went back to work._
Patrick returned to work with the absorbent pads in-situ. He “made sure it was covering where it needed to cover” and “wore it for a fair bit longer than I really needed to”. He did not want to reveal any visible signs of incontinence or vulnerability at work, especially given that he had only been working for his current employer for six months. The absorbent pads concealed leaking urine that otherwise might be seen and/or smelt despite his loss of urinary control. He was initially child-like with the use of a “nappy”, then feminised by the discreet “little pouch” synonymous with absorbent menstruation pads, and finally masculine through reclaiming and entrusting his urinary control. Throughout Patrick’s incremental recovery, he “didn't doubt that I would recover [urinary continence] and I was always positive”.

Most participants used absorbent pads whilst they were re-establishing urinary continence. The absorbent pads signified departure from hegemonic masculine ideals of control and self reliance and were framed as feminine and/or child like by some participants. Bob complained to his wife Gwen about the absorbent urinary pads he used “for a couple of weeks” following his prostatectomy. Gwen
referred to the menstruation pads she had used and warned Bob “don’t you grizzle to me about them after all these years”. Ben referred to one particular pad as a “panty liner” that was sufficient for absorbing small amounts of urine when his loss was minimal. Arthur noted that the packaging of the absorbent pads was also feminine, “they come in pink, this Barbie Doll Pink and they are called Poise”.

Clark felt “very lucky” to regain urinary continence soon after his prostatectomy. He “had to do some floor exercises” and “found that a bit of a challenge…because that was part of the recovery, and I would have done anything to be right afterwards”. Clark “wanted to be right” and would “go for a walk and get your [his] energy back” and “come back totally exhausted and have to go to bed”:

> Regardless, I was going to be right, I was going to be big and fit and I was going to be okay…I felt it was the guys who weren’t fit, the old people that couldn’t do things…but I was young enough…I’d make sure that I was better than I was.

Clark connected the ability to regain urinary continence with physical fitness and maximised his chances of recovery through exercise. He saw himself as relatively youthful in the population of men with prostate cancer and believed he had the physicality to regain his urinary continence. He embraced the challenge and exhibited hegemonic masculine grit and determination.

The majority of participants in this study re-established urinary continence within six months of their prostatectomy. Most participants attributed their recovery, in part, to Kegel or pelvic floor exercises. Argonaut’s “pelvic floor muscles were pretty strong” and he “had been doing Kegel exercises very assiduously before the operation”. Max “was like a man possessed with it [Kegel exercises]” and Top Cat “ultimately got on top” through “Kegeling [sic] like mad”. Most participants contributed to their recovery of urinary continence through practising, pre and post surgery, conscious control of the muscles that assist with voiding. Many participants also correlated general physical fitness, positive attitude and relative youth as key determinants of their successful re-establishment of urinary continence. The findings from this study show that the majority of participants expected to be continent of urine because they knew what it felt like to have that control and were able to reclaim it through physical and mental strength.

Furthermore, the incidence of incontinence post prostatectomy was perceived by
many participants to be minimal. Therefore, their chances of being incontinent were small.

**Ongoing urinary incontinence**

Two participants, Don and Ben experienced ongoing urinary incontinence following prostatectomy. They relied on dominant social constructions of embodied masculinity but redefined how they controlled urinary continence.

Following his prostatectomy, Don planned to re-establish urinary continence before attempting to treat his impotence. However, after twelve months, he was still incontinent and decided to investigate how he might re-establish potency. He used injections that resulted in a “painful erection”, and during sex he had “to alter positions because you are worried about [urine] leakage” and “thinking about those things take[s] your mind off what's going on”. Three years after his prostatectomy, Don continued to be challenged by the interconnectedness of incontinence and impotence. After all, his “libido depends on circumstances” and if he was leaking urine during foreplay, “it’s a bit of a turn off”.

Ben also decided to try to regain potency despite his unresolved urinary incontinence. Nine months after surgery, still incontinent and impotent, he used the VED but “unfortunately” his erection was “all volume, no rigidity” and “it has not allowed us to have penetrative sex”. Ben reverted to his initial plan because:

> It's important to make progress on the incontinence first. You can't consider sexual activity when you have a little urine leakage...it's just a cold practical reality...it's not something that I'm comfortable with. So unless I can control that leaking I don't think I can really see how sex would be.

An intercepting relationship between urinary incontinence and impotence existed for both Don and Ben. The loss of urinary control created embodied tensions in which the penis leaked urine and detracted from the physical freedom and emotional connectedness ordinarily associated with penetrative sex. Kirschner-Hermanns and Jakse (2002) have previously found that embarrassment about loss of urinary control can result in sexual withdrawal.

Urinary incontinence demanded precautions and was a source of anxiety and distraction when Don was working as a teacher because “I will be sitting…and if I
have to stand up I have to tense the muscles and you…are holding”. He needed an absorbent pad “that is going to last a few hours”:

*I am always conscious that if...there has been leaking and you sit down on the pad...you end up with a wet patch there which is very embarrassing...it doesn't get to the stage where I am really upset but it is on my mind all the time*

Don felt most like a man when he was “lugging heavy things around” during renovations to the family home. He explained “it is more than just a strength thing”, it was the achievement of doing it “ourselves”. However, Don’s enjoyment was inhibited by urinary incontinence:

*You are up and down ladders and you can’t be concentrating and holding you just get physically exhausted holding...on a bad day I can go through five pads...the morning is not bad but as the day goes on you get fatigue and...it is a real nuisance.*

Socially, Don was also restricted; he was “very conscious if I go to the beach” and can’t go on long walks because “I know that at the end of it I am going to have a very wet pad”. He summated “I have to watch out all the time if I am out”. Ben also experienced some “pretty serious lifestyle challenges”. He had “some friends down to drink some wine and I…felt something wet on my legs”. He was at home and discreetly excused himself to change his wet trousers. But “if you’re sitting on someone else’s furniture it is a bit unpleasant…embarrassing”. Ben decided to either “not go out or I won’t drink alcohol” in order to minimise the visibility and discomfort of his incontinence. The freedom to engage socially with other people and experience familiar as well as new places was affected by incontinence. Ben was forced to choose what he was capable of doing rather than engaging with the independence and self-reliance hegemonic masculinity prescribes.

Inhibited work performance, enforced sedentary lifestyle and social isolation, all of which potentially contribute to physical, mental and social health problems, were experienced by Don and Ben. The restrictions undermined characteristics of hegemonic masculinity including control, sexual prowess, self–reliance, independence, physical prowess, success and strength which have previously been described by Cheng (1999), Connell (2000), and Nicholas (2000).
In the absence of a cure, participants attempted to minimise the visibility and lifestyle effects of incontinence. When control could not be re-established, concealment and stoicism were revered masculine responses to incontinence. Trent, who was not incontinent, affirmed that he “admired” a man he knew with “extreme incontinence” and “continual dribbling” because of “the way he coped” so that “nobody else in the community would know that he was like that” or “what he had to put up with”. Thus, it appeared that participants with long-term incontinence invested considerable time and effort to adapt various strategies to conceal their lack of embodied control.

Ben described photograph 20 and explained how he minimised the visibility of his incontinence and its treatments:

_They're just disposal bags I carry with the replacement incontinence pads, just to put the old one in, so that I don't have something horribly messy to leave…this little black pouch is something that I sometimes use…inside it will be a spare pad in a plastic bag, and a spare pair of underpants…So that's my little emergency pack…it fits in the brief case._

**Photograph 20**

Participants with long-term urinary incontinence redefined how they controlled their urinary elimination. Urinary continence was planned, anticipated and consciously constructed rather than being spontaneous and effortlessly controlled. Provisions of pads, underpants and prosthesis were concealed and carried; ‘awkward’ situations that might result in the visible loss of urinary control were
avoided. Oral intake and exercise were monitored and the cause-effect of undertaking social activities such as sharing wine, coffee and/or a long walk were anticipated. In these ways, participants redefined how they controlled their bodies, but were reliant on hegemonic ideals of embodied masculinity.

In the absence of embodied control, participants controlled what was visible. In this way they responded to the dominant constructions of masculinity by problem solving how best to ensure their incontinence remained private. Furthermore, they stoically endured the limitations that incontinence imposed rather than admit their marginality.

**Summary of findings and discussion**

The findings from this study thesis show that urinary continence was central to participants’ recovery from prostatectomy, and chronologically, continence was ideally re-established prior to managing impotence. Regaining continence was a significant milestone and performance indicator that some semblance of social and embodied control had returned. Most participants had experienced acute stress, anxiety and loss of control through the continuum of screening and diagnostic tests, as well as prostatectomy.

Urinary incontinence was anticipated and experienced by most participants as manageable and temporary, not something they expected to endure indefinitely. The findings from this thesis study show that the majority of participants relied on physical and mental strength, self-reliance and problem solving abilities, commensurate with characteristics of hegemonic masculinity, to regain continence. Moreover, participants were reliant on hegemonic ideals that the masculine body is controlled and disciplined, and therefore continence was expected to return. Morgan (1993) and Connell (2000) have previously identified control and discipline as ideals of hegemonic masculine bodies.

In the short term, participants managed their incontinence using absorbent pads which enabled them to conceal a temporary lack of embodied control and re-enter public arenas through work and social activities. These arrangements were initially tentative, however, when continence was fully established participants’ freedom to engage in social, work and physical worlds were re-instated. In this
way the masculine body, its presence and power were publicly reaffirmed. In summary, most participants were reliant upon, and for the most part fulfilled, dominant cultural expectations that they would be continent.

Participants who experienced ongoing urinary incontinence were affected in sexual, social, physical and emotional ways over long periods of time. This finding has previously been reported by Palmer, Fogarty, Somerfield and Powel (2003). The findings from this thesis study show how long-term urinary incontinence is at odds with embodied ideals of hegemonic masculinity. The masculine body is supposed to be kept strictly under control (Morgan, 1993), and strong, enduring and self-reliant (Lee and Owen, 2002). Participants with long-term urinary incontinence had lost these embodied controls risked being subjugated to the realm of the ‘abnormal’, the ‘feminine’, or the ‘not male’. Loeser (2002) has previously reported these consequences of not living up to embodied masculine ideals in a study of boys who were deaf. The incontinent body is not disciplined, and unable to dominate public arenas because it lacks the power that is deeply embedded in Australian masculine cultures. Furthermore the penis is de-sexed regardless of potency because it leaks urine uncontrollably. In this way, sexuality and intimacy can be deeply affected by urinary incontinence.

Participants in this thesis study who had long-term urinary incontinence were forced to redefine how they achieved continence and simulated embodied expectations of hegemonic masculinity. Although they were unable to meet hegemonic masculine ideals, participants could control the public visibility of their deficits by concealing the evidence of uncontrolled urinary elimination. Loeser (2002) has previously reported that men with disability often attempt to pass as able bodied men. In the context of urinary incontinence, participants preserved the appearance of their body exterior despite the internal disabled urinary controls in order to pass as able-bodied men.

**Recommendations**

The findings from this study showed that incontinence was a significant problem for a few participants. Longitudinal research to investigate men’s experiences of
incontinence over time, following prostatectomy would provide information about how health care services and professionals might best support men with long-term incontinence. This recommendation is developed in Chapter Seven, Conclusion and Recommendations.

Section 2: Lost testosterone and radiated masculinities: Androgen Deprivation Therapy (ADT) and/or Radiation therapy

Just under a half of the participants in this study were treated with ADT for advanced prostate cancer that was thought to have metastasised to other parts of the body, outside of the prostate gland. ADT is used to slow the growth and spread of prostate cancer, which is ‘fed’ by testosterone, by inhibiting the testes’ production of testosterone. This chemical castration results in many side effects including diminished libido, impotence, muscle wasting, increased body fat, weight gain, labile mood, reduced concentration, hot flushes, fatigue, and gynecomastia (breast development) as previously reported by the Australian Cancer Network (2001). Many participants undergoing ADT were also treated with radiation therapy for what was often initially diagnosed as localised prostate cancer—cancer confined to the prostate gland.

Comparatively, some findings presented in Part one, Two new I’s – Impotence and Incontinence following prostatectomy, are repeated in the cohort of participants undergoing ADT and/or radiation therapy. Specifically most participants:

- accepted impotence in the pursuit of living longer.
- reformulated hegemonic masculine ideals of penetrative sex based on the recent diagnosis of a potentially life-threatening illness, advanced age, and the constructions, functionality and longevity of their intimate relationships.

While there were similarities in the findings from this study across all treatment modalities, ADT and/or radiation therapy affected participants’ sexuality and intimate relationships in diverse cognitive and physical ways. Specifically,
participants’ experiences of ADT revealed that despite low levels of testosterone, most participants continued to enact socially constructed ideals of hegemonic masculinity. This finding is considered and discussed in the context of the interconnectedness, rather than the dualism, of essentialist and social constructionist theories. This approach has previously been applied by Chapple and Ziebland (2002).

We join Trent and Randwick as they, along with other participants, shared their experiences of ADT and/or radiation therapy.

**Meeting Trent**

*A white beard reaches around Trent’s face; lines of experience carve deeply across his furrowed brow and sad eyes. We sit next to each other, both of us looking straight ahead. In an arrangement similar to a confessional box, an imaginary partition precludes us from looking directly at one another. Trent’s wife, Samantha, delivers a half smile along with coffee and biscuits before she leaves the dimly lit ‘interview’ room. Trent is thoughtful, deliberate and responsive. He is a prostate cancer activist; however the personal reflections that ‘reach out’ during the interview belie that persona. Beneath and between the ‘business of prostate cancer disease’, we explore his prostate cancer illness. Three hours later it is only the smoldering aromas of a Christmas Eve dinner that remind us of the time.*

**Observations and interpretations integrated with retrospective summary-Trent interview, field notes 12/2001.**

Trent said “I don’t think there is anything like a diagnosis of cancer for changing things. Whether you like it or not it is a fantastic agent for change”. About two months after completing radiation therapy, he commenced ADT:

*I went into…a nervous breakdown…everything just packed up… it seemed to hit me very hard. I just couldn’t cope. Mentally, emotionally couldn’t cope. Couldn’t cope with anything.*

His “wife took control” and they went away until he “settle[d] down”. Trent’s “nervous breakdown” was due to a “loss of energy” which he found “quite debilitating”:

*I just could not physically cope with things that I had been used to doing. I would go to do things and found I ran out of energy very quickly. ¼ hr of exertion and I was absolutely buggered.*
Trent explained photograph 21 was about the fatigue he “had to come to terms with”. His garden had always been a place of activity and work, however after treatment[s] he had to “just sit in a chair and read the paper”. He “really had to convince myself [himself] that there are things that needed doing and they can all wait”.

Trent regarded gardening as a “sort of therapy…to be able to get my hands dirty in the bush” which “probably goes back to my upbringing. I was brought up on a rural property”. His loss of physical performance disrupted his enjoyment of “doing” rather than “just sitting”. A lifetime of work in the garden was replaced by a passive, helpless view of the work that needed to be done. Trent was forced to reformulate how he connected with the land which he culturally constructed as an integral part of being an Australian man. The physical work was no longer possible and he was left passively contained within the parameter of the garden but unable to engage with its soil as he once did. Trent was invisible in his own garden; an empty chair resided as a signifier of his absence.

Although not clearly visible, Trent explained that, in photograph 21, a copy of ‘Men’s Health’ magazine sat atop his chair.

It was one of the publications that contained prostate cancer information which Trent regularly read, critiqued and shared with other men. His physical work had
been replaced with the intellectual work of researching and raising community awareness of prostate cancer. Although sitting in the garden was espoused as a form of leisure, Trent remained busy with his prostate cancer work:

\[
I\ don't\ mind\ sitting\ around\ reading\ but\ at\ the\ moment\ I\ have\ got\ myself\ into a\ position\ where\ I\ can't\ keep\ up\ with\ the\ reading\ I\ should\ be\ doing\ with some\ of\ the\ work\ I\ do\ in\ connection\ with\ prostate\ cancer\ groups.
\]

Many aspects of Trent and Samantha’s relationship changed following his prostate cancer treatments, including previous divisions of labour within their home. Trent spent less solitary time working in the garden and more collaborative time cooking in the kitchen. In effect, he reformulated traditional gendered roles in order to accommodate his reduced physical abilities. He was “more health conscious particularly in relation to food” and shared the daily preparation of juices and meals with Samantha. They prepared “the morning juice, a…green juice…with spinach, silver beet, celery, parsley and apple and then during the day we have carrot and apple”. They ate “more healthy food” and had eliminated “fatty-type foods and red meat”. Their food preparation had also changed to “steamed type cooking or wok cooking”. Trent was not certain what these changes had done for him because “the scientists tell us…nothing is proven”:

\[
All\ I\ know\ is\ I\ think\ I\ feel\ healthier…I\ think\ I\ can\ recall\ one\ cold\ in\ the\ last two\ years.\ So\ we\ feel\ that\ this\ must\ have\ done\ something\ to\ help\ our immune\ system\ which\ is\ basically\ what\ it\ is\ about.
\]

Trent embraced traditional feminine pursuits of cooking and caring about and maintaining his health. Moreover, rather than stoicism, he publicly talked about his illness. Indeed, he felt most “like a man these days when I can get up in front of a group of men and say ‘look this is what happened to me’…these are things you should be looking out for”. He described how time and illness had changed his constructions of masculinity:

\[
I\ don't\ go\ much\ on\ the\ macho\ stuff\ these\ days.\ I\ don't\ have\ to\ go\ out\ and punch\ somebody's\ lights\ out\ to\ make\ me\ feel\ like\ a\ man.
\]

Instead, Trent shared his experiences of illness and sought to educate and inform other men about prostate cancer. He was a wiser, older man who had reformulated hegemonic masculine characteristics that reflected his current circumstances and capabilities. Prostate cancer and its treatments forced Trent to choose from non
hegemonic masculine roles, perhaps for the first time. Suddenly, he was forced to reformulate and critically question what masculine roles were possible for him.

Although many of Trent’s current roles were traditionally feminine, he enacted them in masculine ways. Cooking was a form of self treatment that allowed him to contribute to his prostate cancer recovery. Advising men about prostate cancer through his experiences required courage and demonstrated expertise amongst other men. His work as a prostate cancer activist occasionally afforded him a voice amongst powerful men who legislated health services. In these ways, Trent reformulated the ways, but not the intent, of demonstrating many characteristics of hegemonic masculinity.

Trent’s libido and erectile function fluctuated during radiation therapy but he lost “all interest in sex completely” when treated with ADT. Absent libido reduced the significance of his impotence, because without desire, erectile ability was redundant. Trent suggested the “end of any sex life” was an inevitable side effect of ADT.

The majority of participants reported that impotence was not difficult to accept because their desire for sex was diminished when treated with ADT. Eddie had “no desire, no erection” because ADT “just cuts it off completely”. Although he “thought that would be a problem” it was not because “in your brain…you know that’s it”. Sam said “it’s just like turning off a tap, you don't think about it, it doesn't worry me…you’re not thinking about it so it doesn't matter”. Ron’s potency was “just not there in a physical sense” which “made no difference emotionally” because he did not have any sexual desire. John’s libido was also absent:

> You would rather cuddle up with your wife and pat her on the bottom and just go off to sleep. You think isn't it peaceful and nice. I have just come to bed and I am going to go to sleep instead of the carry on of the last 30 years trying to plan how you are going to get the wife to have sex.

Most participants reported that reduced libido helped them reformulate previous constructions of penetrative sex. Most participants reported more touch and shared activities with partners in the absence of potency and libido. Participants reformulated the ways in which they expressed their sexuality and incorporated
more traditionally female aspects of non sexual touch and physical closeness.
Trent had “more appreciation” of Samantha:

Just being together…support within the home…in some ways…it has brought us closer together…we tend to do more things together. I am more conscious of my wife just being there, being more around me.

Steve and Molly “have an emotional togetherness that…overcomes it [impotence]”. Ron and Sheryl “touch and feel and cuddle and kiss each other”. Impotence did not bother Royboy, he had:

...had a good life, been successful in many...achievements...have a wonderful wife, and I still think of her as when I met her, sweet 16, going on 17...plus, I am 83, God struth.

The majority of participants treated with ADT and/or radiation therapy did not attempt to re-establish potency through chemical or mechanical means. Advanced age, prognosis and reduced libido were key factors in participants’ reformulation of previous constructions of penetrative sex. No participants explicitly rejected penetrative sex as society’s dominant construction; rather participants reformulated the need for penetrative sex in the context of their lives and intimate relationships.

Samantha joined us momentarily as I was about to leave following the interview with Trent. During the course of the conversation, she nominated that Trent’s penis and testes had gotten smaller since his treatments. An awkward silence ensued, Trent’s eyes diverted to the floor, and an alternative subject was grasped as a buffer to dissipate his visible discomfort. I walked from their home, wondering about the dialogue Trent and Samantha might be privately exchanging. I drove home to my parent’s home. It was Christmas Eve, champagne and family awaited me. However, before we toasted, I took a moment to write myself a field note:

Illness is not always marginalising in the lives of ill men. Marginalisation can be cast by the hands of those who speak of and for ill men.

Christmas Eve 2001, Adelaide, South Australia.

The cork popped and Christmas began. My interactions with Trent and Samantha demonstrated how masculinities are also contextual and socially constructed in
research interviews. I was reminded that Trent (and all the research participants) ultimately defined the limits of our discussion and the details of his illness experiences.

Many participants reported that their penis and testes were reduced in size following ADT and/or radiation therapy. Soon after Eddie commenced ADT, he noticed his “shrunken penis” and although “the drug company said ‘no there are no effects like that’...I tell you it definitely shrinks”. Berti’s testes “instead of being like a chicken’s egg” had shrunk to be “like a pigeon’s egg”. John did not “seem to be as large in that department as I [he] used to be” but was unsure “what that is a result of”. Kevin’s “testicles have shrunk to damn near nothing”. Royboy did not “know how long it took for it [ADT] to shrink things up, change me…but it did”. William suggested that “everything seemed to get smaller”. One evening he looked down as he took a spa with his wife and noted:

I could see this tiny...really shrivelled-up looking little penis, and the boys [his sons] came in. I said, 'Have a look at this. This is what happens to you when you take these bloody female hormones. You see, your old man's got nothing to show.'

William’s advice to his sons also demonstrated how hegemonic masculinist messages are transmitted to young boys.

Most participants rationalised their reduced testes and penis size through essentialist constructions in which ADT inhibited testosterone production and resulted in their smaller genitals, but were not aware of this potential side effect prior to commencing ADT. Furthermore, few participants discussed the unexpected side effect with their doctors. Many participants dismissed penis and testes size as irrelevant in the absence of erectile function and libido. However, emotionally, as evidenced by Trent, the loss or change may have been a source of internal tension. Edgar (1997) and Martino and Pallotta-Chiarolli (2003) have previously discussed penis size as a measure of hegemonic masculinity that is perpetuated by dominant social constructions.

**Picking up Randwick’s photographs**

It is such an unusual experience picking up other people’s photographs, because I never know what will be present. I ‘read’ Randwick’s...
photographs without text and therefore without context prior to interviewing him. One photograph in particular, photograph 22 in this thesis, I read as an ‘older guy’ in pretty good physical shape. The subsequent discussions with Randwick about this photograph demonstrated how photographs can be read in many ways – depending on who is looking.

Reflection integrated with retrospective summary- Randwick Interview two, field notes 8/2003.

Meeting the other Randwick

Randwick is less self-assured during our second interview. He ‘tears up’ a couple of times at which point we suspend the interview. He tells me, over a meat pie lunch, that this morning he has been to the doctors for his three monthly ADT injection. We resume the interview and he talks about some of the changes that accompany his ADT treatment.


Randwick pointed to the body in photograph 22 (Photograph 22 has been cropped to exclude Randwick’s face and protect his identity) and explained that he had “breasts…I [he] think some of the females would be quite happy to have”:

From the neck down to the waist, it's not my normal body. I've always had a truck driver's body, because I've always been a working person...now, that body to me is not mine.
Randwick told the story of his body over time; he described a muscular working class body from the past and asserted “there are truck drivers and then there are truck drivers”. Randwick was a ‘real’ truck driver because he not only drove the truck; he “packed and unpacked the load” that it carried. This demanded strength and muscularity which his normal masculine body provided. Truck driving was also an exclusively male occupation and historically revered in Australian cultures during Randwick’s working life. However, the body in photograph 22 had been invaded by an unfamiliar feminine torso. Breasts that he thought would be better appreciated by women owners disrupted Randwick’s perceptions of how his masculine body should look. Reductionism and binary were present in that the body in photograph 22 had breasts; therefore it was feminine and could not be a truck driver’s body. Hence, it was not representative of Randwick’s body, its history or its achievements.

Randwick explained that since being treated with ADT, he “always have [has] sore breasts” which was a constant reminder of their presence. “Spare tyres” were visible, “the muscles have gone” and he “wonder[s] whether I [he] have the strength there”. Furthermore, Randwick described the body in photograph 22 as “unsightly” and “very flabby” despite exercise and not “eating any more than I [he] ever did”. He grieved the loss of muscularity and strength, and dissociated and distanced himself from the feminine torso in which he now resided. As Loeser (2002) has established, the muscular body is one way in which the power of men is seen. The binary, in the context of Randwick, was that the loss of a muscular body rendered him unrecognisable and/or invisible without presence.

His working class body was missing, yet Randwick was surrounded by working class achievements. The mantle and glass case backdrop (in Photograph 22) contained many artefacts. Each had a story, represented a moment, and signified achievement. Glass jars (each side of Randwick, at the bottom of the photograph in front of the heater) contained souvenir matchbooks from places he and Bess had visited in their travels. Overseas destinations such as Los Angeles, Turkey and Egypt were remembered through these mementos and demonstrated the rewards of hard work. Crystal glassware wedding gifts (contained in the glass case behind Randwick) from more than 40 years ago, rarely used but always
displayed, celebrated their man and wife union and its longevity. Indeed, the entire backdrop in photograph 22 was filled with trophies from, and signifiers of, a successful marriage and working class life. However, the body at the forefront was not a muscular working class, husband body—according to its owner.

Most participants treated with ADT lost physical masculine characteristics and developed feminine breasts. William was “worrying about whether my [his] breasts are increasing in size, I check them every now and again”. He suggested “I should have just bought myself a 36 D cup” prior to commencing ADT. Sam was “embarrassed” that he “got a couple of boobs” and Vincent had “little breasts”. Participants reported embodied changes that depicted a gender duality in which some ‘flesh on the chest’ was immediately about being female.

Randwick also got “hot flushes” and “emotionally-wise I’ve always been quite a happy-go-lucky fellow”. However, he was “much more sentimental” and “will quietly wander away” for a cry if something upsets him, “I hope that nobody notices”. Randwick assured me that he was “not turning into a guy that prefers all smooching…but I feel a little bit of touching creates more in life”. Although he had “never been one to give all the ladies [Bess’ friends] a smooch as they come in”, he had “turned a bit more that way”. He was also physically closer to his grandson than he was with his own son:

> My grandson has always been one to come in and kiss his grandfather…but my son, that was never there. I thought the world of him…but the physical contact not so much at all. But it is definitely there now.

Randwick explained his atypical masculinity and feminisation as a by-product of ADT. He relied on essentialist constructions in which the outcome of reduced testosterone was a feminine body with breasts, void of musculature, and the loss of masculine characteristics such as stoicism and competitiveness. Rather than illness creating emotions of sadness, fear and vulnerability these changes were attributed to hormones.

Although Randwick rationalised his body changes through essentialist constructions, he was reliant on dominant social constructions of masculinity. This was evidenced in his rejection of what he saw as a feminised body and concealed sentimentality. In these ways, he responded and relied on the
prescriptions of hegemonic masculinity in two ways. First, he distanced himself from femininity and constructed his masculinity in opposition to his feminised body. Second, he was reliant on dominant masculine displays of stoicism in which he hid his emotions. In summary, without testosterone, Randwick remained reliant on dominant social standards of hegemonic masculinity.

Shifting social constructions of Australian masculinity, rather than low testosterone levels, had allowed Randwick the freedom to enjoy touch with his grandson, which was culturally prohibited a generation earlier with his son. Randwick was socially conditioned from a young age that sturdy handshakes were permissible between men, while females greeted other females with more feminine touch, hugs and or kisses. The physical closeness he now enjoyed with his grandson reflected the less prescriptive masculine practices negotiated between two diverse generations of Australian men. Randwick responded to shifting social constructions about legitimate physical contact between men, and non sexual contact between men and women.

Contextually, Randwick’s earlier subscription to a traditional breadwinner role resulted in long working hours and extended absences from his family. As a result he did not, nor was he expected to be, physically close and spend time with his children as they grew up in the 1960s and 70s. In many ways, Randwick was an absent provider and breadwinner during this period. In retirement, he had more time, inclination and social affirmation to be close to his grandson. Furthermore, his illness experiences raised issues of emotional connectedness in light of the inevitability of death and/or further physical and emotional changes.

Most participants rationalised ADT side effects through essentialist constructions. Side effects such as the loss of body hair, muscle mass and strength were understood and accepted in the absence of testosterone. Hot flushes associated with female menopause and mood swings espoused as a by-product of pre menstrual tension and female hormone fluctuations were also experienced by many participants. Seagull was told by a nurse that he would “probably get hot flushes” when he started ADT. The nurse suggested, ‘that's our revenge on you blokes’. Verlow was “losing muscle power…I haven't got a great deal of strength”. When treated with ADT Berti would “get grumpy” and “wouldn't talk”
to his wife, “sometimes I blamed her, but it was me really”. James “lost quite a bit of hair around my pubic area” and the “blanket off my back and off my chest”. John had “put on weight” and was “even fuzzier [mentally] than you usually are”. He confirmed his essentialist constructions of the changes:

> We think our way through things and we act according to our thoughts and we find out that a heck of a lot of what we do is hormone driven which I guess shouldn’t be any great surprise.

Kevin explained the cause of his hot flushes through detailed essentialist explanations of how ADT interacted with his body. However, his stoicism and egalitarian resilience remained over a lifetime despite the relative absence of testosterone since being treated with ADT:

> I’ve never been a bouncy jovial, sort of optimistic type of person. I’m more sort of your stoic that expects that things will be tough, and invariably they are and you cop it sweet.

The influence of dominant social constructions of masculinity was further evidenced by the participants, all of whom were treated with ADT, in their answers to an interview question in which I asked, ‘When do you most feel like a man?’:

> Working or doing normal chores…I definitely feel fully male there. (Randwick)

> I have a typical male ego…Can’t say that I have developed any effeminate tendencies…I don’t wear lace on my underpants or anything like that…I don’t ever not feel like a man. (Ron)

> You have scared living hell out of the other side and you are running down the field and they are all ducking for cover…they are picking themselves up from the ground saying I will get that bastard, next time. (John)

> I pride myself as a bit of a handyman…so lumping wood around and hammers and saws…when I’m with my granddaughter…I still fill the old function footing the bill for bloody near everything…I’m able to be a good provider. (Kevin)

> When I’m with my wife. (William)

> When I’m with [my partner], because I can protect her. I can love her…I can be with her. I can be her escort. (Berti)
Despite having little testosterone, the majority of participants felt most like a man when they were demonstrating characteristics of hegemonic masculinity. This included traditional masculine roles of breadwinner and protector and/or dominant masculine performances of competitiveness and physical strength. Clearly, dominant social constructions of masculinity influenced many participants in the relative absence of testosterone. ADT may influence the masculine body shape and size and some of its expressions but most participants were reliant on dominant social constructions of masculinity to guide their gendered performance. This finding is consistent with recent discussions by Chapple and Ziebland (2002).

**Summary of findings and discussion**

The findings from this thesis study show that the majority of participants treated with ADT, many of whom were also treated with radiation therapy, reformulated predominant standards of penetrative sex. When compared to prostatectomy, most participants who were treated with ADT reported a profound loss of libido in addition to impotence. Furthermore, many participants reported that the loss of libido made it easier to accept impotence because they were no longer thinking about sex. This may explain, in part, why the majority of participants did not use medical treatments for their impotence. In contrast to the current thesis study finding, Chapple and Ziebland (2002) found that when compared to other treatment modalities, participants treated with ADT were adversely affected psychologically by the loss of libido and physically by impotence. The level of abstraction offered by Chapple and Ziebland (2002) was not possible in this thesis study. Furthermore, the findings from the current thesis study suggest that libido and potency were interconnected rather than separate.

Participants rationalised the connectedness of their impotence and reduced libido through essentialist constructions. However, many contextual factors were likely to influence their reformulation of hegemonic masculine ideals. Participants treated with ADT were generally older and had poorer prognoses due to the advanced stage and likely spread of their prostate cancer. Both older age and advanced illness were likely to have contributed to participant’s reformulation of
their sexuality and intimate relationships. This finding has previously been reported by Chapple and Ziebland (2002).

Survivorship and emotional togetherness were highly valued, and contextually, penetrative sex was not a priority for most participants. This finding illustrates how sexuality shifts over time, as identified by Weeks, Holland and Waites (2003). It also demonstrates how social constructions of masculinity are contextually bound as suggested by Connell (1995, 2000). Many participants’ vulnerabilities were especially visible to their female partners as a result of prostate cancer and ADT and/or radiation therapy. For the majority of participants, intimate relationships were not dependant on penetrative sex. This finding is consistent with Kilmartin’s (2000) prediction that intimacy involves letting someone into the most private and vulnerable parts of the self. Shared activities, togetherness and commitment to jointly fighting prostate cancer were also strongly represented in this thesis study.

ADT and/or radiation therapy resulted in many systemic changes including altered muscularity and body size, shape and control, which affected participants in deeply gendered ways. Many participants’ bodies were at odds with ideals of hegemonic masculinity. For example, the promise of power previously described by Loeser (2002); embodied control discussed by Morgan (1993); the ideals of strength defined by Evans (2001), Lee and Owens (2002) and Peterson (1998), were often diminished following ADT and/or radiation therapy. Most participants recognised that they were at odds with dominant social constructions of how masculine bodies are disciplined and the power that they promise. Participants were reminded by altered, feminised, fatigued bodies that they did not reach hegemonic masculine ideals. However, most participants demonstrated philosophical ideals of hegemonic masculinity. As Connell (1995) and Larsson (1997) have noted, masculinity is not about being, it is about doing. So although a masculine mind/body separation existed for many participants, ideals of hegemonic masculinity were still enacted and expressed.

The findings from this thesis study also contribute to theoretical discussions about the exclusivity and/or duality of essentialist and social constructionist theories. Participants conceptualised physical body changes and altered emotions through
essentialist frameworks, but were reliant on dominant social constructions of
gender in how they enacted masculinity. This was especially evident in
participants’ responses to the question “When do you feel most like a man?” As
Connell (1987, 1995, 2000) has explained masculinity refers to male bodies
directly, symbolically and indirectly, but it is not determined by male biology.

Chapple and Ziebland (2002) have previously suggested that the physical body as
well as culture, be considered when trying to explain what it means to be
masculine and how illness may affect men’s sense of masculinity. From a social
constructionist perspective, Chapple and Ziebland’s (2002) recommendation is
most appropriately achieved by investigating how testosterone (and its absence)
is socially constructed by participants treated with ADT. DeLamater and Shibley
Hyde’s (1998) assertion that essentialism and social constructionist theories are
incompatible is supported by the theoretical frames of the current thesis study.
However, that is not to deny the worthiness of Turner’s (1992) and Chapple and
Ziebland’s (2002) suggestion to interrogate the dichotomy with further research.

**Recommendations**

The findings from this thesis study show that ADT and / or radiation therapy
interconnects with masculinity in complex and diverse ways. Of particular interest
and relevance to social constructionist gender researchers is further exploration of
men’s experiences of ADT. This recommendation is developed in Chapter Seven,
*Conclusion and Recommendations.*
Chapter Seven

Conclusion and Recommendations

In this thesis, I reported the results of a study of 35 Anglo-Australian, heterosexual men that had prostate cancer. The purpose of the research was to illuminate participants’ experiences and perspectives of living with prostate cancer. Through preliminary fieldwork, photographic novella, in-depth semi-structured interviews and participant observation, rich cultural insights were made available. A social constructionist gendered analysis was used in this research that provided insight into how dominant social constructions of masculinity interconnected with participants’ experiences of prostate cancer.

Summary of the outcomes of the literature review

In the present thesis the literature was reviewed in three sections;

1. Prostate cancer disease

2. Masculinity, men’s health and prostate cancer illness

3. Heterosexual Anglo-Australian culture and masculinity

In Section One, Prostate cancer disease, literature was presented in three parts. In Part A, Biomedical prostate cancer research, biomedical information and prostate cancer research studies were reviewed and provided the reader with contextual insight to this thesis research. In Part B, Health promotion and prostate cancer, an overview of the theoretical frames of health promotion was provided and the literature review showed that few Australian men’s health promotion programs specifically included prostate cancer information. In Part C, Anglo-Australian men’s health and health service utilisation, diverse theoretical meanings of men’s health, and explanations of men’s utilisation of health services were outlined.

Overall, Section One of the literature review highlighted the complexities of prostate cancer, including the efficacy of PSA screening, comparisons of treatment modalities and the variance of illness trajectory.
In Section Two, **Masculinity, men’s health and prostate cancer illness**, literature was presented in four parts. Part A, *Essentialist and social constructionist debates on Anglo-Australian masculinity*, provided an overview of the ongoing nature-nurture debate and considered the theoretical perspectives in the context of prostate cancer and its treatments. Part B, *Hegemonic masculinity*, Part C, *Masculine hierarchies and marginalised masculinity* and Part D, *Masculinities*, presented an overview of the social constructionist gender analysis framework used in this research and outlined how dominant social constructions of masculinity interconnect with men’s health.

Overall, the literature review did not yield any previous ethnographic, social constructionist gender studies of Anglo-Australian heterosexual men with prostate cancer. However, previous studies by Charmaz (1995) and Sabo (1995) provided examples of social constructionist gender frameworks in men’s health. Furthermore, recent studies by Chapple and Ziebland (2002) in the United Kingdom and Fergus et al. (2002a,b) in Canada explored how prostate cancer and masculinity intersect.

In Section Three, **Heterosexual Anglo-Australian culture and masculinities**, the reviewed literature was presented in two parts. Part A, *Historical analysis of Anglo-Australian masculinity*, showed that older participants in this study grew up during a period when many males were privileged through patriarchal advantage. However, it was also a period when the code of masculine beliefs was being challenged. Part B, *Male heterosexuality: relationships, gendered social constructions and sexuality*, detailed dominant social constructions of male sexuality and various aspects of men’s heterosexual relationships.

The literature reviewed revealed shifting social, economic and other influences during Australian history and provided contextual information about Anglo-Australian men, masculinity and heterosexual relationships. Dominant social constructions of egalitarian, patriarchal Australian masculinity were both refuted as myth and revered as legend in the literature. However, a general consensus was that many men were complicit in sustaining hegemonic ideals of Australian masculinity.
On the basis of the overall literature review, it was concluded that much of the men’s health research was not connected to gender, men and masculinities. Specifically, the status and experiences of heterosexual Anglo-Australian men with prostate cancer was found to be poorly understood.

The research questions addressed in this thesis were:

1. What roles do health promotion services play in relation to prostate cancer for men in the cohort?

2. What recommendations do participants offer for the future role of men’s health promotion services in relation to prostate cancer?

3. What roles do health services play in relation to prostate cancer for men in the cohort?

4. What recommendations do the participants offer for the future role of men’s health services in relation to prostate cancer?

5. How do prostate cancer and its treatments affect the sexuality and intimate relationships of the men in the cohort?

In order to address the research questions, the following research was performed:

- Preliminary fieldwork was conducted at monthly meetings at two Melbourne-based PCSGs for six months. My observations and interpretations informed the specificities of this research thesis design and provided cultural insights to men with prostate cancer.

- Thirty-five participants were invited to use a disposable camera containing colour film and asked to imagine that they were being paid to mount a photographic exhibition entitled ‘Living with my Prostate Cancer’. Nineteen participants provided photographs through this medium that were subsequently discussed during individual in-depth semi-structured interviews. Sixteen participants who did not take photographs were also interviewed.

- In-depth, semi-structured interviews were completed in a series of two or as single interviews with 35 participants. The interview questions
were both inductive and deductive, in that themes and questions were anticipated. However, leads that emerged were also pursued and participants were encouraged to talk about their feelings and experiences of living with prostate cancer.

- Descriptions of the interview settings, participant observations and interpretations were made during formal interviews. They were documented as field notes and provided adjunct data to the interview transcripts, participant photographs and artefacts. The field notes included throughout this research thesis were intended to make participants visible, as well as provide a sense of me (as the researcher) ‘being there’ in the collection, construction and analysis of the data.

**Major findings of the thesis and how they integrate with previous work**

The research questions were addressed in several different ways as outlined in the aforementioned data collection methods. The findings presented in this research thesis addressed each of the research questions, and were presented separately in Chapters Four, Five and Six. In Chapter Four, *Australian Men’s Health Promotion*, I presented the findings related to participants’ experiences of, and recommendations for, prostate cancer health promotion. Chapter Five, *Prostate Cancer and Health Services*, participants’ experiences of, and recommendations for, prostate cancer health services were presented. In Chapter Six, *Sexuality, Intimacy and Prostate Cancer*, the interconnections between prostate cancer, its treatments and participants’ sexuality and intimate relationships were presented. The major findings, recommendations and future avenues of research for each chapter of results follows:
Chapter Four: Australian Men’s Health Promotion and prostate cancer

Major Findings

There were three major findings from this study related to prostate cancer and health promotion. First, research participants were asked about their health and illness experiences when growing up in Australia. It was found that health promotion was a recent construct for most participants and during their earlier lives, different concepts of health care existed. The absence of health promotion from participants’ lives is most likely an artefact of the different concepts of health in the 1930s, 40s, 50s and 60s. Furthermore, the findings revealed that diverse rather than unitary participant constructions of health existed. The findings from this study demonstrated the relevance of participants’ experiences and social influences on how they conceptualised and practiced health maintenance and illness prevention. The present thesis research offered contextual, micro life-course insights and understandings to assertions made by Bilmes (1992), Lee and Owens (2002), and Taylor et al. (1998) about men’s disinterest in health promotion programs. The findings from this thesis research demonstrated the appropriateness of sociologically informed approaches to men’s health promotion, previously recommended by Courtenay (2000), Lambevski et al. (2001) and Watson (2000).

Second, many participants confirmed the centrality of female partners in their health practices. Participants’ recognition and report of physical symptoms was more likely when pain and loss of performance was experienced, rather than altered sensation and voiding patterns. In relation to prostate cancer screening, it was shown that context or reasons other than health maintenance prompted most participants to undertake screening. Participant preference for PSA rather than DRE was found to be reliant on dominant constructions of male heterosex. The findings from the present thesis provided contextual prostate specific understandings of men’s health promotion practices reported by Huggins (1998), Gibson and Denner (2000), Lee and Owens (2002), and Taylor et al. (1998).
Third, findings from this study showed that the majority of participants endorsed and encouraged PSA screening and recommended that men be able to choose to have a PSA test. Government health services legislation and a lack of inter-sectorial health promotion agreement on PSA screening policy was perceived as discriminatory by many participants. The findings from this study are consistent with claims and criticisms made by Watson (2000) that many men are submerged beneath anonymous profiles of men’s health promotion. The present study revealed that health promotion is a politically motivated and articulated model that can result in competing victims when inequity and subordination are perceived.

**Recommendations**

Australian men’s health promotion and its compatibility with prostate cancer should be re-assessed. A discordant relationship exists in which prostate cancer is a much-cited statistic and disease in men’s health discourse, but ill-defined in health promotion practice. The most likely health promotion prostate cancer application—screening—lacks clear guidelines. Ironically, it appears to be the government and government-funded health promoters that are cautious about recommending PSA screening. Ongoing health service debates about whether men may be better not to have asymptomatic screening are confusing and contradictory to men’s health promotion philosophy. The suggestion that men wait for symptoms is reflective of the therapeutic era of public health rather than contemporary health promotion practice. The danger herewith is that health promoters are encouraging and perpetuating behaviours consistently cited as major challenges to engaging men in their own health maintenance.

In summary, health promotion and prostate cancer appear to be a mismatch at the current time. The recommendations, based on the findings from this study, are that targeted screening programs, aimed at older men and men with familial history of prostate cancer be implemented as a priority. Furthermore, the current patient cost for PSA be removed to enable all men to access screening if they so desire.

Two key practice recommendations based on the findings from this study are offered for the consideration of prostate cancer health promotion programs. First,
men should be encouraged to establish ongoing relationships with their doctors through annual medical checks, rather than acting on symptoms. Genito-urinary examination should be included, especially given that the prostate gland enlarges after age 50 in most men. The practice suggested is similar to women’s regular obstetric and gynaecological checkups. This would help men to establish rapport with doctors and encourage monitoring and maintenance health practices, rather than problem solving symptoms.

The workplace would be a suitable venue for men to have regular medical checkups and could be established as an occupational health and safety mandate, supported culturally and financially by employers as well as governments. If these practices were established during men’s working lives, then they may be continued in retirement when the incidence of prostate cancer is more prevalent. In this way, health maintenance would be constructed as masculine through its association with work and work performance.

Second, if a prostate cancer community-based health promotion campaign was developed, consideration should be given to how the prostate gland is depicted and for whom the information is targeted. If health promotion seeks to make men responsible for their health, there needs to be a rethink of the use of female partners as conduits for men’s health. A direct line of communication with men should be a priority, rather than perpetuating the profile of women looking after the health of men. After all, the ultimate aim of men’s health promotion is to empower men. However, men’s empowerment is reliant on context and clear guidelines, recommendations and informed consent will be integral to engaging men with their prostate health.

**Future avenues of research**

There are many future research avenues for prostate cancer health promotion. The findings from this study suggest further longitudinal research to men’s constructions of health would inform the development of health promotion programs for middle-aged and older Australian men. Life-course or life histories are an appropriate methodology to explore health practices over extended periods of time and could be adapted to explore specific groups of men. For example, the present thesis identified the centrality of female partners in the promotion of many
participants’ health. It would be a salient line of enquiry to investigate how heterosexual men without female partners negotiate their health and illness, especially in relation to prostate cancer. What are the health care practices of single men? Where do they go for support, advice and discussion about health and illness?

Given the current lack of intersectorial co-operation in prostate cancer screening, health promotion is most likely to reside with men who have prostate cancer. I observed health promotion practices at PCSG early in my fieldwork for this study. Members requested and shared information on prostate cancer such as treatment options, side effects, and biomedical research results. Sexuality, self-care strategies, health maintenance and well-being were discussed. Many PCSGs also raised prostate cancer awareness in the general community through fund raising events and activities.

Many of the functions and interactions that occur at PCSGs disrupt three commonly held beliefs regarding men’s health promotion. First, men are unlikely to take an active interest in maintaining their health. Second, men do not speak publicly about illness. Third, men are unlikely to engage in health promotion activities. The function of PCSGs and their influence on health promotion has not been well described. I recently completed a pilot research study of three PCSGs in British Columbia, Canada, which posed the following research questions:

- What health promotion roles and functions do PCSGs perform for their members?
- How do PCSGs contribute to public awareness of prostate cancer?
- What recommendations and strategies do PCSG members offer for the future of prostate cancer health promotion?

This was a particularly useful line of investigation and the preliminary analysis showed that there is much to be learnt from men at PCSG about how men’s health promotion can be negotiated and conducted.
Chapter Five: Prostate Cancer and Health Services

Major Findings

There were three major findings in Chapter Five, Prostate cancer and health services. First, participants’ experiences of ‘Moving in’ showed that the anticipation of illness, and the TRUS-Bx in particular, were significant for many participants leading up to a diagnosis of prostate cancer. The findings from the present thesis showed that pain and anxiety were experienced by many participants undergoing TRUS-Bx. This is consistent with previous research results published by Zismen et al. (1999, 2001) and Kim (2000). Furthermore, the present research demonstrated the interconnections between masculinity and TRUS-Bx, and the need for more sophisticated sociological approaches to pain management.

Second, the present research demonstrated that participants’ prostate cancer treatment choices were contextual, complex and diverse. Collaborative relationships with doctors were reported by many participants which is consistent with previous research findings by Davison and Degner (1998), Davison, Degner and Morgan (1995) and Davison et al. (2002). However, the findings from the present thesis study showed that most participants’ choice of doctor and treatment decision was inextricably connected. Therefore, participant definition and experience of collaborative treatment decision making was contextual and constructed with their doctor. The findings from this thesis study demonstrate the centrality of doctor-patient relationships and connections with gender during prostate cancer illness.

Third, the research findings in the present thesis are consistent with Nicholas (2000) and Gordon’s (1995) suggestion that some characteristics of hegemonic masculinity may benefit participants’ recovery from illness. The present research demonstrated that characteristics such as competitiveness, problem solving, self-reliance and independence are used by many participants to conceptualise and recover from prostate cancer. The findings from this study demonstrated the need for contextual understandings of how dominant social constructions of masculinity and illness recovery interconnect.
Recommendations

The experiences of men undergoing TRUS-Bx must be considered in the development of best practice guidelines. The current diversity in TRUS-Bx administration is problematic and does not acknowledge patient individuality or preference for anaesthetic. The findings from this study showed that with permission, men will speak about TRUS-Bx pain and anxiety. Further qualitative interview based research is well suited to contributing further information for TRUS-Bx evidence based practice.

The findings from this thesis research showed that communication with health care professionals and doctors in particular, was an integral part of participants’ experiences of prostate cancer health services. Gendered constructions informed and influenced participants’ perceptions of helpful and unhelpful communication with health service professionals. The moment of diagnosis, treatment decision making and after care can be particularly stressful for participants and the findings from this study showed that gender-sensitive considerations across the prostate cancer illness trajectory can assist men to cope with illness cultures.

Based on the findings from the current thesis, contextualisation and consideration of compatible aspects of masculinity and health are appropriate. The identification of how aspects of hegemonic masculinity may assist men in their recovery from prostate cancer could also benefit clinical practice. Dominant constructions of masculinity, such as competitiveness and problem solving, may be anticipated and guided by health care professionals as a way of empowering men in unfamiliar illness cultures.

Future avenues of research

Given that little research has been conducted regarding masculinity and TRUS-Bx, there are numerous possibilities for future investigation. The results from this thesis study informed many questions for further study. For example, what are men’s experiences of TRUS-Bx in other countries? How are social class and ethnicity interconnected with men’s experiences of TRUS-Bx? An ethnographic study conducted at TRUS-Bx clinics, inclusive of patients and clinicians would provide contextual understandings of the dynamics that occur during TRUS-Bx.
Prostate cancer communication is a pertinent line of inquiry to address how men interact with health professionals. I am working with a team of researchers at the University of British Columbia to investigate cancer care communications between men and their urologists, using a social constructionist gendered analysis. The research, planned for February 2004, is informed by the findings in the present study, which showed that communication is a critically important element of men’s experiences of prostate cancer health care services.

The findings from this study support future longitudinal research to investigate the compatibility of dominant forms of masculinity, recovery and health maintenance over time. A study of prostate cancer specialists, who have been diagnosed and treated for prostate cancer is one possible line of inquiry. This would provide both doctor and patient experiences of prostate cancer from a single source. This information would be especially powerful and insightful about the advantages, demands and assumptions of hegemonic masculinity in the context of prostate cancer.

**Chapter Six: Sexuality, Intimacy and Prostate Cancer**

**Major Findings**

There were three major finding in Chapter Six, *Sexuality, Intimacy and prostate cancer*.

First, in Section One, Part A, *Impotence*, the findings showed that most participants reformulated previous constructions of penetrative sex. This finding is consistent with Fergus, Gray and Fitch’s (2002b) research that showed men with impotence following prostate cancer treatment[s] redefined phallocentric models of sex. Many participants in the present thesis used more traditionally feminine expressions such as non-sexual touch and emotional connectedness to express their sexuality and intimacy with female partners. This finding was consistent with Fergus, Gray and Fitch (2002a), Gordon (1995) and Gritz et al. (1989) who reported that cancer can bring men and their female partners closer together.

Second, in Section One, Part B, *Incontinence* the findings showed that the majority of participants regained urinary continence within six months of surgery.
However, two participants experienced long-term urinary incontinence which they concealed and/or controlled with various pads. Urinary incontinence affected participants’ sexuality, intimate relationships and the freedom to engage in physical and social activities. This finding has previously been established by Palmer et al. (2003).

Third, in Section Two, Lost testosterone and radiated masculinities: Androgen Deprivation Therapy (ADT) and/or Radiation therapy, the findings showed most participants reformulated constructions of penetrative sex when they became impotent. Furthermore, ADT and radiation therapy, when compared to prostatectomy, were shown to result in additional side-effects such as reduced libido, fatigue, muscle atrophy and altered body size and shape. These treatment side effects impacted on many aspects of participants’ embodied masculinity. The findings from this thesis research provided further empirical data to consider Chapple and Ziebland (2002) theoretical debates about social constructionist and essentialist frameworks in the context of men’s experiences of ADT.

**Recommendations**

The findings from this study showed that most participants reformulated dominant constructions of penetrative sex when they become impotent following prostatectomy. However, treatment side effects such as penis shortening were poorly understood by some participants, as were the rehabilitative aspects of medical treatments for impotence. Based on the findings from this thesis study, extensive counselling and discussion of all potential side effects should precede and follow all prostate cancer treatments. Participants’ sexualities and intimate relationships were complex, and individual support and contextual information would best meet patients’ and partners’ diverse needs.

Participants with long-term incontinence were affected in deeply gendered ways through the loss of embodied control. Based on the findings from this thesis study it is recommended that extensive Australia-wide men’s prostate cancer services capable of supporting men preceding, as well as following, prostatectomy be developed. State-based services such as “The Prostate Health Information Line” and “The Pre-op Education for Radical Prostatectomy Program” could be
extended to provide nationwide services to men and complement current health services.

The use of ADT and radiation therapy, although comparatively non-invasive when compared to surgery, affected many participants in deeply gendered ways. In particular, loss of libido, impotence and functional and aesthetic body changes occurred which disrupted many participants’ dominant social constructions of masculinity. Some participants who chose these active treatments were deeply affected by the profundness of the treatment side effects. Based on the findings from this study, it is recommended that watchful waiting be more explicitly considered and discussed as an option for some men.

Future avenues of research

Future research should include further patient-informed experiences of prostate cancer treatments, three of which are detailed as follows. First, an investigation of the effects of impotence on female partners of men would provide valuable contextual insight to how penetrative ideals of hegemonic masculinity are experienced and negotiated. In particular, the effects of impotence on female partners of men following prostatectomy would provide insight to how reformulation, reliance and rejection of penetrative sex is constructed by women in heterosexual relationships.

Second, longitudinal research that investigates men’s experiences of incontinence following prostatectomy would inform health care services and professionals—as well as men who are making treatment decisions—of the challenges encountered as a result of long-term urinary incontinence. The information could be used to develop future prostate cancer health services.

Third, the interconnections of ADT and masculinity are an important area for further social constructionist gender research. In particular, how the masculine body and testosterone is socially constructed by older men requires further investigation. The data would provide further contextual patient experiences of what is often perceived as a conservative, relatively non-invasive treatment.
**Strengths and limitations of the research**

Findings from the present research were based on observations of PCSG meetings, participants’ photographs, data from in-depth semi-structured interviews, and participant observations. The participants’ stories reflected their experiences of prostate cancer, its treatment, and the health care professionals with whom they come into contact. The participants described what they experienced and these experiences are real from their point of view. However, their accounts may differ from those that would be obtained by interviewing health care professionals and/or female partners. These realities are no more correct or more sophisticated than scientific truth; however, they are participants’ real versions of the situations in a particular context and at a particular point of time in their prostate cancer illness.

Causal-effect and generalisation were not the outcome of interest in this study. It was the subjectivity and construction of multiple realities from participants who experienced prostate cancer that was valued. The major strength of this research is that it offers new culturally informed information about 35 Anglo-Australian heterosexual men who have prostate cancer that may be useful in understanding the experiences of men from Anglo-Australian and other backgrounds who have prostate cancer. The information, as well as the way it is presented through participant photographs and text, contributes to the understandings of men’s health and masculinity. It also offers possibilities for how those understandings might be communicated in the future.
Epilogue

Moments of finishing

I am 38 years old as I find myself talking with my aunt in the living room of Bronch’s old house. I push open a door to the room I shared with Bronch as a ten-year-old boy. The door creaks back on its hinges and familiar dark musty spaces embrace me. I think about the men I have spoken with in this research. I think about being 10 years old, and sharing this room with Bronch. I think about the 28 years of spaces in-between. Perhaps now I am able to claim some understanding of the past through the present.

I am 39 years old as I walk from the emergency room at the Western Hospital Sunshine in Melbourne. My last shift is complete and next week I leave for Vancouver. I have been in the extraordinary position of seeing illness and disease up close. I have transgressed normative codes between men and been let into other men’s private lives. It has been confronting, informative, amazing, scary and contradictory, often all at the one time. I am older than my years; perhaps I have matured and become a better man due to an understanding of what inevitably lays ahead, age, illness and ever-shifting constructions of masculinity.

I am 40 years old as I complete this thesis. The journey has been a little turbulent at times, especially so for the people around me. The writing pendulum swings between a labour of love, the fatigue of rewrites, and the anxiety of knowing nothing is written until it is read. I had not anticipated that this research would raise more questions than it answered. But perhaps therein lays the multiple realities of meeting the person behind the patient. The moments that led me here, continue to lead me.
Appendix A: Demographic data questionnaire

What is your country of birth? ________________________________

What is your year of birth? ________________________________

What was your father's country of birth? ____________________

What was your mother's country of birth? ____________________

Where do you currently live? _______________________________

Do you have a female partner? (Please tick)

[ ] Yes [ ] No

What year were you diagnosed with prostate cancer? ________________

Have you been treated for prostate cancer? (Please tick)

[ ] Yes [ ] No

Are you currently being treated for prostate cancer? (Please tick)

[ ] Yes [ ] No

Are you willing to be interviewed about your experiences relating to prostate cancer and its treatments?

[ ] Yes [ ] No

Are you willing to take photographs of your experiences of living with prostate cancer?

[ ] Yes [ ] No

If yes, please complete the following:

Name: ____________________________________________________

Address: __________________________________________________

Contact phone number: ________________________________________
Appendix B: Deakin University Ethics Committee Plain Language Statement

My name is John Oliffe and I work as a registered nurse in the emergency department of the Western Hospital Sunshine and as a lecturer in the undergraduate nursing program at Deakin University, Melbourne campus. I am also a PhD student in the School of Health Sciences at Deakin University, Melbourne, Victoria. This research project is supervised by Dr. Maria Pallotta-Chiarolli, Senior Lecturer, Faculty Health and Behavioural Science, Deakin University, Melbourne Campus. I am undertaking this research because I feel that providing an in depth description of your experience of prostate cancer will inform health care professionals and policy makers to develop men’s health programs and practices.

The demographic data questionnaire that you filled out provided information that confirms you have qualified to take part in the study. However you need to carefully read this letter before deciding to participate in the study. It gives you the full details of your participation. If after having considered this invitation you decide you would like to be involved, you will be asked to sign a consent form. I will answer any questions you have about the study prior to you signing the consent.

Here are the details of your participation in the study. If you decide to take part, I will ask you to use a disposable camera supplied by me to take photographs that illustrate your experiences of prostate cancer. I will ask you to imagine that you are being paid to mount a photographic exhibition entitled ‘Living with my Prostate Cancer’, an exhibition that shows prostate cancer from your own unique perspective. I will ask you to have taken your photographs within two weeks from the date that I give you the camera. After you have taken your photographs I will meet with you to collect the camera on a date and at a location that we predetermine so the photographs can be developed at my expense.

After the photographs are developed we will meet on a date and time that is mutually convenient and in a location that is free from distractions and where we can talk privately. I will bring your photos and ask you questions about them and I anticipate that this conversation will take between 1 and 1.5 hours. The photographs will not have your real name on them. If there are any photographs that you don’t want me to have or use, I will give them to you or destroy them, along with the negative. Likewise I will not use any photographs that identify you in any way. At the end of the first conversation I will arrange another date, time and place to meet that is mutually convenient for a second meeting that will again take between 1 and 1.5 hours. In discussing your photographs during these conversations I will seek your thoughts in regard to the following research questions:

- What roles do health promotion services play for you in relation to prostate cancer?
What recommendations do you offer for the future role of men’s health promotion services in relation to prostate cancer?

What roles have health services played and continue to play in relation to your prostate cancer?

What recommendations do you have for the future role of men’s health services in relation to prostate cancer?

How has prostate cancer and its treatments affected your sexuality and intimate relationships?

There is a possibility that when you are talking about your experiences of prostate cancer you may become stressed. Should this happen I will suspend our conversation until such time as you are ready or wish to resume. However you may withdraw from the study at any time and I will advise you to seek the support of the Jenny Clifton (Phone 0412-025375) or Jim Houston (Phone 9483-4392) who are experienced counselling psychologists. In the event of your withdrawal from the study your photographs and the negatives will be returned to you and any information that I have learned from you about prostate cancer will not be used and the audiotapes will be erased.

During the time that we are talking our conversations will be tape recorded. Afterwards I will transcribe our conversations word for word so I can analyse what you said and try to understand your unique experiences of prostate cancer. You will be given the opportunity to read and comment, approve or disapprove the transcript (the written record of the taped interview), to make sure it is correct. When the interviews are finished I will retain your photographs for possible use within my thesis, any subsequent publications arising from this work and for professional presentations. Therefore if you agree to take part in this research I am asking you for permission to retain and use your photographs.

As a participant in this study every effort will be taken to protect your identity and maintain confidentiality. You will be asked to choose a pseudonym for yourself and it is completely up to you who you disclose this pseudonym to. You are free to withdraw from the study at any time. Your interview audio tapes and photographs and negatives will be kept in a locked cabinet in my office, Room Y 2.31 School of Nursing, Faculty of Health and Behavioural Sciences, Melbourne Campus, Deakin University for a period of at least six years (a six year term is the minimum requirement for secure data retention). Your consent form and any other information that links your pseudonym to your real name will at all times be stored in a separate locked cabinet at the same location for the same duration. If you would like to be advised of the study findings and subsequent publications arising from the study please advise me and I will mail copies to you.

If you would like to have further information about this research please do not hesitate to telephone me at the telephone number listed below. Thank you for taking time to consider this request.
John Oliffe
Lecturer in Nursing, PhD student
Ph. (03) 9244-6625

Should you have any concerns about the conduct of this research project, please contact the Secretary, Ethics Committee, Research Services, Deakin University, 221 Burwood Highway, BURWOOD VIC 3125. Tel (03) 92517123 (International + 61 3 9251 7123).
Appendix C : Deakin University Ethics Committee

Consent Form:

I, of

Hereby consent to be a subject of a human research study to be undertaken by John Oliffe, Lecturer in the School of Nursing, Deakin University, Victoria, Australia, under the supervision of Dr. Maria Pallotta-Chiarolli.

and I understand that the purpose of the research is to explore the interconnections what it means to me to have prostate cancer and what my own personal experiences have been. I understand that if I am involved in this research I will be asked to use a camera supplied by John Oliffe to take photographs that show my experiences of living with prostate cancer, and that the photographs I take will be developed at Johns’ expense and then used to trigger our interview discussions about prostate cancer. I understand that these discussions will be audiotaped and held in private on a date, time and in a location that is mutually satisfactory. I understand and agree that through participating in this research I give John permission to retain and use my photographs and excerpts from my story, when he makes public what he has found out about prostate cancer and masculinities.

I acknowledge

1. That the aims, methods, and anticipated benefits, and possible risks/hazards of the research study, have been explained to me.

2. That I voluntarily and freely give my consent to my participation in such research study.

3. I understand that aggregated results will be used for research purposes and may be reported in scientific and academic journals.

4. Individual results will not be released to any person except at my request and on my authorisation.

5. That I am free to withdraw my consent at any time during the study, in which event my participation in the research study will immediately cease and any information obtained from me will not be used.

6. That I am free to contact Dr. Maria Pallotta-Chiarolli, Ph. (03) 9251-7198 or the Deakin University Ethics Committee, Ph. (03) 9251-7123 with any concerns or criticisms with the project.

Signature: Date:

NOTE: In the event of a minor's consent, or person under legal liability, please complete the Ethics Committee’s "Form of Consent on Behalf of a Minor or Dependent Person".
Appendix D: Speech therapy by Melissa Sweet

Speech therapy

Much was left unsaid during “Bronch” Oliffe’s life. Like many men of his generation, he did not talk of his personal troubles, although he told his son just before he died that “I never wanted to be the way I was.” Bronch, born in 1912 in the small South Australian town of Quorn, was a drover and then a railway shunter. He was 27 when struck by a bitter disappointment that shaped the rest of his life: the armed forces wouldn’t accept him during World War II because of a medical condition.

Not long after, he went to pub for the first time. It was the beginning of a long battle with alcohol. His children—and their children—grew up in the shadow of Bronch’s anger and disappointment.

This only intensified after surgery for prostate cancer left Bronch incapable and impotent for the last years of his life. He felt further marginalised when excluded from the crucial consultation where his surgeon broke the news to the rest of the family that the cancer had spread. His teenage grandson John was acutely aware of Bronch’s distress as they shared a room on family holidays.

More than 20 years later, Bronch’s story lives on through John Oliffe’s work, analysing men’s experiences of prostate cancer from a sociological perspective. An emergency nurse completing a PhD on prostate cancer and masculinity at Deakin University, Oliffe believes many of the issues that affected his grandfather are relevant for the current generation of prostate cancer patients.

Like his grandfather, many have difficulty discussing their personal concerns, partly because they feel expected to be stoic and “guy” and bear it. Many also feel excluded from decisions about their care.

Addressing support group meetings to research his thesis, Oliffe became aware that many men had found one procedure particularly distressing, although it has received relatively little attention from researchers or clinicians.

Most men thought to be at risk of prostate cancer because their PSA blood test result is suspicious then undergo an invasive procedure called a transrectal ultrasound (TRUS) prostate biopsy. As many as 30,000 Australian men have this test each year.

It typically involves being in a front position and having an ultrasound probe inserted into the rectum to guide the biopsy. A needle is then fired into the prostate to collect tissue samples. How many needles are fired varies greatly; partly because it is not clear how many samples are needed to provide the best balance between an accurate result and minimum trauma. Some men have six samples taken, others as many as 30.

Whether an anaesthetic is offered—and what type—also varies. Recent consumer guidelines on localised prostate cancer advise that men “do not usually need to have an anaesthetic.” However, Oliffe’s interviews with 12 men who had the procedure without anaesthesia suggest it is painful or uncomfortable. Oliffe believes many doctors may not appreciate the procedure can be painful because their patients have not spoken up. As well, the issue has probably been overlooked because the focus of the debate is on prostate cancer screening, he says.

“Anaesthesia for TRUS attract a Medicare rebate and hence all should have the option of having an anaesthetic for the procedure,” Oliffe says. “Perhaps provision of anaesthesia for TRUS biopsy should be based on the patient’s estimation of their pain and pain threshold rather than the clinician’s assumptions.” Patient groups are also concerned that some men are not prescribed antibiotics before the biopsy to prevent infections. Says Max Gardner of the Prostate Cancer Foundation of Australia: “I have spoken to men who were not given antibiotics and later developed serious infections.”

Villis Marshall, clinical professor of surgery at Royal Adelaide Hospital, says debate about how many biopsies should be taken is one of many uncertainties in the diagnosis and treatment of prostate cancer.

Biopsies are interpreted can also vary, while there is still not reliable evidence about which approach—surgery, radiotherapy or watchful waiting—is most likely to benefit the individual with non-advanced cancer, he says. For many men, the approach recommended will depend on whether they are first referred to a surgeon or a radiation oncologist.

Given these uncertainties, it is infeasible that national clinical practice guidelines for management of localised prostate cancer are still not finalised, despite work starting some five years ago. It is widely hoped that guidelines, developed by the Australian Cancer Network, will finally get National Health and Medical Research Council endorsement by the end of the year.

Many factors conspired to produce the delay, including polarised opinions about which are the best treatment approaches. The NHMRC’s Adele Green says the hold-up is regrettable but that the council has new powers in place to help prevent further similar delays.

“All men should have the option of having an anaesthetic for the procedure”

[Box: All men should have the option of having an anaesthetic for the procedure]

http://www.prostate-health.org.au or phone 131120

svolino@big.com.au

Appendix E: Interview guide

Research questions

Photographic novella

- Tell me about this photograph
- What is happening in this photograph?
- What are you saying with this photograph?
- What makes this place significant?

Without photographs

- Tell me about growing up in Australia
- How did your prostate cancer start?
- Can you give me an example of that?
- What was that like?
Interview theme lists concept maps

**Growing up male**

- **Mates**
  - Groups / subgroups

- **Occupation**
  - Attraction and influences

- **Successful and unsuccessful men**
  - Criteria

- **Influences**
  - Feminism
  - Media
  - Family and friends
  - Culture

**Criteria**

**Family and friends**

**Culture**

**Media**

**Feminism**
Diagnosis

- Symptoms vs asymptomatic
- PSA
- DRE
- Biopsy / ultrasound

Hospitalisation vs Outpatient

Treatment [s]

- Watchful waiting
- Radiation Therapy
- Surgery
- Androgen Deprivation Therapy
- Decision criteria / influences
Recommendations for future men's health services in relation to prostate cancer

Role of health services

Influences on health promotion practices

Post diagnosis

Growing up and Pre diagnosis

Health promotion and prostate cancer

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Appendix F: Extracts From Brisbane Prostate Cancer Support Group Newsletter Aug 2002

Last meeting:

About fifty-five members and guests were entertained by John Oliffe, a Registered Nurse studying for his PhD at Deakin University, Melbourne. John presented a fascinating and very pertinent power-point lecture on some of the findings of his studies of 35 men diagnosed with prostate cancer.

John’s unique perspective concentrated on some of the psycho-social legacies which men, the “Men’s Health Movement” and Medico-Health Professionals are now just addressing. He re-enforced the need for men to move out of their social role model of being only defined as interested in work, war and women. He also pointed out that men are now beginning to see it’s alright to stand up and acknowledge our vulnerability and humanity. Also that it is important to share experiences and “spread the word” amongst other men”. His research also validated the necessity and value of support groups. We did appreciate John’s thoughtful presentation, balanced as it was, with a touch of humour and meaningful engagement. (See Bill’s article on P.5)

Reflections on John Oliffe’s presentation - “Prostate Cancer and Lived Experiences”. By Bill McHugh

John’s material drew on the experiences of 35 men who underwent TRUS prostate biopsies as a diagnostic procedure for suspected prostate cancer, as well as many other aspects of prostate cancer illness.

Apart from providing interesting technical information, John’s presentation reflected on the emotional roller coaster ride that many of us have experienced as we journeyed through the count down process that ultimately confirmed that we did have prostate cancer.

That process included three stages, each providing information through particular “scores” that needed to be understood – a sort of numbers game. First there was number provided by the PSA blood test. Then the Digital Rectal Examination (DRE) provided another piece of information combining letters and numbers. Finally the TRUS Biopsy delivered a Gleason Score – a definitive set of numbers that completed the diagnostic jigsaw.

For many of the respondents this was a time of anxiety with which we could all align – and they were being encouraged to become meaningfully involved in making the decision on what next to do about where they found themselves to
be. So many factors were involved – relationships of trust with our medical specialist/s; becoming informed of the options recommended for our very own individual situation; our belief in western medicine; the likely side effects and their impact on our masculinity; relationships with our partner; quality of life in general; how it would impact on our social life and work; the costs involved . . . The list goes on, and some would also have been presented with the option of doing nothing!

A significant impact of John’s presentation was the implication that it had that morning in relation to two important elements of the unique role that support groups can provide in the decision making process for those newly diagnosed. (i) The group provides a “safe house” environment in which each individual can talk openly about his medical situation and the emotions that he is experiencing, and (ii) this depth of sharing enables individuals who have already “travelled the journey” to come forward with offers of information and support that is highly relevant and can have a settling effect that enables the newly diagnosed to be more rational than emotional in deciding what to do.

John’s presentation will be remembered not only for the relevance of its content to our support group, but also for the depth of sharing that it triggered on the day.
Appendix G

John Oliffe (Staff)
C/- The University of British Columbia
School of Nursing
T201-2211 Westbrook Mall
Vancouver
British Columbia, Canada V6T 2B5
Email – jlo@deakin.edu.au

Dear ….,

I am writing to update you on the prostate cancer research which you took part in last year. In total, thirty five men participated in the research and I am currently ‘writing up’ the findings from the study. I anticipate my thesis will be submitted early 2004 and am hopeful that when approved the findings will be published as a book in 2005.

I also wish to advise that I have accepted a prostate cancer research position at the University of British Columbia (UBC) in Vancouver, Canada. The two year appointment will allow me to continue to research prostate cancer and conduct collaborative studies with international researchers in the area. It is my genuine hope the opportunities at UBC will assist me in developing expertise in prostate cancer research, that I can bring ‘home’ to Australia. I am contactable at the above postal and email address and welcome your correspondence, should you wish to contact me.

Again, thank you for your participation in the research, I hope you are well and I take this opportunity to wish you a merry Christmas and happy and healthy 2003.

Yours Sincerely,

John Oliffe

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