PROSTATE CANCER SUPPORT GROUPS: AN EVALUATION

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Abstract

The population of Australia is increasing in age, consequently the incidence of cancer diagnoses is rising. This rise will have a dramatic impact on hospitals with much of the disease burden extending to psychological support for cancer care. At present few men diagnosed with cancer seek support. This study sought to explore men’s perceptions of support and prostate cancer support groups.

The benefits of support groups for men with prostate cancer have been well documented in international studies. In Australia however, relatively few men diagnosed with prostate cancer join such groups and few studies have examined the factors that influence membership and attendance. This study investigated the experiences of a sample of 181 Australian men diagnosed with prostate cancer, 80 of whom were members of support groups and 107 who were not. The participants were recruited from prostate cancer support groups and an outpatient department of a major cancer hospital, in Melbourne, Australia. The two groups were compared on a range of factors, including disease characteristics, illness perceptions and views of prostate cancer support groups. Further, members of support groups rated a number of objectives to determine the effectiveness of the groups.

The majority of members recommended prostate cancer support groups to other men with prostate cancer (92%), however of the non-members of prostate cancer support groups, almost half (48%) had never heard of them. Factors that discriminated between support group members and non-members were emotional perceptions of the illness, symptom reports and illness coherence, with support group members reporting higher scores on these variables. Length of diagnosis and age were also factors that discriminated between the groups with support group members
younger and diagnosed longer than non-members. There were no differences between the groups on personal control, both groups reported high perceptions of control over the disease. Members reported more benefits and less costs associated with prostate cancer support groups than non-members. Benefits included information, support, sharing experiences, and supporting other men with the disease. Costs included negative discussions, other men dying, and the distance required to travel to the groups. Both members and non-members reported distance to travel to the groups as a major barrier to attendance. The majority of members had heard of the groups through friends and, for non-members who had heard of the groups, through hospital staff. General practitioners were one of the least likely sources of information about prostate cancer support groups reported by members.

Prostate cancer support group members reported high levels of satisfaction with the groups on a range of objectives outlined by the Cancer Council of Victoria. Making friends and accessing community assistance exceeded men’s expectations of attendance, however men reported a desire for more information and communication. A need for more funding, advertising, and recognition of prostate cancer support groups by medical staff was also reported.

Many men with prostate cancer are unaware of support groups, however a number of benefits were noted by both members and non-members. Greater recognition of prostate cancer support groups by medical staff may provide men with prostate cancer an opportunity to access those benefits. Health service providers should consider the important role prostate cancer support groups play in the recovery of men from prostate cancer and consider ways of dispelling myths men may hold regarding the notion of support.
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Declaration

This thesis contains no material which has been accepted for the award to the candidate of any other degree or diploma, except where due reference is made in the text of the thesis.

To the best of the candidate’s knowledge the thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

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Prostate Cancer Support Groups: An Evaluation

Chapter 1
Coping with Prostate Cancer

1.1 Introduction and Overview of Chapter

This chapter reviews the characteristics, prevalence, and, awareness of prostate cancer in the Australian community. Masculinity and health seeking responses in men with prostate cancer and the theoretical underpinnings of the present study are also discussed.

Prostate cancer is a leading cause of cancer among Australian men (Anti-Cancer Council of Victoria, 2000) (ACCV). Many men, however, are unaware of the prevalence of prostate cancer and the symptoms of the disease (Prostate Cancer Foundation of Australia, 2000) (PFA). As a consequence, men diagnosed with prostate cancer may be totally unprepared for the diagnosis, and the challenges which having the disease may entail. Challenges include facing difficult decisions regarding treatment options, the impact of treatment side-effects, and the effect cancer may have on family, work, and future (Cliff & McDonagh, 2000; Whitrod, 1996).

The literature on prostate cancer is reviewed in light of masculine social roles and help seeking behaviours. Traditionally, men seek little support when faced with a health crisis, many using strategies such as non-disclosure and avoidance, to cope (Helgeson & Lepore, 1996). However, whilst men traditionally attempt to avoid responses evoked when facing a health threat, dealing with emotions can be an important part of recovery (Lepore & Helgeson, 1998). Indeed emotional rumination and non-disclosure are related to psychological distress, while support is seen to improve psychological recovery (Helgeson & Lepore, 1997). Coping difficulties stem
largely from disease and treatment outcomes such as loss of sexual, urinary, and bowel function (ACCV, 1999)

Gaining information can increase one’s understanding about a disease, which can in turn assist coping (Cella, 1990; Dunn, Steginga, Occhipinti, McCaffrey, & Collins, 1999; Sanson-Fischer, Girgis, Boyes, Bonevski, Burton, & Cook, 1999; Taylor, Helgeson, Reed, & Skokan, 1991). Information on prostate cancer, compared to information on breast cancer, is often not visible or available in doctor’s surgeries and is rarely seen in advertising or media (PFA, 2000). However, men with prostate cancer report a need for more information than they are routinely given (Faden, Becker, Lewis, Freeman, & Faden, 1981; Pinnock, O’Brien, & Marshall, 1998) and report information about prostate cancer is difficult to obtain and retain (Crawford, 1998; PFA, 2000). Inconsistencies between what medical practitioners report and what their patients recall, regarding prostate cancer discussions (Crawford, 1998) suggests a need to address more thoroughly the information needs of men with prostate cancer. Further, prostate cancer patients report that emotional support and/or referral to support services is generally not provided in the course of their medical consultations (Whitrod, 1996) suggesting a need for additional support services and a review of how men access support when needed.

The theoretical underpinning of the current study was based on the creation of personal models of health. People’s health models or illness perceptions are created through cultural and social experiences, previous experiences with illness, and information about the disease to inform both cognitive and emotional perceptions of the illness (Leventhal, Meyer, & Nerez, 1980). Knowing the perceptions men hold of their illness can help to identify factors that determine support and information seeking and those that do not. Such factors can be used to create support programs
that are tailored to the unique needs of men with prostate cancer, to dispel myths men hold of their disease and to adopt positive health perceptions of illness that lead to illness adjustment.

The literature reviewed in Section 1.2 provides a description of prostate cancer with section 1.2.1 explaining the causes, symptoms, diagnosis and treatment of prostate cancer. Section 1.2.2 looks at the incidence, prevalence, and mortality of prostate cancer and section 1.2.3 gives an overview of the current debate on prostate specific antigen testing. Section 1.3 looks at public awareness of prostate cancer and whether men are receiving the information necessary for early medical review, detection and recovery. The literature reviewed in Section 1.4 examines the means by which men attempt to cope with prostate cancer. The provision of information as a source of coping for men is covered in Section 1.4.1 and masculine identity and help seeking is examined in Section 1.4.2. The literature reviewed in Section 1.4.3 examines the psychosocial and emotional adjustment to prostate cancer and Section 1.4.4 examines the literature on masculine identity and prostate cancer. Section 1.5 examines the quality of life research on prostate cancer. The influence of illness perceptions on coping and seeking support are explored in Section 1.6 and the theoretical underpinnings of illness appraisal through Leventhal’s self-regulation model are examined in Section 1.7. This critical review of the literature is summarised in section 1.8.

1.2 Description of Prostate Cancer

The prostate is an accessory reproductive organ in the male, located next to and under the bladder and completely surrounding the urethra (the urinary vessel that runs through the penis) (Miller & Keane, 1978). It is about the size of a walnut and secretes an alkaline fluid through the ducts and into the urethra. The urethra carries
urine from the bladder and semen from the reproductive organs (Miller & Keane, 1978). The main function of the prostate gland is to produce the major part of the fluid that makes up semen. As the prostate is a sex gland, its growth is influenced by male sex hormones, in particular testosterone, the prostate growing in size as a function of hormonal influence (ACCV, 2000). Until the age of 45-50 years the prostate remains fairly constant in size. After this age the gland can enlarge and change the normal process of passing urine (Miller & Keane, 1978). Most often prostate growth is benign (benign prostatic hyperplasia (BHP)) however in some cases prostate enlargement is caused by cancerous cells.

Prostate cancer is a malignant growth of the prostate gland (Miller & Keane, 1978). Very early prostate cancers are contained within the prostate gland and are called localised cancer. These early cancers often do not produce symptoms and may not necessarily become advanced cancer. Some prostate cancers however, grow and spread to the tissues around the prostate gland, this is called invasive or advanced prostate cancer (ACCV, 1999).

Prostate cancer is medically defined in regard to its spread and cellular change. This is measured through a system of grading (how abnormal the cells have developed) and staging (how far the growth has spread) assigned to samples of prostate tissue taken through trans-rectal biopsy (National Cancer Institute, 2000). The grading system assigns a grade to each of the two largest areas of cancer obtained through the tissue biopsy. The grades are added together to produce a Gleason score (out of 10) with low scores (Gleason scores 2, 3, 4) indicating slower growing cancer cells and high grades indicating more aggressive cell growth (Gleason scores 8, 9, 10). Staging consists of, stage 1 (localised to the prostate and non-palpable), stage 2 (localised to the prostate and palpable), stage 3 (regional, grown through the prostate
capsule to nearby tissues) and stage 4 (metastatic, distant spread to other parts of the body including lymph nodes, bones, liver or lungs). Results obtained through staging and grading of prostate tumours indicate treatment options and curability of the disease.

Compared to most cancers, cancer of the prostate generally tends to grow slowly (ACCV, 2000). Typically the clinical course of the disease is insidious, indolent, or relatively slow but progressive (Herr, 1997) with the majority of all prostates on autopsy having evidence of cancerous cells (ACCV, 2000). However some prostate cancers can spread rapidly if untreated.

1.2.1 Risk Factors, Diagnosis, Symptoms and Treatment of Prostate Cancer

Prostate cancer develops when cells in the prostate grow in an abnormal way as described in Section 1.2. For most men the cause of this is not known. There are however risk factors that may increase a man’s chance of developing prostate cancer. These include increasing age, family history, diet, race, and nationality (American Cancer Society, 2002). Increasing age is the most important risk factor, the chances of having prostate cancer after the age of 50 increases rapidly with a mean age at diagnosis of 65 and is rare in men under the age of 50 (Australian Health Technology Advisory Committee, 2003) (AHTAC). A family history of prostate cancer also appears to increase a man’s risk, suggesting a genetic or inherited factor. Having a father or brother with prostate cancer doubles a man’s risk of developing prostate cancer. The younger one’s father is diagnosed with prostate cancer, the greater the risk of developing the disease. A further risk factor is race. Prostate cancer occurs almost 70% more often in African-American men than it does in white American men, with African-American men twice as likely to die of prostate cancer than white men (American Cancer Society, 2002). There has also been some debate as to
whether a diet high in fatty foods and red meat, and low in fruits and vegetables, increases the risk of developing prostate cancer, however dietary links have not yet been clearly established (American Cancer Society, 2002).

Prostate cancer is diagnosed by a number of exploratory techniques including Prostate Specific Antigen (PSA) blood test, digital rectal examination, and biopsy of the prostate by the use of transrectal ultrasound (a small needle is directed by an probe in the rectum into the prostate) with six cores of prostate tissue withdrawn from different parts of the prostate gland (ACCV, 1999) (see staging and grading, Section 1.3). Further diagnostic assessments are aided by bone scans, x-rays, and computerised tomography scans, intravenous pyelograms and lymph node detection to identify disease spread (ACCV, 1999).

The symptoms of prostate disease are generally related to urinary function. When symptoms are present men complain chiefly of urinary indicators which are due to pressure from the prostate on the urethra. These symptoms include difficulty in passing urine, with some men experiencing pain urinating, a greater frequency of urination, difficulty stopping the flow of urine, and taking longer to pass urine due to a weak urinary flow. Other urinary symptoms include needing to pass urine urgently, feeling the need to pass urine even though there is little urine produced, straining to void (pass urine), reduced calibre, and force of the urinary stream and night time urination (nocturia) (ACCV, 2000).

Most men experience urinary symptoms, however advanced cancers may have spread without a man necessarily experiencing symptoms, or experiencing very mild symptoms. Later stage prostate cancer may cause obstructed urine flow as for localised cancer in addition to pain in the crotch, lower back, pelvis or upper thighs, pain or burning when voiding, pain during ejaculation, or blood in urine or semen.
Malaise, uraemia and lymphoedema are symptoms which are associated with disease spread beyond the prostate gland (ACCV, 1999; Cleeve, 1995).

Various treatments exist for prostate cancer and men are faced with difficult choices about those that are most suitable to their cancer and life style. Treatment depends on the type of cancer, the stage and grade of the cancer and the age of the man, his general health, symptoms, and personal choice (National Cancer Institute, 2000). Treatments include prostatectomy (surgical removal of the prostate), radiotherapy, brachytherapy (a form of radiotherapy where the radiation source is placed in the area being treated), hormone treatment (suppression of testosterone), in some cases orchidectomy (surgical removal of the testes) and possible combinations of therapies, depending on the stage of the disease (ACCV, 1999). Some men choose not to treat and remain under medical observation and PSA monitoring. This is termed “watchful waiting” (ACCV, 1999). The side effects of all treatments are similar, with men losing sexual function and urinary function with surgery, radiotherapy, and hormone treatment (see Section 1.4.3 for percentage rates of treatment related dysfunction). Depending on the treatment, men also may experience tiredness, nausea, vomiting, and diarrhoea related to radiotherapy, and hot flushes, swelling of the breasts, fluid retention and progressive hardening of the arteries with hormone therapy (ACCV, 1999). Choosing watchful waiting may spare the invasive side-effects of treatment, however increases the chances of disease spread with higher rates of clinical disease progression (McLaren, McKenzie, Duncan, & Pickles, 1998; PFA, 2000). Further, men choosing watchful waiting may also experience urinary and sexual potency problems related to tumour size and compression (Steineck, Helgeson, Adolfson, Dickman, Johansson, Norlen, & Holmberg, 2002).
1.2.2 Incidence, Prevalence and Mortality of Prostate Cancer

Carcinoma of the prostate or prostate cancer is internationally the most common type of cancer diagnosed in adult males (Sestini & Packenham, 2000). The incidence is highest in western countries (Northern America, North Western Europe and Scandinavian countries), lowest in Asia (Japan and Singapore) and less common in Africa, Central America, and South America. The incidence is however showing rising trends worldwide (American Cancer Society, 2002; Haas & Sakr, 1997).

Prostate cancer is the most commonly diagnosed cancer in Australian males after non-melanocytic skin cancer and has been so since 1989 when rates began to increase (ACCV, 2000). In Australia the incidence of prostate cancer rose steeply between 1987 to 1995 largely due to the detection of cancers before the onset of clinical symptoms by PSA testing. The lifetime risk of being diagnosed with prostate cancer is 1 in 11. For each decade the chance of developing prostate cancer increases. In 1996 10,055 new cases of prostate cancer were diagnosed in Australia with an age-standardised rate per 100,000 of 79.1 (ACCV, 2000). In Victoria between 1987 and 1997 the number of prostate cancer diagnoses more than doubled. In 1987, 1,117 new cases of prostate cancer were diagnosed in Victoria and by 1997 this had risen to 2,436, representing a 118% increase in new cases over a ten-year period (ACCV, 2000). Victorian statistics show an age standardised rate of 40.5 per 100,000 in 1987 and in 1997, 72.8 per 100,000, an increase of 80%, with a declining median age from 74 to 72. Eighty four percent of new cases of prostate cancer are reported in men aged 65 years and older. Currently over 3,000 men are diagnosed with prostate cancer in Victoria each year (ACCV, 2000).

Prostate cancer is the second most common cause of death among Australian men and is the third ranking cancer causing death after lung cancer and bowel cancer.
in Victorian men (ACCV, 2000). In Victoria, mortality in 1997 was 658 men, an increase by 50% since 1987 when 438 men died. This represented an age standardised rate of mortality in 1987 of 16.1 per 100,000 and in 1997, 17.3 per 100,000 representing a 7% increase over the 10 year period (ACCV, 2000). The mortality from prostate cancer has been increasing more so in elderly cohorts than in young men (ACCV, 2000). The survival rates of prostate cancer tend to be more favourable for patients detected at an early stage, when the cancer is still clinically localised within the prostate gland (ACCV, 2000).

In Victoria in 1993, the five year survival rates reported by the Cancer Council of Victoria (CCV, formerly known as ACCV) on a sample of 1,048 men diagnosed with prostate cancer, was 98% for clinically localised disease, 81% for locally advanced and 35% for distant spread (ACCV, 2000). Similarly the United States report a five-year relative survival of 93% for localised and regional disease and 34% for distant stage disease (ACCV, 2000). Gerber, Thisted, Scardino, Frohmuller, Schroeder and Paulson (1996) report early detection of localised prostate cancer is associated with a 10 year survival rate of 94 % for grade 1 cancer, 80 % for grade 2 and 77 % for grade 3 after treatment with a radical prostatectomy. While both international and Australian survival rates are encouraging for localised disease, trends suggest a rise in mortality rates, a declining median age at diagnosis (ACCV, 2000) and an increasing population of men over the age of 65 (Australian Bureau of Statistics, 1998).

Previous research suggests that many men with prostate cancer die of causes other than their prostate cancer, as the disease is slow growing (ACCV, 2000). However, contrary to this finding, there is evidence that the majority of men diagnosed with prostate cancer die of the disease. According to Borre, Nerstrom and
Overgaard (1997) the majority of patients (62%) in a Danish study of 719 new cases of prostate cancer died primarily of their cancer. Australian trends show 10,850 years of premature life lost in 2002 for men with prostate cancer (AIHW, 2002).

At present it is not possible to predict cancer growth, whether slow or rapid, suggesting that the disease is not one to which the public can become complacent. The unpredictable nature of prostate growth is currently creating debate regarding screening, treatment options, and health outcomes (see Section 1.3.3) and is suggestive of the inherent challenges men face in obtaining an accurate and early prostate cancer diagnosis (Prostate Cancer Foundation of Australia, 2000).

1.2.3 Prostate Specific Antigen Testing (PSA)

The prostate specific antigen test (PSA) is a method of detecting the stage of cancer through an analysis of blood. The test is used for diagnosing prostate cancer and for subsequent monitoring of the cancer after diagnosis.

There is current debate amongst the medical professions regarding prostate cancer screening using PSA testing (AHTAC, 2003; Shickle & Chadwick, 1994). The debate suggests that screening for prostate cancer can be fraught with problems. Early testing may subject men to more harm than good by identifying cancers that would otherwise never have become clinically apparent (slow growing tumours), thereby exposing men to an escalation of investigation and treatment with significant attendant morbidity (AHTAC, 2003). On the other hand, early diagnosis is the key to successful treatment and survival of prostate cancer (PFA, 2000) and by not offering screening the longevity and quality of men’s lives are being compromised (AHTAC, 2003). Further, early detection provides the opportunity for men to access information regarding treatments, to monitor and/or treat the disease without the fear of disease spread, to seek further medical advice, and to share discussion with
families and seek support. Due to the unnecessary morbidity early testing may expose men to and the difficulty differentiating tumours which are slow growing or aggressive (AHTAC, 2003) there has been a subsequent decline in screening since 1997 and prostate cancer incidence rates have fallen by 33% (ACCV, 2000).

The World Health Organisation’s (WHO) principles on screening were used as the basis for assessment of the effectiveness of prostate cancer screening by AHTAC (2003). The key criteria include ten factors to be met for screening to occur. At present the principles for screening guidelines suggested by WHO are not being met (AHTAC, 2003). The key criteria not being upheld for prostate cancer screening include, 1) the screening test is unable to discriminate between differing stages of prostate cancer; 2) it is not possible to predict tumour aggressiveness; 3) treatments for early or pre-symptomatic disease are not known to necessarily improve the course and prognosis and 4) testing may be reporting a high number of false positive results. Other reasons not to screen include that there is no epidemiological data that defines risk groups sufficiently for targeted screening activities and a man who tests negative in one test may go on to have the disease at a later stage. On the basis of the AHTAC’s findings, there is a lack of evidence that screening leads to an improvement in health outcomes.

The prostate screening debate is under constant review and at present under the guidelines of the AHTAC (2003), screening is not recommended unless a man appears to be at risk or showing symptoms of prostatic disease. However despite the findings of the AHTAC there remains concern in the general community that prostate cancer screening should be reintroduced (PFA, 2000). Concerns have been expressed by the medical professions, individual men (Pinnock, O’Brien, & Marshall, 1998) and community groups (PFA, 2000) which are fuelled by a lack of readily available,
balanced, and comprehensive information regarding prostate cancer screening (AHTAC, 2003).

There is also uncertainty about treating cancers detected by early testing. According to the AHTAC “there is no agreement among doctors as to how cancers that may be detected early through screening should be treated, or whether they should be treated at all” (AHTAC, 2003, p.12). The ambiguity of early testing and treatment adds to the uncertainty men face with regard to prostate health and seeking appropriate treatment. According to Lefevre (1998), men deserve sufficient information to allow a more informed personal decision in regard to prostate cancer diagnosis and treatment.

1.3 Community Awareness of Prostate Cancer

Over the past decade there has been increased interest in men’s health, with much of the focus on prostate cancer (Horner, 1996). As in many developed countries prostate cancer in Australia has become an important public health issue (Commonwealth Department of Human Services and Health, 1994). However much of the current discussion regarding the disease surrounds the screening debate which remains much contested within scientific and medical fields. While prostate cancer discussion is increasing within the scientific and health professions, much of the discourse surrounding prostate cancer fails to reach the public. As a result, many Australian men continue to remain unaware of prostate cancer or the symptoms of prostate disease and are unprepared for the risks they face (PFA, 2000). Thus information about prostate cancer may not be readily available to the public to provide a preventative or early treatment action (Association of Prostate Cancer Support Groups, 2002; PFA, 2000). The Support and Advocacy Committee of the Prostate Cancer Foundation (2000) state that unless prostate cancer is diagnosed and treated early, it is unlikely that the disease can be cured. The committee comment
that, as more than one in four men already have advanced prostate cancer by the time they are diagnosed, some men experience anger as a result of a system that fails to warn them of the risks that they face if diagnosed with prostate cancer (PFA, 2000).

Greater prostate cancer awareness can be instrumental in the health of all Australian men. For men not yet diagnosed with the disease it is of importance that they are aware of the signs and symptoms of prostate cancer so as to ensure early detection of the disease. For men already diagnosed with prostate cancer it is important that they are aware and informed of services that provide ongoing information regarding treatment, lifestyle management, and support in dealing with the illness. Visser and van Andel (2000) suggest that patient education and knowledge of prostate cancer is an important area of men’s health that requires attention in order to change men’s possible erroneous ideas about the prevention of prostate cancer. However educational and support programs appear to be lacking in Australia. Pinnock et al. (1998) suggest a substantial need for community and professional education about prostate cancer and for health promotion focused on preventable morbidity for Australian men. Further, the Prostate Cancer Foundation of Australia (2000) (PFA) observes there is an urgent need for a national program of public awareness of prostate cancer. The PFA (2000) observes that a national awareness program “is one of the essential ingredients in any effort to reduce the unacceptable prostate cancer death toll” (PFA, 2000, p.1). Given the uncertainty regarding prostate cancer screening, it would seem advantageous to advance programs that make more visible the signs, symptoms, and treatments of prostate cancer so men can detect early signs of the disease and make informed decisions about their treatment.
As opposed to the well-publicised information on breast cancer awareness, which includes media campaigns urging self-examination, breast cancer awareness week, and the abundant availability of information in doctor’s surgeries, health centres, and hospitals, there is little available publicised information that is reaching men, urging awareness and investigation for prostate cancer (PFA, 2000). Women with breast cancer, according to PFA (2000), are exposed to a greater range of information and have a disease that is more widely recognised and talked about in the community.

The limited awareness of prostate cancer in the community might be tied more broadly to men’s health policy failures at both state and federal levels of government. There has been limited government program development or budget allocation to men’s health in general (Lumb, 2003). On the whole, the objectives of the discarded National Men’s Health Policy (draft) (Commonwealth Department of Human Services and Health, 1996) has provided little development for the advancement of men’s health in Australia, despite the fact that overall, men’s health outcomes are significantly poorer than women’s (National Health Strategy, 1992). The lack of commitment to men’s health initiatives would contribute to patient education and counselling remaining a neglected area of health for men with prostate cancer (PFA, 2000).

1.4 Coping with Prostate Cancer

1.4.1 Information as a Coping Resource

Providing sound information has been shown to have several benefits in dealing with an illness. These include increased participation in decision making (Cassileth, Soloway, Vogelzang, Schellhammer, Seidman, Hait, & Kennealy, 1989); improved mental health and better coping skills (Johnson, Nail, Lauver, King, & Keys, 1988).
The acquisition of information is one way a patient can gain a sense of control over their illness. A patient’s perception of control is a significant factor in coping with stress and is central in adjusting to serious illness (Taylor, Helgeson, Reed, & Skolan, 1991).

Studies of cancer patients have identified patients need accurate information about their disease (Dunn, Steginga, Occhipinti, McCaffrey, & Collins, 1999; Pinnock et al., 1998; Sanson-Fischer et al., 1999) and, in general, want more information about their disease than they are routinely given (Faden, Becker, Lewis, Freeman, & Faden, 1981; Pinnock et al., 1998).

Men with prostate cancer seek information to enhance their decision-making regarding treatment options, side effects of treatments, and disease outcomes (Crawford, 1998). Treatment options are varied, therefore information is crucial in gaining a full understanding of the impact of each treatment. Wong, Stewart, Dancey, Meana, McAndrews, Bunston and Cheng (2000), in a study of 101 Canadian men with prostate cancer, observed men who wanted more information and to have their questions answered, generally had a higher level of optimism. As observed by Perczek (2000) reduced optimism is a predictor of post diagnosis anxiety among cancer patients.

Written information such as booklets, brochures, and fact sheets can be valuable for men when considering treatment options for prostate cancer. Shapira, Meade, McAuliffe, Lawerence and Nattinger (1999) in a survey of American men newly diagnosed with prostate cancer, observe that 80% of the participants cited pamphlets as a widely used source of information for treatment advice. Written materials were used frequently and valued sources of information for these men. However as observed in Section 1.3 general information, educational resources, and
media information on prostate cancer, compared to breast cancer, is lacking in
Australia as a readily available resource for men, in particular for men who have not
yet been diagnosed. This would reduce the possibility of men understanding the
warning signs of prostate cancer and seeking early treatment.

In Shapira et al.’s (1999) study, health professionals were reported to be the
main source of information for men with prostate cancer. However, Crawford (1998)
observes that there are wide differences between the role that the doctors see
themselves as providing in terms of discussion and information provision for men
with prostate disease and what men are observing. Crawford in a sample of 1000
American men with prostate cancer, suggests that while the goals of therapy are
viewed similarly by patients and physicians, much of the important cancer and
treatment related information that physicians’ report they have provided, is not
recalled by patients. Whereas 100% of physicians stated that they always discussed
important considerations such as options for no therapy, life expectancy with and
without therapy, costs and sexual function changes, only about one fifth of patients
recalled similar discussions. Crawford suggests that men with prostate cancer have
many informational needs that may not be met by physicians. Moreover although
men see doctors as being an important source of information (Shapira et al., 1999),
Weinman and Petrie (1997) suggest that in medical consultations many patients are
often reluctant to discuss their beliefs about their illness, due to fear of conflict with
their doctor or risk being thought of as being stupid or misinformed. This was also
observed by Pinnock et al. (1998) in an Australian sample of men with prostate
cancer, noting poor relationships with doctors can impose barriers on health action.

Crawford (1998) comments further that many physicians are not a good source
of emotional support or advice for men with prostate cancer. Yet according to
Canadian and Australian surveys, the greatest unmet needs of cancer patients are for information on daily living as well as for general emotional support (Skene, 1994).

Greater dissemination of information for men with prostate cancer would provide both an educative and supportive role and cater for the expressed needs of men with the disease. Further it would prepare men not yet diagnosed with prostate cancer with the information they require to assist in early disease detection. Both the PFA (2002) and the AHTAC (2003) perceive a need for greater information for men about prostate cancer and as was observed in Section 1.3, currently recommend improved access to information about prostate cancer.

1.4.2 Health Seeking, Support Seeking and Prostate Cancer

Not only is there a relative dearth of educative and supportive information available on prostate cancer, many men choose not to acknowledge the possibility of prostate disease even when symptoms do exist and remain reluctant to present to a doctor for either a check up or for symptom concerns. Compared with women, men are reported to consult their general medical practitioners less often (Briscoe, 1987), are less likely to seek information about health (Kassulke, Stenner-Day, Coory, & Ring, 1993) and are less likely to seek emotional support (Ashton & Fuehrer, 1993) and assistance for psychological problems related to their illness (Bland, Newman, & Orn, 1990). Yet more men than women get cancer, more men than women die from cancer, men usually adapt less well than women after a cancer diagnosis, and men are more inclined to be involved in risk taking behaviours such as alcohol consumption and smoking (Nicholas, 2000). Gender differences point to the disinclination for men, compared to women, to access health and support services despite the greater role illness may play in the lives of men.
In general men tend to provide, receive, and seek out less social support than women (Nicholas, 2000). In preference to seeking social support for health related distress, many men cite their spouses or partners as sufficient support for their needs. However many men also tend to avoid discussions with their spouses about their cancer or deny their cancer related anxieties and concerns (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000; Lavery & Clarke, 1999). Lack of disclosure may mean distress is going unresolved or may actually be heightened within the spousal relationship for many men (Lepore & Helgeson, 1998). Gray et al. (2000) interviewed Canadian couples regarding support and coping when the male partner was diagnosed with prostate cancer. The major themes that Gray et al. elicited from interviews with couples at three time intervals (pre treatment, 1 month and 12 months post treatment) included dealing with the practicalities of the illness, stopping the illness from interfering with everyday life, keeping relationships working, managing feelings, and making sense of it all. In an attempt to manage the impact of the illness, men were reported to struggle to stay in control of their emotions and their lives, typically vacillating between the pulls of fierce self-reliance and fearful neediness. Spouses expressed difficulties in being supportive while honouring their partner’s need for self-reliance and men felt the need to minimise the threat of the illness to aid coping and to avoid burdening others. Similarly, the divergent views of American husbands and wives were observed by Ptacek, Pierce, Ptacek and Nogel (1999) with wives of men with prostate cancer consistently reporting that their husbands experience more stress than they report.

Gray et al. (2000, 2002) observe that men with prostate cancer are also reluctant to talk to or seek support from other men regarding their prostate cancer diagnosis or symptoms. Roth, Kornblith, Batel-Copel, Peabody, Scher and Holland
(1998) suggest that reluctance to talk about the disease may be due to the disease and treatment side-effects that impact on part of men’s intimate anatomy that are not ordinarily discussed.

In a study by Lepore and Helgeson (1998) 178 American men with prostate cancer were surveyed through mail-out questionnaires from consenting physicians’ offices. Lepore and Helgeson observed a stronger negative relation between intrusive thoughts and mental health among men who felt socially constrained in talking about their prostate cancer than among men who felt unconstrained. In addition, level of constraints from family and friends was positively associated with level of avoidance in thinking and talking about cancer, which in turn, was associated with poorer mental health. According to Gray et al. (1997), factors relating to limited disclosure for men with prostate cancer include men’s low perceived need for support and fear of stigmatisation.

In a sample of 94 men with various stages of prostate cancer, Balderson and Towell (2002) reported a prevalence rate of 38% of participants reporting psychological distress. Balderson and Towell observe that health professionals should be aware of the potential for psychological distress in prostate cancer patients exhibiting poor physical functioning and those with perceived deficits in support.

1.4.3 Psychosocial and Emotional Adjustment to Prostate Cancer

There have been few studies on the psychosocial and emotional adjustment of men with prostate cancer relative to studies of patients with neoplasms of other sites. However a number of factors have been identified as being related to adjustment to a cancer diagnosis. They include being married, having a high income and level of education, and a positive perception of one’s health (Schnoll, James, & Harlow, 2002).
How one copes with an illness is also a factor in cancer adjustment. Coping strategies include cognitive, emotional, and behavioural responses to the potential threat posed by an illness (Folkman & Lazarus, 1985; Lazarus, 1993). While it is generally accepted that the outcome of any given coping strategy can be a positive or negative adjustment to the illness, certain consistencies have appeared in the research. Strategies such as self-blame, emotional ventilation, and cognitive and behavioural avoidance have generally been related to poorer adjustment to disease while positive reframing, acceptance of the illness, planning, and utilising social support and humour have shown inverse relationships with distress (Carver, Scheier, & Pozo, 1992).

Emotional expression has been seen to be an important factor in cancer adjustment (Cameron, 2000; Helgeson & Lepore, 1997). Inhibiting one’s emotions has been associated with poor mental health not only with cancer patients but a wide range of trauma survivors (Pennebaker, 1989). Concealing emotions in a sample of men with testicular cancer was related to greater sexual impairments (Rieker, Edbril, & Garnick, 1985). In a study of patients with colorectal cancer, Cameron (2000) observed that emotional rumination was detrimental to quality of life and that emotional expression bolstered vigour in patients. In Cameron’s study avoidance coping was not predictive of adjustment to cancer but social support and emotional expression were seen to enhance coping with the illness. Failure to disclose traumatic experiences has been associated with increased trauma related ruminations as well as increased psychological distress, health complaints and physician visits (Pennebaker, 1998). Emotional non-expressiveness when dealing with a cancer diagnosis is further linked to depression and stress (Bjorck, Hopp, & Jones, 1999; Merluzzi & Martinez-Sanchez, 1997).
Bjorck et al. (1999) in a study of the emotional functioning of men with prostate cancer, observed that the men who tended to dwell on their disease with an anxious preoccupation were more likely to be depressed and more likely to have low self-esteem than men who adopt a fighting spirit in recovering from their illness. Bjorck et al. reported that threat and harm/loss appraisals correlated positively with depressive symptoms and anxiety. The authors further reported that men whose mental adjustment to cancer was characterised by helplessness or anxious preoccupation had higher levels of anxiety and depression. The authors concluded that patients who focus on threat or loss appraisals or both (emotional rumination) regarding their illness are more likely to experience negative emotional outcomes. Men exhibiting more optimistic traits displayed emotional well-being and negative associations with depression and anxiety. However, Litwin et al. (1995) observed no differences on emotional functioning between a group of men with localised prostate cancer and age matched controls with no cancer. This finding is noteworthy because depression, which is linked to emotional functioning, is reported to be higher amongst cancer patients than those without cancer (Lynch, 1995). The findings might be related to the reporting of emotional functioning in men, such that some men may deny reporting feelings that suggest vulnerability (Vinerhoets & Van Heck, 1990).

When seeking solutions to coping with cancer, men appear to prefer problem-focussed strategies rather than emotional expression or the seeking of emotional support (Vinerhoets & Van Heck, 1990). Sestini and Packenham (2000) comment that the tendency to avoid emotional support or discussion suggests that gender role factors (see Section 1.4.4) bias traditionally non-expressive or emotionally non-disclosing men toward denial and dismissal of their psychological distress. Helgeson and Lepore (1997) suggest that emotional expressiveness is a stressful situation for
men. However, the propensity for restricted emotionality may mean that psychological morbidity may go unrecognised and untreated in many men (Roth et al., 1998). Lepore and Helgeson (1998) observe that supportive social networks may promote psychological adjustment to prostate cancer, especially for men who perceived they were unable to express their cancer related emotions and concerns.

1.4.4 Masculine Identity and Prostate Cancer

It is generally understood that gender role socialisation and resulting beliefs and attitudes about masculinity influence help-seeking. The literature on masculinity includes such constructs such as gender-role conflict or stress (Eisler, 1995), masculine ideology (Good, Borst, & Wallace, 1994) and the personality trait of unmitigated agency (Helgeson, 1994). Gender role conflict is thought to occur when restrictive gender roles, acquired through socialisation, lead to negative health consequences. Masculine ideology refers to the degree to which the individual subscribes to and internalises culturally determined beliefs about masculinity and unmitigated agency, which occurs more frequently in men than women, is defined as the unhealthy extreme in relationships which results in an absolute focus on self. Tudiver and Talbot (1999) suggest gender role barriers to help and support seeking include that men often deny or mask their feelings (see Section 1.4.3), hold negative attitudes toward health, hold a belief that seeking help was not an acceptable behaviour for men (see Section 1.4.2), and that men have difficulty giving up control. Such barriers reflect the indoctrinated social and cultural experiences of masculinity (Sabo & Gordon, 1995). Indeed the pursuit of help during illness is often not entertained (see Sections 1.4.2 and 1.4.3) as masculine culture calls for stoicism rather than assistance and dictates an avoidance of issues that may presume vulnerability (Sabo & Gordon, 1995). Men may feel that seeking and receiving social support,
expressing emotions, reporting symptoms and treatment side effects, asking for help, and seeking information from healthcare providers are not acceptable “manly” behaviours (Nicholas, 2000).

In many ways avoidance or denial of the health threat and of the need for support, serves to preserve a sense of the masculine self (Cella, 1990; Taylor, Helgeson, Reed, & Skokan, 1991), however is contradictory to health preservation. The use of avoidance would suggest a lack of understanding for many men of how to address a health issue and how to cope in the face of a health crisis (Helgeson & Lepore, 1996). Indeed Pinnock et al. (1998) observe barriers to health action in a sample of Australian men include stoicism, not talking about health issues, and poor relationships with doctors. Good, Sherrod, Dillon and Sanford (1999) describe how society’s expectation that men must be tough and independent can lead to the suppression of emotions, a sense of vulnerability, social isolation, withdrawal, and hesitancy or unwillingness to ask for help. Helgeson and Lepore (1997) in a study of men’s adjustment to prostate cancer, examined how two masculine gender related traits, agency (focus on self) and unmitigated agency (focus on self to the exclusion of others) were related to physical and emotional functioning in a study of 162 American men with prostate cancer. Helgeson and Lepore reported that men showing unmitigated agency style (arrogant, dictatorial, greedy, cynical, hostile) fail to utilise social support and may therefore experience difficulties in emotional and social functioning.

The nature of a man’s experience with prostate cancer reveals the links between masculinity and health and illness. Sexuality and masculinity are highly interwoven and with threats to sexual function through medical or surgical induced impotency, this can pose a significant threat to masculine identities (Fergus, Gray, &
Fitch, 2003). The majority of patients with prostate cancer report at least some problems with erectile function and urinary leakage years after surgery and radiation and many report long term, persistent impotency (see Section 1.5) (Fowler, Barry, Lu-Yao, Roman, & Wennberg, 1995; Gray et al., 1997; Kornblith, Herr, Ofman, Scher, & Holland, 1994). This suggests ongoing threats to sexuality and thus masculinity for many men and the potential for long-term psychological distress (Roth, Kornblith, Batel-Copel, Peabody, Scher, & Holland, 1998). Gray, Fitch, Phillips, Labrecque and Fergus (2000) observe that the life threatening and unpredictable nature, as well as the challenges prostate cancer can impose on daily life, can cause its victims to question core beliefs they hold about themselves and their relationships with others. Similarly, Janoff-Bulman (1992) observes that prostate cancer can be construed as a victimisation experience that threatens one’s view of the self. Prostate cancer can threaten a man’s assumptions about masculinity, being invulnerable to illness, having an active and fulfilling retirement, providing for his family, or satisfying his own and his partner’s sexual desires (Gray, Fitch, Davis, & Phillips, 1997).

Women with breast cancer have reported higher levels of sexual adjustment compared to men with prostate cancer. The predictors of adjustment for women included higher levels of social support, optimism, and meaning in life, and lower levels of avoidant coping styles (Gray et al., 1996). Comparatively, men’s health related schemas do not appear to encourage coping. Instead they may lead to gender-role conflict experienced as a narrow, rigid, and restrictive set of behaviours influencing early disease detection, help seeking, and psychosocial adaptation to cancer. Lumb (2003) suggests that Australian male political elites are in most cases embedded in the values of the hyper-masculine culture and are thus unlikely to champion policies and programs that make the acceptance of hegemonic masculinity
problematic. The challenge, according to Lumb, is to address the cultural definitions
of masculinity and those dominant masculine values and practices that may
subordinate and marginalise behaviours that provide positive health outcomes (Lumb,
2003).

Despite the social and political influences on masculine health outcomes,
masculinity roles are not necessarily fixed and, according to Connell (1995), may be
open to transformation. For some men to maintain a sense of their own masculinity
and personal control over prostate cancer disease, part of the masculine coping
process may involve redefining the cancer experience in a way that reaffirms rather
than threatens masculine identity (Gray et al., 2002). This would suggest a role for
educational and support programs which encourage changing behaviours that result
from adherence to masculine scripts and making health support and education more
acceptable for men. Nicholas (2000) suggests that increasing awareness about the
impact of gender role and masculine ideologies on health seeking and providing
programs that encourage positive approaches to help seeking would serve men well in
adjusting to the cancer experience.

1.5 Quality of Life and Prostate Cancer

Prostate cancer has several unique characteristics including that it is male
specific, that it generally affects older men, and that it is linked to the urogenitary
system. Men diagnosed with prostate cancer experience cancer-related adjustments to
their life with many of the factors related to the disease-specific course and treatment.
Findings from many quality of life cancer studies are often derived from or include
female and/or younger participants and therefore may not apply to the specific quality
of life issues of men and, in particular, men with prostate cancer (Visser & van Andel,
2000).
Literature on the quality of life for men with prostate cancer points to men reporting fatigue, weakness, and pain (da Silva, Reis, Costa, & Denis, 1993), reduced quality of life as a result of a diagnosis and treatment related side effects (Kirby, Watson, & Newling, 1998; Litwin, Hays, Fink, Ganz, Leake, Leach, & Brook, 1995) body image issues (Clark, Wray, Brody, Ashton, Giesler, & Watkins 1997) and emotional lability, hot flushes, and loss of libido (da Silva et al., 1993; Ofman, 1995). Clark et al. (1997) reported that the quality of life issues identified as most important in a sample of prostate cancer patients included body image, sexual problems, spouse affection, spouse worry, masculinity, cancer-related self image, cancer distress, and cancer acceptance.

Litwin et al. (1995) assessed the quality of life specific to men treated for clinically localised prostatic cancer by radical prostatectomy, pelvic irradiation or observation, compared with age matched controls and found that although cancer free men were not showing full potency or continence, men with cancer showed significantly worse sexual, urinary, and bowel function. Kirby, Watson and Newling (1998) in a quality of life survey of 401 men with prostate cancer from a number of countries including, Germany, United Kingdom, Italy, and United States, reported the men experienced a perceived loss of sexuality, with treatment having a significant impact on their lifestyle libido, sexual function, and activity.

Significant differences have been reported between the various treatments on quality of life, with patients receiving hormone therapy reporting the greatest negative impact compared with those receiving prostatectomy, radiotherapy, and no treatment (Green, Packenham, Headley, & Gardiner, 2002; Kornblith, Herr, Ofman, Scher, & Holland, 1994). Radical prostatectomy for localised prostate cancer has been reported to have complications as high as 63% incontinence and 89% impotency (Maklan,
Greene, & Cummings, 1994). The Cancer Council of Australia (ACCV, 1999) report 50% to 85% of men undergoing a prostatectomy and 40% to 80% of men undergoing radiotherapy experience sexual impotence and urinary incontinence is reported to be up to 35% for prostate surgery and a relatively low 5% for radiotherapy. Watchful waiting for localised prostate cancer has been associated with 45% erectile dysfunction and 49% urinary dysfunction in a Swedish sample of men with prostate cancer (Steineck, Helgeson, Adolfson, Dickman, Johansson, Norlen, & Holmberg, 2002).

Not all men experience side effects of treatment or even undergo treatment for prostate cancer, however a diagnosis of prostate cancer can produce, for many men, feelings of fear and anxiety regarding their future (Gray et al., 2000). Men choosing watchful waiting, for example, spare themselves treatment and possible treatment side effects, however face monitoring and uncertainty of their future outcome once diagnosed. Kornblith et al. (2000) observe that men with prostate cancer can become ‘worried waiters’ as they await their prostate specific antigen (PSA) results, the PSA level being the totem on which men and their families plan their futures.

Many quality of life issues lie with the ongoing and long term psychological distress associated with the disease and treatment which impact both men with prostate cancer and their partners and families (Cliff & Macdonagh, 2000; Roth, Kornblith, Batel-Copel, Peabody, Scher, & Holland, 1998; Whitrod, 1996). Green, Packenham, Headley and Gardiner (2002) report although hormone therapy in their study was associated with a greater decrease in sexual function compared to other treatments for prostate cancer, there were no differences between treatments on emotional distress, existential satisfaction, and subjective cognitive function. All men reported similar levels of dissatisfaction and cognitive dysfunction. The potential for
long-term psychological distress appears to be greater for men with prostate cancer than for men with other cancers. Shag, Ganz, Wing, Sim and Lee (1994) report that compared to lung and colon cancer patients, the perceived quality of life of survivors of prostate cancer actually declined with time.

1.6 Illness Perceptions

The onset of illness gives rise to a range of problems, which can vary from patient to patient, even in those with the same illness condition. Health psychologists have shown that, in order to make sense of and respond to their problems, patients create their own cognitive models or representations of their illness (Weinman, Petrie, Moss-Morris, & Horne, 1996). The term illness perception has been used to describe the mental activity that helps people interpret traumatic illness events in personally meaningful terms, integrate threatening or confusing aspects of the experience into a coherent and non-threatening conceptual framework, and reach a state of emotional acceptance (Greenberg, 1995). Research on illness perceptions can help to explain why individuals adapt differently to the same disease episode, with some patients far less disabled and distressed than others and are thought to be associated with seeking and utilisation of health services (Heijmans, 1999).

Moss-Morris, Weinman, Petrie, Horne, Cameron and Buick (2002) suggest that patients’ illness perceptions are based around distinct components, which in turn determine coping. Moss-Morris et al. suggest how one identifies with the illness, perceives the duration of the illness and represents the causes and consequences of the disease determine coping when faced with a health threat. Further, perceived control over the disease and treatment, emotional responses to the illness, and how one understands the illness also determine coping. For example, illness identity is concerned with patient’s ideas about the label and the nature of the condition
(associated symptoms); illness coherence is an indicator of how helpful an individual’s model of illness is to the individual and indicates how patients understand or comprehend their illness and personal control is a measure of self-efficacy beliefs, indicating how much control an individual feels he or she has over the illness and emotional perceptions are affective responses to the illness and have been used to predict health related responses such as help seeking (Moss-Morris et al., 2002).

Perceptions of an illness can be positive or negative depending on the underlying information that directs the perception. The more negative the illness perception the more difficulty an individual may have in coping with an illness and thus the more psychologically distressed the individual might be in relation to their illness. For example, a person perceiving the illness to be severe, with severe consequences, who feels he or she has no personal control over the illness and who perceives their illness with high emotional representation may be less able to cope psychologically than people perceiving their illness with more personal control, less consequences, and with less emotional representations of the illness.

Illness representations have been used in studies of illness adaptation in patients with a wide range of conditions, including heart disease (Cooper, Lloyd, Weinman, & Jackson, 1999; Petrie, Weinman, Sharpe, & Buckley, 1996; Steed, Newman, & Hardman, 1999), rheumatoid arthritis (Murphy, Dickens, Creed, & Bernstein, 1999; Pimm & Weinman, 1998), breast cancer (Buick, 1997), psoriasis (Fortune, Richards, Main, & Griffiths, 2000; Scharloo, Kaptein, Weinman, Vermeer, & Rooijmans, 2000a); chronic obstructive airways disease (Scharloo, Kaptein, Weinman, Willems, & Rooijmans, 2000b); chronic fatigue syndrome (Heijmans, 1998; Moss-Morris, 1997); diabetes (Griva, Meyers, & Newman, 2000) and Addisons disease (Heijmans, 1999). Evidence from studies point to the links between illness
representations and a range of psychological outcomes including coping (Heijmans, 1999; Heijmans & deRidder, 1998; Moss-Morris et al., 1996; Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman, & Rooijmans; 1998; Scharloo et al., 2000); mood (Fortune et al., 2000; Murphy et al., 1999); functional adaptation (Heijmans, 1998, 1999; Moss-Morris, 1997; Petrie et al., 1996, Scharloo et al., 1998) and adherence to a range of medical recommendations (Cooper 1999; Griva, Myers, & Newman, 2000; Weinman, 2000).

In a study of 233 chronic fatigue sufferers in Auckland, New Zealand, Moss-Morris, Petrie and Weinman (1996) observed that participants with a strong illness identity, who cognitively appraised their illness as being out of their control, caused by stress, and having serious consequences were most disabled and psychologically impaired. Moss-Morris et al. reported that positive cognitive reinterpretation of the illness representation was positively related to psychological well-being.

Petrie, Weinman, Sharpe and Buckley (1996) in a study of patients’ prediction of return to work after myocardial infarction found that illness representations were a strong indicator of recovery. Patients’ beliefs that their illness had serious consequences were related to later disability for work, around the house, recreational activities, and social interactions. Petrie et al. reported that patients with a strong illness identity had greater sexual dysfunction at both three and six months follow up intervals. According to Petrie et al. specific illness representations need to be identified at an early stage of illness as a basis for optimising outcomes for people with an illness and for designing rehabilitation programs. Petrie et al. observed that attendance at cardiac rehabilitation was significantly related to a stronger belief that the illness could be cured or controlled.
Little research has identified the role of illness perceptions in cancer recovery. However illness perceptions were seen to play a role in breast cancer patients (Buick, 1997). In a study of women with breast cancer, illness perceptions were seen to comprise a component of the cognitive-interpretative framework within which the cancer experience was defined and understood. No studies exist however, that measure the illness perceptions of men with prostate cancer.

Illness perceptions are informed by social and cultural scripts, by previous experiences with an illness, and information from a wide range of sources (Weinman et al. 1996). To the extent that prostate cancer shatters men’s basic assumptions about life, integrating and redefining the cancer experience into pre-existing mental models, and masculine scripts should promote psychological adjustment (Lepore & Helgeson, 1998). Knowing how the illness is cognitively and emotionally perceived would provide greater information on how men with prostate cancer define and in turn cope with their illness.

Much of the previous illness perception research has not included participants’ emotional perceptions of their illness. As emotional expression was seen to positively influence health outcomes, and emotional rumination or denial to negatively impact (see Section 1.4.3), exploring men’s emotional perceptions of the illness would lend insight into the impact of emotional perceptions on adaptation to the illness.

1.7 Leventhal’s Self Regulation Model

People construct common sense models to define and understand their illness experiences. These models guide health behaviour. Self-regulatory theory describes the process by which people form common sense models and provides a contextual approach for understanding the cognitive and emotional factors influencing health behaviours and decisions (Leventhal, Nerez, & Steele, 1984).
The most influential theoretical framework associated with illness appraisal is the self regulation model of Leventhal and colleagues, who have proposed that patient’s illness representations are based around distinct components which in turn determine coping (Leventhal, Nerez, & Steele, 1984; Leventhal & Difenbach, 1991). According to Leventhal (1984) illness representations lie along five broad cognitive dimensions, the label and symptoms of the illness, the perceived cause of the illness, how long the disease will last, the consequences of the disease on the person’s life, and beliefs about the controllability and curability of the disease (see Section 1.6). These illness perceptions signify an individual’s cognitive representation of their illness, reflecting a person’s beliefs about the severity of their illness and the psychological impact of the illness (Weinman, Petrie, Moss-Morris, & Horne, 1996).

Within Leventhal’s self regulation model, processing is suggested to work along two integrative parallel dimensions 1) processing the cognitive representation of the illness and 2) processing the emotional representation of the illness (Leventhal, Nerez, & Steele, 1984). Thus people can generate both a cognitive representation of illness and an emotional reaction to that representation (Weinman & Petrie, 1997). Leventhal, Meyer and Nerez (1980) propose that there are three important principles to the model. First, that both objective events, as understood by the individual, and subjective emotion, establish goals for coping. Second, behavioural regulation requires the specification of goals in a picture or representation of danger and the structuring and planning of goals for action. Third, highly concrete information plays a central and critical role in the formation of both the representation and the plan for action. The self-regulatory model thus proposes that the individual is an active problem solver, seeking information and testing hypotheses about the meaning of somatic sensations. The formulation of an illness representation through
hypothesising, guides coping and appraisal of the health action. Studies on preventative health and those on stress control have demonstrated the need for concrete information on the threat and on methods of coping, two important components of behavioural regulatory action (Leventhal, Meyer, & Nerez, 1980).

Illness representations are highly individual and not necessarily formed in accord with medical facts. When people experience an illness threat they employ implicit or lay themes for the purposes of interpretation (Buick, 1997). The themes are specific to each individual’s knowledge and experience. Theoretically, the formation and elaboration of an illness representation is suggested to be initiated when a health threat first becomes apparent, most commonly in the form of symptoms, or a disease label when asymptomatic. If symptoms are present, an individual is assumed to compare their present experience with previously formed illness schema, which integrates information from one’s culture, social communication, and prior symptoms and illness experiences (Leventhal et al., 1984). If patients are asymptomatic however, it may be speculated that individuals are forced to rely more on social communication or cultural information sources to elaborate their representation.

Models depicting how the individual builds an understanding of the disease process and how coping is directed (and, in turn, constructed) by the representation of illness, are rich in suggestions for patient education. The self-regulatory theory of illness perceptions therefore has great potential for understanding and developing effective methods of intervention for many disease types. Effective intervention would focus on the development of valid self-regulatory processes that can assist in positive psychological and physical responses to the health threat and minimise distress.
1.8 Summary of Chapter

The review of the literature presented in this chapter revealed that although prostate cancer is the second most common cause of death among Australian men and is the third ranking cancer causing death after lung cancer and bowel cancer in Victorian men (Section 1.3.2) there is little public awareness about the disease in comparison to breast cancer, which is well publicised in the community. Prostate cancer remains little understood by men and many men may be leaving investigation too late due to the lack of public information regarding the disease. There is much confusion surrounding prostate cancer screening (Section 1.3.3) and many Australian men are unaware of the symptoms, risk factors, and treatments of prostate disease (Section 1.3.1) however with greater awareness men can prepare themselves for prostate health and early detection of the disease (Section 1.2).

It was observed that providing sound information for cancer patients was seen to have several positive effects including pain reduction, speedier recovery, increased participation in decision making, improved mental health and better coping skills (Section 1.4.1). Men with prostate cancer were seen to desire more information about their disease and treatment, however much of the important cancer and treatment related information that physicians report they have provided to their prostate cancer patients, is not recalled by patients or is reported to not be provided.

How men approach health seeking was described (see Section 1.4.2). It was seen that men traditionally do not talk at length about their health concerns and generally seek little assistance relating to their health. It is possible that a disinclination to talk about health concerns may be denying many men early detection, cure and psychological recovery from the disease. Compared with women,
men were seen to seek less information and support when experiencing a health threat.

Research on the emotional functioning of men with prostate cancer (see Section 1.4.3) has been relatively ignored, although existing research points to some men being disinclined to discuss health related issues with both medical staff and their families. Adjustment to illness was seen to emanate from masculine gender traits and socio-cultural norms, which suggests a need to feel in control and a corresponding reduction or avoidance of emotional responses evoked by the health threat. However non-disclosure of cancer related distress or rumination was seen to negatively impact on men’s mental health. Masculinity was seen to be a dominant social force in Australia, influencing the formulation of perceptions of illness and methods of coping for men (Section 1.4.4).

Previous studies suggest that men experience a reduced quality of life related to treatment effects including sexual impotency and urinary dysfunction (see Section 1.5). The research suggests that many men with prostate cancer, despite the stage of the disease, suffer long term reduced quality of life due to treatment effects. Men report a declining quality of life relative to men with other cancers and report experiencing psychological morbidity including anxiety and fear of the future.

Adjustment to cancer requires both cognitive and emotional adaptation to the illness. Positive emotional and cognitive interpretations of the illness were seen to provide a helpful alternative to disengaging from the illness and thus was seen to be a factor in cancer recovery. The self-regulatory model of health (Section 1.7) (Leventhal et al., 1984) suggests that past experiences with illness, knowledge of an illness and social and cultural values are important in how a person represents and subsequently copes with the illness. Therefore, social constructions of masculinity
and exposure to information about an illness would determine and define how one elaborates their illness perceptions. Illness perceptions (see Section 1.6) were seen to influence coping, attendance at rehabilitation, treatment management, return to work, and recovery for several disease studies. The self-regulatory process of cognitive and emotional adaptation to illness was seen to offer a sound framework with which to understand the impact of illness perceptions on adjustment to illness and help seeking in men with prostate cancer.
Chapter 2
Support Groups

2.1 Overview of Chapter

This chapter discusses the notion of support and, in particular, the benefits of support and support groups for men with prostate cancer. The literature reviewed in Section 2.2 reviews the role of support in cancer care and recovery. Section 2.3 discusses the literature on cancer support groups and includes the correlates of support seeking that have been previously identified for cancer patients in Section 2.3.1. Section 2.3.2 observes the history of support groups and demonstrates that support group interventions now form an important adjunct to medical treatment in recovering from an illness. Section 2.3.3 describes the types of cancer support groups, detailing the differences between self-help groups and psycho-educational groups. Section 2.3.4 observes the guidelines of cancer support groups that define their purpose and provide a basis by which to evaluate the effectiveness of support groups.

Section 2.4 reviews the literature on the benefits of support groups, which includes coping, education, empowerment, and cost savings and Section 2.5 examines sex differences in the use of support groups.

Section 2.6 reviews the literature and research on prostate cancer support groups observing the benefits for men with prostate cancer through information, practical advice, and alleviating disease related anxiety. Studies show men in support groups receive information, the support of like diagnosed others (Gray, Fitch, Davis, & Phillips, 1997), reassurance and an increase in understanding the disease (Gregoire, Kalogeropolous & Coros, 1997), and exhibit lower levels of helplessness and hopelessness than men not attending (McGovern et al., 2002). Section 2.6.1 reviews previous evaluations of cancer support groups and Section 2.6.2 reveals the literature on Australian prostate cancer support groups, observing there are few studies in
relation to other countries, much of the research on prostate groups being conducted outside of Australia. The little Australian information regarding prostate cancer support groups and the small number of Australian prostate cancer support groups was seen to indicate a need for further research and review of Australian men and their support group experiences. The lack of research and educational groups for men with prostate cancer was seen to be indicative of a lack of available support and information for men with prostate cancer. A summary of the chapter is provided in Section 2.7.

2.2 The Role of Support in Cancer Care

Social support can be defined as the existence or availability of people whom we can rely on, people who let us know they care about us, value us, and love us (Bottomley, 1995). Weisman and Worden (1975) observe that there is a relationship between higher levels of social support at the time of an illness diagnosis and a subsequent reduction in emotional distress.

Diagnosis with a chronic disease such as cancer requires extensive medical treatment and support. Bloom (1982) observes that with a diagnosis of cancer there is an increased need for social support in order to assist in providing an appropriate psychological adjustment to the illness. Social support networks, both formal and informal, have been seen to be essential in the maintenance of treatment regimes and in coping with an illness and associated fears (Guidry, Aday, Zhang, & Winn, 1997). Informal support includes relationships with spouses or significant others. Formal support includes relationships that are agency based such as hospital programs and community based support groups (Guidry et al., 1997).

While a person’s support system is a significant determinant of how he or she manages a crisis situation (Caplan & Killelea, 1976), people’s existing informal
support networks may prove to be inadequate in times of crisis. For many patients, their families, and friends, the diagnosis of cancer can have a negative impact on existing relationships. In times of crisis, social relationships that previously buffered the effects of stress and assisted with coping may become difficult or fail (Wortman & Dunkel-Schetter, 1979). This was suggested in Section 1.4.2 where spouses of men with prostate cancer expressed difficulty coping with balancing a supportive role whilst allowing men their need for personal control.

Formal support networks can normalise the cancer experience. Festinger (1954) notes that individuals search for a sense of normality and accuracy about their world by seeking the experiences of others and in particular others with a like diagnosis. According to Festinger, in times of uncertainty or anxiety, particularly in the face of a potentially life threatening illness, affiliative behaviours increase as people seek opinions of like persons, of how they should think and feel. This can be achieved by talking with supportive and empathic others, which may facilitate cognitive processing of the illness and adjustment to the trauma. Thus formal support can validate a person’s thoughts and feelings and affirm that they are cared for. Further, formal support helps people find meaning in their experience and can reduce levels of arousal, which interfere with cognitive processing of the event.

Support needs have been identified for cancer patients in Australia. Sanson-Fischer et al. (2000) surveyed patients at medical oncology departments of nine major public cancer treatment centres in New South Wales, Australia. The results revealed many unmet supportive care needs of patients with cancer. Patients reported their highest perceived needs were in the psychological, health system and information, physical, and daily living domains. The highest area of need was found to be in the psychological domain. Sanson-Fischer et al. reported that people in the 31-60 age
group reported the highest unmet needs. The authors suggest that this may be due to a difference in attitudes toward reporting unmet needs, that is younger people may be more amenable to disclosing their needs, in contrast with older adults, who may believe that they should be able to cope and therefore keep their needs more private. It would be likely therefore, that illness related distress might not be detected, acknowledged, or treated in an older population of cancer patients.

### 2.3 Cancer Support Groups

#### 2.3.1 The Correlates of Support Group Attendance

Not all people seek support in times of crisis. During an illness, some people exhibit higher levels of concern about their health status than others. Women seek more support than men, young people seek greater support than elderly persons, and well educated persons are more likely to seek support than less educated persons (Bauman et al., 1992; Deans, Bennett-Emmslie, Weir, Smith, & Kaye, 1987). Cancer support groups are generally attended by middle class white women who often make use of other services for their emotional and physical needs, and men and lower socio-economic groups are under-represented in support group attendance (Krizek et al., 1999). Older men of lower educational background are the least represented in support group attendance (Krizek et al., 1999).

Davison, Pennebaker and Dickerson (2000) observe that support seeking is also influenced by how the person views the illness. In an American study across 20 disease categories, Davison et al. reported that when a person identifies the illness as disfiguring, embarrassing, and stigmatising this leads to seeking the support of others. However in Davison et al.’s study knowing the cause of the illness, how disabling the illness is, or how friendly the person is, were not indicators of support group attendance. The seeking of support is further influenced by a want to learn more
about the illness, to share concerns, and to compare physical and emotional progress with others (Krizek et al., 1999).

A generational factor in support group attendance has been observed by Wellich (1993) who comments that post World War II ‘baby boomers’ may be more likely to attend groups as this generation has grown up with an affinity for support groups. Wellich observes that self-help groups such as stress reduction and parenting classes, for example, have been a more familiar concept of health care and education with this generation. Therefore, it is reasonable to expect that this will extend to cancer support groups as baby boomers approach a prime age for cancers to develop.

2.3.2 History of Support Groups

The history of group work began in the 1800’s. Early accounts demonstrate educational groups and community action programs for the poor, to help deal with social, economic, and personal problems (Fobair, 1997). These programs provided information, education and support, and encouraged needy immigrants to help themselves. Early group intervention began in 1905 with recognition for the need to treat tubercular patients’ psychological health as well as their disease (Fobair, 1997). Weekly group meetings were encouraged by a medical practitioner to keep up patient’s spirits so that they might “persist in the regimen prescribed, live within [their]...physical limitations, and preserve or develop [their]...sense of responsibility” (Canon, cited in Fobair, p. 66, 1997). A degree of cohesiveness and mutual support was created in the tubercular classes as a result of mutual reporting of progress in weight gain and testimonials by successful patients. Psychiatrists began to experiment with group methods with psychotic patients in the 1920’s and group psychotherapy for interpersonal and intrapsychic conflicts began in the United States in the 1930’s (Yalom, 1975).
Medical practitioners today focus their practice primarily on the physical health of their patients with a reluctance to address patient’s personal experiences with illness. Patients have therefore sought alternative support, cancer support groups becoming increasingly greater in number and gaining more influence over the latter half of the 1950’s (Bottomley, 1997). The lack of a medical model to address the psychological needs of patients was therefore supplemented by the support group.

In Australia, support groups for cancer became popular in the 1970’s. The Cancer Council of Victoria commenced coordinating cancer support groups in 1984. Prior to this time there were already 24 self-help groups operating in Victoria (Dobson, 1992). The number of cancer support groups has risen in Victoria from 24 in 1984 to 118 in 1990, 72 of which were situated rurally. Today there are over 200 cancer support groups in Victoria, known to the Cancer Council, assisting people with a variety of cancer related diseases (ACCV, 2000). Early cancer support groups in Victoria varied in their individual history, membership, and activities (Dobson, 1992) however no groups were prostate cancer specific at that time. Internationally, prostate cancer support groups commenced in the United States in the early 1990’s and exist in many other countries (Coreil & Behal, 1999; Kaps, 1994). Similarly, prostate cancer support groups commenced in Australia in the early to mid 1990’s.

2.3.3 Types of Cancer Support Groups

Cancer support groups are part of the broader category of self-help groups. Cancer groups are not a replacement for a person’s health care, but a unique form of added support (ACCV, 2000). A basic feature of the support group is control of the group by its members. Groups adopt a structure which involves minimal bureaucracy and formality and which allows for maximum participation in decision making and participant empowerment (ACCV, 2000; Borkman, 1990). The self-help support
concept stems from the assertion that people facing a similar challenge can help each other by coming together for mutual assistance in satisfying a common need (Festinger, 1954; Katz & Bender, 1976). The power of this approach lies in the belief that a collective wisdom is born through the shared experience of participants (Davidson et al., 2000).

Self-help support groups known to the Cancer Council of Victoria are facilitated either by health professionals or non-professionals. Self-help groups are open to people with cancer and their families, are of no fixed duration and new members are welcomed at any time. Professionally led self-help groups are generally run through medical or community health organisations and are often facilitated by social workers, oncology nurses, or counsellors. Both professionally and non-professionally led self-help groups invite guest speakers, both professional and others experiencing the disease, to inform the group. Non-professionally led self-help prostate cancer groups are often facilitated by men who have experienced a cancer threat. Some non-professionally led groups run with external professional advisors as well as guest professional speakers (ACCV, 2000).

A second type of cancer group is the psycho-educational group. These groups are generally run with a duration of time allotted. Psycho-educational groups are always run by professionals and generally operate through health service facilities. Psycho-educational groups are sometimes referred to as professionally-led groups, and they differ from self-help groups in that they are generally of a fixed duration, are not open to new members once commencing and tend to be more structured in time and content. These groups can also be defined by their more specific focus or location. Supportive-expressive groups, cognitive behavioural groups, patient
education groups and hospital based open-ended groups have also been described (Fobair, 1997).

Professionally and non-professionally led self-help groups and psycho-educational groups follow similar objectives, providing treatment information, emotional support, coping skills, practical advice, and discussion for group members (Gregoire, Kalogeropoulos, & Corcos, 1997) (see Section 2.3.4). In Victoria prostate cancer support groups, affiliated with the Cancer Council of Australia are self-help groups, the majority of which are run by non-professionals.

2.3.4 Guidelines of Cancer Support Groups

In an early description of cancer support groups, Katz and Bender (1976) described the key attributes of support groups as small face-to-face group interaction, emphasis on personal participation, voluntary attendance, an acknowledged purpose for coming together, and provision of emotional support. Later Falke and Taylor (1983) and Feldman (1993) proposed it was desirable to implement a strong informational component to the groups. Support group objectives were also expanded to include; helping patients and significant others voice their concerns about the physical, psychological, and sexual implications of their disease in an emotionally supportive context, providing objective information to enhance the patient’s understanding of their disease and its treatments, complications and side-effects, and promoting the use of more actively involved coping strategies like being more involved in treatment and maintaining a realistic yet optimistic outlook.

According to ACCV (2000), support groups offer shared experiences and the freedom to speak freely, reinforcement of the normalcy of relations, and the ability to develop new relationships through socialisation, support, encouragement, hope, and a sense of belonging. The Cancer Council of Victoria outlines eight guidelines for its
support groups in Victoria, these include 1) belonging (removing the isolation of people with cancer and their families), 2) coping (assist people to cope with a diagnosis of cancer through a greater understanding of cancer, treatment and self help skills, problem solving and health maintenance), 3) coordinating (local community referral, advocacy, bereavement support, hospice and palliative care services), 4) communicating (encourage and facilitate communication between people with cancer, their families and members of the health/welfare team), 5) accommodating patient’s rights (respect differences including coping, physical, emotional social, cultural, and spiritual values), 6) protecting (advise against unsafe therapies and a non-profit open format providing access to people with cancer at no cost), 7) preparing (preparation and support for various tasks including hospital or family visiting, driving patients and telephone advise) and 8) reviewing (annual reviews and reassessments of goals to suit the needs of a changing membership).

The objectives or guidelines of support groups assist facilitators guide activities to cater for the needs of cancer patients. The guidelines set down by the Cancer Council of Victoria were based on experience gained from groups, both through review of past activities and through decision making regarding future directions. The guidelines of support groups have been employed as parameters in international studies, by which to assess support group effectiveness in meeting the needs of the members (Deans, Bennett-Emslie, Weir, Smith, & Kaye, 1988).

2.4 The Benefits of Support Groups

Illness support groups have a number of advantages, including health benefits for those attending the groups and also reducing the medical system burden through provision of support and information, with a subsequent reduction of costs in support and medical stays.
Support groups can be useful at all stages of cancer from early education, during the initial cancer diagnosis, during treatment, and for adaptation to life after cancer treatment (ACCV, 2000). Support groups are therefore a potential resource for millions of people who live with a chronic illness. Although most support groups are not preventative in orientation, they can be conceptualised as mental health interventions that aim to prevent the adverse psychological sequelae of a stressful health related event (Bauman, Gervey, & Siegel, 1992). Krupnick, Rowland, Goldberg and Daniel (1993) report there has been virtually unanimous agreement that support group participation facilitates psychological adaptation. This has been evidenced by research on a number of illness groups. For example, rheumatoid arthritis, cancer, heart attack, and epilepsy patients in support groups have been shown to exhibit more health benefits than non-participating controls or waiting list controls (Dracup, 1985; Droge, Arnston, & Norton, 1986; Telch & Telch, 1986). According to Lorig, Mazonson and Holman (1993), rheumatoid arthritis patients participating in peer-facilitated groups reported mean pain reductions of 20% and increases in self-efficacy, which was attributed to result from group attendance.

Research has shown the benefits of group support for cancer patients include, improved coping (Ferlic, Goldman, & Kennedy, 1979), adjustment (Cain, Kohorn, Quinlan, Latimer, & Schwartz, 1986), education (Jacobs, Ross, Walker, & Stockdale, 1983), maintaining treatment regimes (Guidry, Aday, Zhang, & Winn, 1997), and a longer life span (Spiegel, Bloom, Kraemar, & Gottheil, 1989).

Studies report short and long term benefits for cancer patients. Fawzy, Fawsy, Hyun, Elashoff, Guthrie, Fahey and Morton (1993) randomised melanoma patients to a control or a six-week psycho-educational intervention and demonstrated that those receiving the intervention, showed a significant improvement in psychological
functioning. At a five-year follow-up, the intervention group had a significantly lower rate of recurrence and mortality than those in the control group. Spiegel et al. (1989) observed the supportive-expressive cancer support group attended by women for one year which focussed on cohesion, sharing of fears and emotional self-disclosure, improved psychological adjustment to the illness, and improved survival. A 10 year follow up study by Spiegel et al. found that women with metastatic breast cancer, who participated in the support group, improved not only their quality but also their quantity of life, with survival time for group participants averaging almost 18 months longer than that of controls. The group members in Speigel et al.’s study reported less mood disturbances, fewer maladaptive coping responses, and fewer phobias than women receiving routine care.

Measuring the effects of a short-term cognitive support and education group for patients with cancer, Ferlic, Goldman and Kennedy (1979) found that group counselling produced significant positive changes in patients’ hospital adjustment, knowledge about the disease, and self-concept. Cella, Sarafian, Snider, Yellen and Winicour (1993) in a study of 77 people with cancer who completed a group-facilitated eight-week support program reported that quality of life improved significantly as a result of group attendance.

Comparing three interventions for psychologically distressed patients, including 1) a cognitive coping intervention (coping skills, relaxation, problem solving), 2) a supportive group intervention and 3) no group intervention, Telch and Telch (1986) reported the coping skills group fared best while the no treatment group actually deteriorated. The coping skills group showed significant improvements in lower depression, anger and fatigue, and higher vigour scores than the support group. While the support group showed no significant improvement in the scores, it did not
show the same deterioration as the no treatment group. This would suggest a buffer effect from the support intervention. Further the six-week support group intervention may not have allowed time for significant improvements. Bottomley (1997) observed group cohesion may not have developed fully in Telch and Telch’s study due to the short duration of the program and the heterogeneous nature of the sample.

In contrast to the considerable research on psycho-education groups, few studies exist on self-help support groups largely because of failures of researchers to accommodate to the ethos of self-help (Chesler, 1991). Self-help support groups exist in a wide range of styles and structures and precise boundaries around self-help categorization are not only difficult but also impractical (Davison, Pennebaker, & Dickerson, 2000). Studies with self-help groups however have reported similar benefits to those of professional structured groups, including being accepted and affirmed; sharing of information; reconstruction of a positive identity; a sense of affiliation and community; personal transformation, and opportunities for advocacy and empowerment (Kurtz, 1990). Maisiak, Cain, Yarbro and Josof (1981) evaluated a self-help group of 139 mixed diagnosis cancer patients, who attended monthly. The groups were facilitated by a social worker, the role of whom was to allow open expression of physical and psychological concerns. The authors reported improvements in coping with cancer. Deans et al. (1988) in measuring members expectations and satisfaction with their attendance at cancer self-help support groups in Scotland, found the groups enabled members to make new friends, find out more about their cancer, and meet others facing similar difficulties.

Support groups also benefit the community at large through medical cost savings and lessening the burden on an already demanding health system as resources for health care are increasingly scarce, becoming difficult to afford, or difficult to
attend with long waiting periods (Australian Nurses Journal, 2003). Diminishing resources means that hospital stays are becoming shorter. Medical and nursing staff have little time to deal with the psychological aspects of disease and the demands on social workers is in many cases hospital stay limited and not ongoing when long term health and psychological management may become a burden on family and care givers. For American arthritis sufferers attending self-help groups, the four-year savings on arthritis care alone would amount to $650 million (Davison, 2000).

Cancer costs Australia $2 billion per year. Prostate cancer comprises 5% of the health system costs for cancer, amounting to $101 million. Of the total cancer costs, 45% is for the age group of aged 65 and over and 33% for the 35-45 age group (Australian Institute of Health and Welfare, 1994). Similar Australian cost savings may be obtained from cancer support groups as has noted with American self-help groups.

Wellisch (1993) comments on six events in the United States that have implications for support groups for patients with cancer and their families, beyond the year 2000. They include increasingly scarce resources for physical and mental health care, an aging population with the baby boom generation entering middle age, increasing incidence of cancers in younger adults, cancers becoming chronic illnesses, and bereavement as a wide spread social issue. Similar comparisons might be drawn in the social and medical evolutions in Australian society. A social affiliative model of health may thus become increasingly sought to maximise individual health outcomes, relieve the financially and demanding overstrained medical system, and support current population and illness trends.

2.5 Sex Differences in the use of Cancer Support Groups

Health seeking behaviours vary between men and women. Furnham and Kirkcaldy (1997) suggest that women rely less on “provider control” (doctors being in
charge) and believe more than men that psychological factors play an important part in the aetiology of illness. Women believe in the help that social support can provide when dealing with a health crisis and men report the support of their medical practitioners and spouses as most beneficial. In crises, women have been shown to confide in a wider circle of family and friends than men (Harrison, Maguire, & Pitceathly, 1995; Lowenthal & Haven, 1968).

Both genders report utilising cancer support services and groups, however men tend to utilise the services less than women (Krizek, Roberts, Ragan, Ferrara, & Lord, 1999). Krizek et al. in a study on gender and cancer support group participation, compared breast and prostate cancer patients’ support group participation. Thirty three percent of the women, compared to only 13% of the men in the study, attended at least one support group meeting. Even though male participation rates were much lower, once attending the groups, both men and women continued in the group for approximately one year.

Krizek et al. (1999) report that men with prostate cancer state that learning about their disease is ‘very important” more often than women with breast cancer. Similarly Gray, Fitch, Davis and Phillips (1996) observe that men with prostate cancer report seeking informational support as their primary reason for joining a support group with intimacy and emotional support reported as secondary factors. However regardless of their intentions, over time most men who join a support group report that they had become more open with other group members and that they had developed important friendships. Once attending support groups men show no less interest than women in sharing their concerns and comparing their emotional and physical progress with like diagnosed others (Krizek, 1999). Both men and women report benefits from their group experience, however the benefits received by men are
less widely reported (Gray, 1996). This difference may be due to a number of factors, the preponderance of women in support groups, that few men join, and that there are few men only illness support groups. The small number of men in support groups may suggest that support groups fail to attract men to attend. Indeed support groups may fail to attract the very persons whose support needs are denied or are not met by traditional health services or their own social support network (Taylor, Falke, Shoptaw, & Lichtmann, 1986).

2.6 Prostate Cancer Support Groups

Prostate cancer support groups provide an immunological, supportive, and informational role in the recovery from prostate cancer. It has been observed that the reduction of stress resulting from attendance at support groups may influence the psycho-immunological response in men with prostate cancer by increasing natural killer cells (Para, 1998, cited in Sestini & Packenham, 2000). Most of the research on prostate cancer support groups however, has focussed on psychological and informational benefits of the groups and Whitrod (1996) comments on the effects of no support for men with malignant prostate cancer.

Psychological interventions that offer support have proven successful in other cancers and yet the psychological needs of men with prostate cancer is a relatively neglected field of research (Whitrod, 1996). In an interview of twenty Australian men with prostate cancer, Whitrod recorded that methods of coping ranged from acceptance and prayer to suicide contemplation as a means to alleviate intrusive thoughts related to invasive cancer, however none of the men had sought nor received help from an organised support service. According to Whitrod the principle sources of stress for many prostate cancer sufferers appear to be the difficulty in making significant decisions in conditions of much uncertainty and for many men only having
a small repertoire of coping options available to them. Whitrod observed that coping was little understood and men’s responses to the health threat stemmed largely from previous experiences of coping. Previous coping experiences, however, may not assist many men in dealing with a health threat. According to Whitrod all men reported much emotional distress at different times. The men perceived their diagnosis as a sentence of premature and painful death and felt that they had made irrevocable treatment decisions under conditions of much uncertainty. None of the men were aware of the range of information and support available and nor had any of the men sought help other than from their general practitioner. However communications with their general practitioner were often reported as insufficient for their needs.

Prostate Cancer support groups provide a forum where people can meet with one another and receive information and support on how to deal with the problems of prostate cancer. Through support groups, survivors of prostate cancer and their families come together to share their feelings and concerns and learn from each other. By keeping up to date on accurate information relevant to the disease, survivors of prostate cancer are better able to work through the dilemmas of their disease and move forward with their lives (Kaps, 1994). According to Helgeson and Lepore (1998), following a traumatic event people may experience residual arousal as a result of the emotional distress the trauma causes. Talking in forums such as support groups can reduce levels of arousal and help to cognitively integrate the experience. Among prostate cancer survivors the arousal reducing, perspective broadening, and information providing functions of talking to others may help to re-establish a coherent worldview, and assist in the adjustment to cancer and its ongoing side effects (Helgeson & Lepore, 1998). The use of support services can also facilitate
cognitive processing and emotional adjustment to traumas by providing an optimistic reframing of negative illness appraisals and communicate that a man’s thoughts and concerns are appropriate for the circumstances and not to be avoided. Seeking support can be helpful not only to a man’s physical and emotional recovery from prostate cancer, but also for enhancing communication between family and friends and for some a return to work and normal routine (see Section 2.6.1).

As evidence of the support men can gain through sharing experiences with other men with a similar disease, Weber (2002) randomly assigned 30 men who were recently diagnosed with prostate cancer, to an experimental group (paired with long term prostate cancer survivors) or a control group (usual and customary care). The experimental group met eight times during eight weeks to discuss feelings, thoughts, and concerns associated with prostate cancer. After the eight-week period there were significant improvements on self-efficacy in the experimental group that was not seen for controls. Controls showed no change in depression at four weeks, but by eight weeks showed a 20% increase in depression. Participants teamed with other men with prostate cancer had significantly lower depression both at four weeks and at eight weeks, representing an 88% and 82% decline in depression, respectively.

Kaps (1994) reports his experiences with prostate cancer before joining the American prostate cancer support group ‘US TOO’ as, “Originally I was very private and isolated with my disease. It was too painful to discuss and I became depressed and angry. Because I like so many men aged 60 years and older, was raised to believe that boys don’t cry or talk about their feelings, I really did not know how to talk about the emotions of fear and isolation that were deep within me” (Kaps, 1994, p. 2188). Kaps’ experiences speak of the barriers masculinity creates in health and support seeking and the benefits gained once seeking assistance.
Commenting on Australian prostate cancer support groups, Gardiner (2002), chairman of the Association of Prostate Support Groups notes, almost every aspect of prostate cancer is mired in controversy or confronts men with choices that challenge their traditions, personal beliefs, or social conventions. According to Gardiner, most men are taught from childhood to be self-reliant to the point that it is almost unthinkable to visit a doctor for any health problem that is other than virtually life-threatening, being unmanly to do so. Gardiner suggests that men are taught that big boys do not cry and in the rigidly masculine culture, admitting to having prostate cancer is something many men simply refuse to do. According to Gardiner, denial is more common in Australia than overseas. Gardiner comments that the idea of discussing misfortunes is counterintuitive and confronting for men. Regarding support groups, Gardiner envisioned old men swathed in blankets being offered their last rites. However he found an atmosphere of optimism and confidence, excellent personal information and the aura of gloom that had enveloped him when first diagnosed with prostate cancer “miraculously lifted”. For Gardiner it became much easier to accept reality and to make the critical decision of which treatment to have, his fear was replaced with optimism. He suggested that contrary to traditional male beliefs, it is only by openly discussing these matters with others that men can come to terms with them.

Calabrese (1998) suggests that although members may be at different points along the treatment continuum, men with prostate cancer continue to identify common ongoing needs regarding information, quality of life issues and coping. Many men are willing to discuss their feelings and fears in a peer-group setting. They can and do talk to each other about living with cancer. They advise, help, and support each other.
In a 1995 National survey of ‘US TOO’ prostate cancer support groups in America, physician and patient perspectives on cancer support groups were compared. A large percentage (85-90%) of both physicians and patients rated support groups as good sources of emotional support for coping with the disease, but physicians underestimated the educational benefits of support groups compared with members own assessments (56 % vs. 71 %). The authors conclude that better links to support groups are needed to ensure that prostate cancer patients’ needs are being met (Crawford, Bennett, & Stone, 1997). This is in line with Gardiner (2002) who suggests that many doctors have not yet appreciated the benefits patients and their partners would get from being introduced to a support group and Krizek et al.’s (1999) findings that one third of men with prostate cancer in their American study had not heard of prostate cancer support groups as they may not have been informed of the groups by their medical team. Indeed Steginga (2005) observes a higher satisfaction with support groups where there is a higher perceived clinician support for group participation.

McGovern, Heyman and Resnick (2002) in a survey of American men with prostate cancer observed that of the sample of men who had never attended a support group, 57% were unsure whether they would join a support group. Being ‘unsure’ may suggest for men in this American sample, their primary approach to social support is amenable to change. The challenge, according to Krizek et al. is getting men to attend the first session of prostate support groups, which would encourage ongoing participation and through participation, coping. Krizek et al. (1999) suggests that if support groups are marketed to men who otherwise would not attend, the support aspect that comes with being with other cancer patients will be valued by all members. Attracting men to support groups may be an issue of marketing groups as
informational rather than supportive. Promoting support groups for men in a way that targets their reported needs may be vital in gaining men’s interest in support groups. According to Coreil and Behal (1999), early access to support groups for men newly diagnosed with prostate cancer, is a key to providing early education, support, and coping.

Knowing the myths and barriers Australian men perceive in relation to prostate cancer support groups, may lend greater insight into how much they know about the groups and their function in cancer recovery. Many Australian men may be unaware of prostate cancer support groups (Whitrod, 1996) and may not be informed through their treating medical team, as found in the American studies (Crawford et al., 1997; Krizek et al., 1999). The lack of suggestion by medical staff may account in part, for the small number of men with prostate cancer who join prostate cancer support groups.

2.6.1 Prostate Cancer Support Group Evaluations and Research

There is limited available literature on prostate cancer support group evaluations. The existing literature is generally confined to studies from American, Canadian, and British experiences and mainly describe the effectiveness of group programs in meeting the needs of the members. Other international studies compare members and non-members of prostate support groups focussing on quality of life issues in an international sample.

Gray et al. (1997) report the results of interviews of 12 men involved in Canadian self-help prostate cancer support groups. Open-ended questions were employed, focussing on the men’s experience of the benefits of their self-help group. Four men from each of three different support groups were interviewed. Overall, participants reported their group involvement to be helpful, especially in terms of
accessing information. Additional benefits included finding communality with others, being able to talk about difficult issues, being productive and to accomplish tasks, advocacy to make a difference, and engaging with family members around health issues. Gray et al. (1997) conclude that self-help groups assist the challenge inherent for men in dealing with prostate cancer and counteracts the tendencies to minimise the suffering which they experience.

Gregoire et al. (1997) evaluated the effectiveness of a professionally led psycho-educational prostate cancer support group in Montreal, Canada. Together a nurse and psychologist provided information on the medical aspects of the disease and treatments and the psychological reactions to a diagnosis of cancer, and encouraged participants to adopt more active, health promoting coping strategies. Fifty-four men with prostate cancer participated in seven different prostate cancer support groups consisting of 10 weekly sessions. A self-administered questionnaire was completed at the end of the sessions to evaluate the effectiveness of the support groups and the overall satisfaction of the participants, and consisted of open-ended questions regarding three key areas, education (about prostate cancer, urinary, sexual, and treatment information); coping (expression of feelings and concerns; relaxation; positive coping strategies); and strengths and weaknesses of the group. The participants reported that they had a better understanding of their illness, and perceived themselves as more involved in their treatment, after the program. The men expressed that sharing their experiences with others gave them reassurance, helped alleviate their anxiety, and provided them with a more positive outlook. One hundred percent of the men commented that they would recommend support groups to other men. The authors concluded that the findings furnished evidence for the effectiveness
of support groups in facilitating perceptions of enhanced coping in men with prostate cancer.

Feldman (1993) used a telephone interview survey to evaluate an open-ended self-help prostate support group led by a social worker and a recreational therapist in Florida, America. Men with prostate cancer in the group were interviewed by telephone after four months of the program, which alternated between didactic and recreational sessions. The interviews revealed that the men believed that they benefited from the program. Feldman concluded that the men achieved a greater sense of control over their situation and coped better with their treatment. As noted by Gregoire et al. (1997) however, little information was reported by Feldman on the specific benefits of the program, suggesting that benefits were mainly based around the social and recreational aspects of the group.

Coreil and Behal (1999) surveyed 38 ‘Man to Man’ self-help prostate cancer support groups in Florida, U.S.A., through mail out questionnaires. The survey included open-ended questions regarding the benefits of the group, satisfaction with the group, and perceived strengths and weaknesses of the group. High levels of satisfaction with the program’s organisation and functioning were reported. Sharing experiences with others and educational support were highly rated as a benefit of the group. Perceived needs included a better outreach to newly diagnosed patients and increasing access to other community services. The reported benefits of Coreil and Behal’s (1999) study further attest to the advantages of group membership.

Bottomley (1997) suggests that the lack of control group in much of the support group research makes the results difficult to determine, as the effects may not be identified as specific to the process and the reported benefits may be some kind of Hawthorn effect. Bottomley further suggests that using waiting list controls are not
effective in that the waiting list group may not have received treatment therefore making the results have different implications.

Using controls, Poole, Poon, Achille, White, Franz, Jittler, Watt, Cox and Doll (2001) in a study of British support group members and non-members for men with prostate cancer, reported that members were more likely to cite other patients as sources of emotional, informational, and practical support. Members cited other patients as their most helpful source of informational support whereas non-members cited medical staff. Interestingly, no differences were found between the groups (members and non-members) regarding coping, quality of life or satisfaction on three types of support; emotional, informational, and practical. Similarly McGovern et al. (2002) found no differences on quality of life between a group of American non-members (37 men) and members (14 men) of prostate cancer support groups. However the study revealed that men in support groups exhibited high fighting spirit and low levels of helplessness and hopelessness. The lack of difference between the groups on quality of life and coping may be due in part, to the small sample size.

In general, research upholds the benefits of prostate cancer support groups for men with prostate cancer (Coreil & Behal, 1999; Feldman, 1993; Gray et al., 1997; Gregorie et al., 1997). However the research is limited and according to Bottomley (1997) much of the existing cancer support group research has limitations in their methodology including lack of control groups and small sample sizes.

2.6.2 Prostate Cancer Support Groups in Australia

There is little Australian literature regarding the support group experiences of men with prostate cancer in Australia. There is more research regarding the effectiveness of prostate cancer groups internationally, perhaps due to the increased number and greater recognition of prostate cancer support groups.
Australian literature has been confined to interviews about self-help experiences (Whitrod, 1996) and men’s preferences for sources of information about and support for cancer (Dunn et al., 1999). More recently however Steginga (2005) conducted a review of 44 prostate cancer support groups across Australia. Steginga (2005) revealed peer support was rated positively by most men. A high satisfaction with support groups was related to better quality of life, lower pain, younger age, lower education, and higher perceived clinician support for attendance. Dissatisfaction with support groups was related to higher psychological distress, lower quality of life, and lower perceived clinician support.

The only known evaluation of cancer support groups in Victoria was by Dobson (1992) when she evaluated the cancer self-help groups known to the Cancer Council of Victoria, however as previously noted (Section 2.3.2), at that time the evaluation did not include prostate specific groups. Prostate cancer support groups in Australia are few in number and there is little information regarding the effectiveness of existing groups particularly when compared to other well-publicised cancer support groups in Australia, such as breast cancer. Currently prostate cancer support groups exist through different organisations in Australia including the Cancer Council of Victoria, the Prostate Cancer Foundation of Australia (PFA) and US TOO Australia (a division of the Continence Foundation of Australia). Prostate Cancer Support Groups are generally affiliated with one or more of the above organisations. There are prostate cancer support groups in each state of Australia. The number of groups in each state that were affiliated with the Cancer Council, PFA and US TOO at the time of the present study include, 13 in Victoria, 22 in New South Wales, one in Australian Capital Territory, one in Northern Territory, nine in Queensland, one in Western Australia, five in South Australia, and three in Tasmania.
In Victoria, at the time of the present study, there were nine prostate cancer support groups affiliated with the Cancer Council of Victoria which were currently operating. Of the nine CCV self-help prostate cancer support groups, two were professionally facilitated groups and the remaining seven were facilitated by non-professionals. Three of the groups were facilitated by women, two being professional nurses and one, the wife of a man with prostate cancer. The groups were located both rurally and within the metropolitan area of Melbourne.

2.7 Summary of Chapter

The review of the literature in this chapter revealed the role of support is important in the recovery from health threats (Section 2.2). Social support was seen to assist emotional distress (Weisman & Worden, 1975) and coping (Caplan, 1976) and to facilitate both physical and psychological recovery from an illness (Sanson-Fischer, 2000). There was seen to be a clear need for formal support as informal support was seen to at times not be adequate for cancer patients needs, or may diminish and fail under the stress of the disease threat (Caplan & Kililelara, 1976; Wortman & Dunkel-Schetter, 1979). It was seen further that formal support networks can normalise the cancer threat and validate one’s thoughts and feelings about the disease.

It was observed in Section 2.3.1 that older men who are married and of low educational background are the least likely persons to attend support groups (Krizek et al., 1999). Although older men are under represented in support groups, in many ways support services have neglected the supportive care needs of older men with prostate cancer (Taylor et al., 1986). Cancer support groups were seen to historically fulfil a support role that was increasingly sought by patients yet was not offered through medical consultations (Section 2.3.2). It was observed that self-help support
groups have had less research than psycho-educational groups which was seen to be due in part to the difficulty in defining self-help groups as they vary in structure and content (Section 2.3.3).

The guidelines for support groups (Section 2.3.4) have aimed to provide for the needs of the members and have been used as a way to evaluate the effectiveness of support groups. Given the lack of research on self-help support groups, the CCV guidelines were seen to provide a means for prostate cancer support group evaluation.

The benefits of support groups were reported in Section 2.4. Participants of support groups reported improved coping, adjustment to the illness, a longer life span and improved knowledge of the disease, suggesting that support groups are an important means by which men and women can learn adaptive health behaviours (Cella et al., 1993; Ferlic et al., 1979; Speigal et al., 1989). Positive identification, affiliation with others, advocacy, and empowerment are also reported benefits of cancer support groups (Deans et al., 1988; Kurtz, 1990). Further benefits were seen to be through medical system burden reduction and cost savings associated with an aging population (Wellich, 1993). Prostate cancer support group research observes benefits such as information regarding the cancer, communality and being able to talk with others (Gray et al., 1997), understanding treatments, reducing anxiety and a positive outlook (Gregorio et al., 1997).

Gender differences in support group attendance revealed that few men join support groups relative to women, however once attending support groups men showed no less interest than women in sharing their concerns with others (Section 2.5). Once participating, men were seen to attend for a length of time similar to that of women (Krizek et al., 1999). As many men are reported to never have heard about prostate groups or were unsure about joining (Krizek et al., 1999; McGovern et al.,
2002) this would suggest that many men may benefit from support groups but are unaware of the services or benefits provided by the groups.

Early access to support groups for men newly diagnosed with prostate cancer, was seen to be a key to providing early education, support and coping. Studies comparing members and non-members of prostate cancer support groups show that participants have higher fighting spirit and less helplessness and hopelessness than non-members however the studies have been less certain regarding the quality of life benefits of support group attendance when compared with non-members (Section 2.6.1). Recent Australian literature (Steginga, 2005) on prostate cancer support groups suggests peer support in groups is on the whole positively rated by group participants. A less current evaluation of Victorian prostate cancer support groups, showed benefits of cancer support groups however many of those groups were heterogeneous, comprising mixed cancer diagnoses and both men and women, suggesting that the reporting of the specific benefits for men was not obtained by the evaluation.
Chapter 3

The Current Research

3.1 Overview of Chapter

This chapter provides an integration of the literature reviewed in previous chapters. The background and rationale for the current research, based on conclusions drawn from the review of the literature, is presented in Section 3.2. The theoretical background to the study is further consolidated in Section 3.2.1. Section 3.2.2 discusses previous illness perception research and Section 3.2.3 discusses previous research on prostate cancer support groups. Section 3.3 reveals the structure of the present study including the aims and hypotheses of the study. Section 3.3.1 presents a series of comparisons between members and non-members of prostate cancer support groups which include their perceptions of prostate cancer support groups and perceptions of their illness. Section 3.3.2 outlines the evaluation of Victorian prostate cancer support groups and Section 3.4 provides a summary of the present research.

3.2 Background and Rationale

As noted in chapter 1, prostate cancer is the most commonly diagnosed cancer among men however has been accorded considerably less public attention than other cancers. For example public awareness, research, and knowledge are far more evident for breast cancer than prostate cancer.

It was observed that many men are unaware of the signs and symptoms of prostate cancer and that many informational and support needs for men with the disease are not being met by their attending doctors (Crawford, 1998). Men with prostate cancer report information as being very important when trying to understand and make treatment decisions about the disease and report a desire for more information than they are given (Crawford, 1998). Further, men with prostate cancer report that their supportive care needs are not necessarily discussed in the course of
the consultation with their doctors. As observed (Section 2.2) a supportive role is reported to be provided by men’s wives/partners however men do not necessarily discuss their concerns with them (Gray et al., 2002).

The lack of disclosure to medical personnel and wives/partners was observed to be related to masculine cultural and socialisation norms which uphold denial and non-disclosure of emotions, and which were seen to be typical responses to a health threat for men (Lepore & Helgeson, 1997). However, dealing with emotions has been associated with better psychological outcomes for men with prostate cancer (Helgeson & Lepore, 1998). The reported lack of information provision as well as the difficulties men face in discussing cancer related concerns suggests additional sources of information and support would be beneficial to many men with prostate cancer such as is provided by prostate cancer support groups.

The role of prostate cancer support groups in helping men with prostate cancer has been slow to emerge in the literature, with a few international evaluations in the early 1990’s. The more recent literature has increased, albeit slowly and modestly over the past eight years, with a small surge of literature over the past five years. The research has, to date, come from international studies and there remains a lack of research of prostate cancer support groups in Australia. Support groups were seen to be excellent forums by which to address identified needs for men with prostate cancer, in particular information provision and support (see Section 2.3). Surprisingly, however, compared to the number of men diagnosed annually in Australia, few men join. The modest membership of prostate cancer support groups suggests many men may not be informed of the availability of prostate cancer support groups. Further those who know about prostate cancer support groups may not perceive a need for them, understand what they offer, or are unable to attend. Thus,
this study sought to provide information regarding why many men with prostate cancer do not join support groups and to highlight the benefits experienced by those who do.

Understanding why men do and do not join prostate cancer support groups would help health services to understand more fully men’s health behaviours in seeking support and target the promotion of prostate cancer support groups in such a way that appeals to men, with the hope that by so doing more men might benefit from the groups.

3.2.1 Theoretical Framework

Self-regulatory theory was the theoretical framework that informed this study (Leventhal, Nerez, & Steele, 1984). It describes the cognitive and emotional processes involved in the construction of illness perceptions. The theory proposes that individuals are active in seeking information and testing hypotheses about the meaning of the illness. Through this process they formulate illness perceptions, which can in turn guide coping (see Section 1.6). The theory explains the cognitive and emotional perceptions of illness that may determine support seeking and adjustment to illness. Self-regulatory theory may further explain how some men can redefine their sense of masculinity, despite the long-term impacts of prostate cancer, to allow a non-threatening adjustment to the illness. In the current study, the Self Regulation Model was used to identify which selected illness cognitions distinguished men joining prostate cancer support groups and those who do not.

Despite Leventhal et al. (1980) describing both the cognitive and emotional processes in self-regulatory theory, to date, there has been little research that has utilised the emotional component of Leventhal’s theory. This study therefore seeks to
examine the emotional as well as cognitive processes that influence help seeking and adjustment to illness in men with prostate cancer.

**3.2.2 Illness Perceptions**

Seeking support was seen to be influenced by a desire to learn more about the illness, to share concerns, and to compare physical and emotional progress with others (see Section 2.3.1). Seeking help was also seen to be influenced by how one perceives their illness experience (Moss-Morris et al., 2002; Weinman et al., 1996). Illness perceptions serve as a conceptual framework for making sense of information from health care professionals and for evaluating the appropriateness of recommended advice. Illness perceptions are influenced by past illness experiences and by one’s social and cultural milieu (Leventhal et al., 1984). Patient’s initial perceptions of their illness were seen to be important determinants of recovery from illness (Petrie et al., 1996).

How one perceives their illness has been observed to influence returning to work, sexual function, and attendance at rehabilitation centres (Petrie et al., 1996) and was observed to influence psychological well being (see Section 1.6). Strong illness beliefs that the disease had serious consequences and caused by stress were seen to be related to psychological impairment (Moss-Morris et al., 1996). That illness perceptions influence coping and psychological adjustment is clearly evident in the research. However Moss-Morris et al. (2002) have suggested new factors in illness perception research which have been little explored, in particular in cancer research. Emotional perceptions of the illness, personal control, and illness coherence are illness perceptions that are suggested to influence an individual’s model of health (Moss-Morris et al., 2002). However, to date, no research has shown the influence of these perceptions on support seeking and in particular for men with prostate cancer.
It was observed how one emotionally perceives their illness influences support seeking with strong emotional responses to the illness prompting support (Moss-Morris, 2002). The inhibition of emotions has been associated with sexual impotence and a lessened quality of life in cancer populations (Cameron, 2000; Reiker et al., 1985) and avoidance of or lack of emotional support is linked to psychological distress and health complaints in men with prostate cancer (Helgeson & Lepore, 1998; Pennebaker, 1998). Therefore, exploring how men emotionally perceive their illness would increase an understanding of the influence of emotions on seeking support and attendance at prostate cancer support groups. Further, as illness perceptions are socially and culturally derived (Leventhal et al., 1984) observing the emotional perceptions of illness held by men with prostate cancer would enable an exploration of the influence of emotions in Australian masculine culture on illness perceptions. That is, Australian male culture may discourage emotional disclosure which may in turn influence the reporting of emotional responses to the threat or seeking support.

Previous research has suggested that a person’s perception of control is a significant factor in coping with an illness (Cohen & Edwards, 1989). Behavioural actions such as information seeking by patients have been interpreted as indicators of attempted mastery over the illness (cited in Fowlers, 1994). However, personal control may also negatively influence help seeking in that for men, the seeking of support may suggest vulnerability, weakness, and lack of control (Sabo & Gordon, 1994; Tudiver & Talbot, 1999). Given the uncertainty of the influence of personal control on support seeking for men, further exploration of the concept is needed. By observing the impact personal control has on help seeking, suggestions of masculine cultural influences, which uphold control, may be explored. The previous measure of cure/control by Weinman et al. (1996) was found to load onto two separate factors.
Firstly personal control and self-efficacy beliefs and second, treatment beliefs. Therefore two new measures were identified. The new measure of personal control was seen to provide a more pure measure of the perception of personal control over the illness. This measure of personal control was seen to require further exploration as it had not previously been tested in a population of men with prostate cancer.

Previous research suggests that many men with prostate cancer seek a greater understanding of their illness and treatment (Crawford, 1998). However, no research has examined men’s understanding or comprehension of their disease and the association with help seeking. Moss-Morris et al. (2002) describe illness coherence as a measure of understanding one’s illness and likens it to a meta-analysis of how one’s illness perceptions give a person a sound or accurate comprehension of the disease. Whether a greater comprehension of the disease influences support and information seeking is not known. Thus, the illness perception of coherence requires further exploration, in particular in light of the lack of awareness and information of prostate cancer reported by men with the disease (see Sections 1.3 and 1.4.1).

Strong identity with the illness is derived from the presence of symptoms and has been suggested to influence both psychological and sexual ability in a number of diseases (Moss-Morris et al., 1996; Petrie et al., 1996). How men identify their illness is also influenced by the stigmatising and embarrassing aspects of disease and treatments (Davison et al., 2000). Understanding how men identify with their illness through the reporting of concrete symptoms would offer a greater insight into the influence disease labelling and symptomatology has on participation in cancer support groups for men with prostate cancer.

Previous studies observing the influence of illness perceptions on illness recovery have not examined a male only population and therefore do not observe the
distinct experiences of men with prostate cancer. Thus further exploration of the influence of illness perceptions on men with prostate cancer in seeking support and information was seen to be needed in order to add to the current illness perception research and prostate cancer support group research. Exploring the influences on participation may lend an understanding of the cognitive and emotional representations men hold of their illness, how they influence support seeking, and whether those perceptions become barriers to attending groups.

3.2.3 Prostate Cancer Support Groups

There has been almost unanimous agreement that support groups can and do benefit members (see Section 2.4). However much of the previous cancer support literature has been conducted on mixed cancer groups. Heterogeneous samples in cancer support group research do not attest to the individual experiences and needs of people with different cancer types. That is, the distress faced by many cancer patients may be specific to their cancer and treatment course. Further as cancer support groups are attended predominantly by women, existing cancer support group research may be biased toward women’s responses to the health threat (Section 2.3.1). Much of the previous research on cancer support groups does not cater for the unique needs of men with prostate cancer and cannot therefore be generalised to men’s cancer related support needs.

Previous evaluations of prostate cancer support groups suggests that men benefit from their group experience (Coreil & Behal, 1999; Gregorie et al., 1997; Gray et al., 1997) in particular in sharing with others and informational support. However the lack of evidence for the experiences of Australian men with prostate cancer would suggest review. Further many of the international studies have been performed on structured, fixed term, professionally led groups, the organization of
which lends itself to pre and post testing, however self-help groups are less structured and research in self-help prostate cancer groups remains limited.

Previous evaluations have observed the effectiveness of support groups by assessing satisfaction with the objectives of the groups (Deans et al., 1998) while others have observed the costs and benefits of the groups as reported by the members (Dobson, 1992). Objective based evaluations were seen to offer a means by which to examine the effectiveness of the groups by the members (Deans et al., 1998). As cancer support groups in Victoria are run with specific guidelines that pertain to the supportive care needs of people with cancer, these were seen as a way to assess the effectiveness of the groups, similar to the objectives based evaluation by Deans et al. (1998). Further examining the costs and benefits of prostate cancer support groups allows an examination of men’s actual perceptions of the groups. Both methods were seen to provide an extensive assessment of prostate cancer support groups.

Much of the previous support group research has not examined factors that differentiate between members and non-members of prostate cancer support groups and therefore do not seek to address why many men do not join the groups. The relatively few studies that exist on self-help prostate cancer support groups include surveys and pre and post program evaluations. Only two previous studies on prostate cancer support groups have compared the differences between support group members and non-members of prostate cancer support groups. The studies reporting differences between members and non-members are to date inconclusive and show no significant differences between members and non-members of support groups regarding quality of life (Poole et al., 2001; McGovern et al., 2002), coping, or satisfaction with three types of support, emotional, informational, and practical (Poole et al., 2001). The reporting of illness perceptions might offer a more logical measure
by which to observe how men construct meanings of their illness and whether those constructions differ between the groups.

Given the lack of research comparing members and non-members of prostate cancer support groups and the inconclusive findings of existing international studies, further research was seen to be needed. Investigating the illness perceptions of men with prostate cancer might provide a more meaningful examination of those differences. Exploring men’s attitudes to prostate cancer support groups and members’ satisfaction with the groups, would also lend valuable information on how the groups are perceived and how they are catering for the needs of men with prostate cancer.

3.3 Present Study

A survey of men who had and who had never attended prostate support groups was conducted. The men were all diagnosed with prostate cancer, those in prostate cancer support groups were recruited through the Cancer Council’s prostate cancer support group co-ordinator and those who were non-members were recruited from a large cancer hospital in Melbourne. Overall the study intended to provide an understanding of who joins prostate cancer support groups and why in an Australian sample of men with prostate cancer. This was achieved by using a series of qualitative and quantitative analyses to address two aims. The first aim was to compare men with prostate cancer who were members and non-members of prostate cancer support groups on a range of factors. These included, opinions of prostate cancer support groups, a number of illness perceptions, and also demographic and cancer variables. The second aim was to evaluate the support groups. This was achieved by determining the importance the prostate cancer support group members place on the objectives of the groups and how satisfied they are with the delivery of
these objectives. Thus the research questions were twofold. First, how do members of prostate cancer support groups differ from non-members and second do support groups meet the needs of the members?

3.3.1 Comparison of Members and Non-Members of Prostate Cancer Support Groups

No previous Australian research has examined the differences between members’ and non-members’ perceptions of prostate cancer support groups. Thus, a series of comparisons between members (all references to members include both current and past members), and non-members explored the differences between opinions of prostate cancer support groups, cognitive and emotional illness perceptions and a range of demographic and cancer variables.

A number of qualitative questions addressed the opinions men with prostate cancer held of prostate cancer support groups. The questions included men’s perceptions of the best aspects of the groups, perceptions of the worst aspects of prostate cancer support groups, and whether there were any situations that may prevent men from attending. The group members were asked to comment on their actual experiences with support groups and non-members were asked to comment on their perceptions of prostate cancer support groups. Both members and non-members were also asked to comment whether they perceived prostate cancer support groups as a positive or negative experience for men with prostate cancer. Further, members and non-members of prostate cancer support groups were asked to mention where they had heard about support groups, if at all, so as to ascertain the actual referral sources for men with prostate cancer and which sources were the most and least effective in informing men about prostate cancer support groups. The questions were designed to elicit the views of men with prostate cancer about the groups, to identify factors that might encourage men with prostate cancer to join prostate cancer support groups, and
those that are deterrents to joining. It was expected that members’ views of prostate cancer support groups would differ from the men who had never attended the groups on a range of questions pertaining to support group attendance.

To determine the illness perceptions that distinguished members and non-members, scores on personal control, identification with the illness, illness coherence and, emotional representations of the illness were obtained. Differences between members and non-members on their perceptions of illness would indicate health perceptions that influence attendance at groups and help to identify men who might benefit from groups but who otherwise do not join. Other illness perceptions described by Moss-Morris et al. (2002) include timeline (acute/chronic and cyclical), causes, consequences, and treatment control. These illness perceptions were not used in this study.

It was hypothesised that the men attending support groups would differ from men never attending a support group in illness identity, illness coherence, emotional representations, and personal control. It was expected that men attend prostate cancer support groups to increase their comprehension of the disease and treatments, to be assisted with emotional support, and to increase their sense of control over the disease through sharing information and support with like diagnosed others.

Previous research suggests that the correlates of joining a support group include, marital status, age, and education with participants tending to be married, young and well educated. To determine the differences between members and non-members in an Australian study on a range of demographic factors, men were asked to record information regarding their age, marital status, and education along with other cancer related variables including the number of years since diagnosis with the disease, the type of treatment received and the stage of the cancer. It was expected
that men in prostate cancer support groups would differ from non-members on their
demographic characteristics in line with support group research, which suggests
members tend to be younger, married, and well educated.

3.3.2 Support Group Members: Evaluation of Prostate Cancer Support Groups

This study examined the satisfaction of members with their support group
experience. The support group guidelines as set down by the Cancer Council (see
Section 2.3.4) provided a framework with which to evaluate whether the groups were
meeting the specific needs of men with prostate cancer. Observing men’s satisfaction
with each objective would provide evidence for the effectiveness of the groups in
meeting the needs of the members. Further, observing whether some objectives are
more satisfied than others would indicate areas that may require improvement in the
groups.

Evaluating Australian prostate cancer support groups serves several purposes;
it establishes whether the groups are catering for the unmet or partially met needs of
men with prostate cancer, it can help inform the groups of their current performance,
and can inform the public by acknowledging the support group experiences of men
with prostate cancer. Further it can inform medical professionals who might
otherwise not be aware of the existence of groups, of how men are particularly
benefiting from the experience.

As there had been no previous evaluation on prostate cancer support groups in
Victoria, it was seen to be important to report how men with prostate cancer in
prostate cancer support groups regarded their group experience. It was expected that
men’s cancer needs would be met by attendance at prostate cancer support groups as
assessed by the ratings on a range of support group objectives.
3.4 Summary

The present study was designed to examine the experiences of Australian men living with prostate cancer. Using a combination of qualitative and quantitative methodologies, the illness perceptions and symptoms, perceptions of support groups and demographic and disease characteristics were examined in men who belonged to support groups and those who did not. The perceived best and worst aspects of prostate cancer support groups and barriers to support group membership were explored and factors that distinguished between support group members and non-members were identified.

An evaluation of the prostate cancer support groups by the members of the groups was conducted to examine the effectiveness of the groups in meeting the support needs of the members. Men’s satisfaction with the groups was examined and objectives not being met by the support groups identified.
Chapter 4

Method

4.0 Overview of Chapter

A survey of men diagnosed with prostate cancer was conducted. All men who were invited to participate were selected on the basis that they had received a positive diagnosis of prostate cancer from their medical practitioner. Section 4.1 shows the characteristics of the study sample. Section 4.2 reveals the procedure followed in conducting the study and Section 4.3 reveals the measures used in the study including illness perceptions in Section 4.3.1 and the assessment tool for the evaluation of the support group members in Section 4.3.2.

4.1 Sample Characteristics

Two groups of men participated in the study. They included, 1) men with prostate cancer who were currently or had previously attended prostate cancer support groups affiliated with the CCV and 2) men who attended the Peter MacCallum Cancer Institute outpatients urology radiation clinic during the months of September and December 2001, who presented with a diagnosis of prostate cancer and had never attended a prostate cancer support group.

Two hundred and fifty five questionnaires were distributed to current and past support group members. The groups included nine current CCV affiliated support groups and past members of some of the groups. One other group which had recently ceased to operate was also included, making 10 groups in total. Of the 255 questionnaires distributed to past and present prostate cancer support group members, 107 were completed and returned, giving a response rate of 42%. Eighty-two respondents described themselves as current members, 16 as past members, 5 were facilitators of groups and 3 did not specify their membership status. Due to the low
numbers of past members both current and past members were combined and referred to as members. Of the respondents, 77% were current support group members while 23% described themselves as past members.

One hundred questionnaires were distributed at the Peter MacCallum Cancer Institute, of which 81 were returned, giving an 81% response rate. Men recruited from the Peter MacCallum Cancer Institute Outpatients Urology Clinic were selected on the basis that they had never attended a prostate cancer support group.

In total, 188 men with prostate cancer participated in the study, 81 men who had never attended support groups and 107 men who were currently or had previously attended prostate cancer support groups. Ninety-four percent of the total respondents, both support group members and non-members, reported that English was their first language and 6% reported English as a second language. All respondents were able to speak and read English as a requirement of participation in the study. The age of the participants ranged between 48 and 84 years with a mean age of 68 years ($M = 68.40$ years, $SD = 6.67$).

Eighty-one percent of the total sample of men with prostate cancer described themselves as either married or in a committed relationship. Fifteen percent were divorced, widowed or separated, 4% described themselves as single and never married and 16% currently lived alone. The level of education of the respondents included 28% educated up to year 9, 11% had completed years 10 and 11, 20% had completed year 12, 16% had completed a TAFE certificate and 25% had completed tertiary or postgraduate qualifications.

Eighty three percent of the respondents were initially diagnosed with localised prostate cancer, 15% with advanced prostate cancer and 2% responded that they did not know. At the time of the study 47% had localised cancer, 18% advanced cancer,
7% recurrent cancer, 12% did not know and 16% described themselves as cured. Of the various treatments initially received for prostate cancer, 26% of the participants had received radiotherapy, 28% had been treated with a prostatectomy, 22% with hormone therapy, 16% had received a combination therapies and 4% received no treatment for prostate cancer. Sixty four percent of the respondents had been living with prostate cancer for less than four years, and 36% greater than four years (see Section 5.1, table 1).

4.2 Procedure

Questionnaires (Appendix A) were distributed at the Peter MacCallum Cancer Institute to men who were attending the outpatient urology department for prostate cancer treatment or review. The participants were approached firstly by their attending doctor for consent to participate in the study. Once they consented, the participants were approached by the researcher who provided an introductory letter about the study and an information sheet detailing the purpose of the study and the rights of participants volunteering in research at the Peter MacCallum Cancer Institute (Appendix A). The participants were given time to read the documentation detailing the voluntary nature of the study and the right to withdraw at any stage. This was also verbally explained by the researcher. Those wishing to continue in the study were given a consent form (Appendix A) to be signed and to be witnessed by their doctor and the researcher or another witness. They were also given the questionnaire and a reply paid envelope. A copy of the signed consent form was retained in the participant’s hospital medical file.

It was estimated that the questionnaires would take 10-15 minutes to complete. Printing was large, widely spaced and in bold print to facilitate reading in a predominantly older population. Participants were welcomed to fill out the
questionnaire whilst at the hospital or to return it in the reply paid envelope, at their convenience. For men with visual disturbances and who preferred to fill out the questionnaire at the hospital, relatives and/or the researcher provided assistance by reading out the items on the questionnaire and recording the responses.

Men attending support groups were accessed through the Cancer Council of Victoria. The CCV provided names of the facilitators of all the prostate cancer support groups in Victoria. At the time of the study there were nine prostate cancer support groups operating in Victoria. The groups were located at Cobram, Maroondah, Altona Meadows, East Coburg, the Mornington Peninsula, Shepparton, Bendigo, Rye, and Wimmera. A tenth group in Mildura had recently ceased operating however the ex-facilitator agreed to distribute questionnaires to the previous members. The support groups varied in membership size with numbers ranging from approximately 8 to 30 men with prostate cancer. The number of men attending the groups at any one time fluctuated depending on illness and time restrictions.

The facilitators of the support groups were contacted firstly by mail by way of an introductory letter (Appendix B). The letter included a statement detailing the endorsement of the coordinator of Prostate Cancer Support Groups from the CCV, the purpose of the research and the steps to be taken to provide the confidentiality of any information provided. The researcher’s contact name and phone number was provided, as was a contact number for the CCV, in the event that any questions pertaining to the study arose. The support group facilitators were then followed up by telephone to invite participation of their groups into the study.

All but one of the facilitators was successfully followed up by phone, leaving nine groups. Those contacted agreed to distribute questionnaires, information statements, and consent forms (Appendix B) to the current members of the group,
either by dissemination amongst those in attendance on the day of the next meeting or by post to those unable to attend on that day. Questionnaires, consent forms, introductory letters, and return envelopes were also distributed by the group facilitators to consenting past members of some of the support groups. These men had remained on the support group’s mailing lists.

Questionnaires for support group members were given to the men in the groups who had experienced a diagnosis of prostate cancer. Some groups consisted of men with prostate cancer only whilst others included friends, family members, or men who attended to acquire information regarding prostate cancer. Family, friends, and information seekers without prostate cancer were excluded from the study. Three of the nine groups invited the researcher to attend the meetings in order to introduce the study to the members. Information provided by the participants was completely confidential. No identifying information was requested on the questionnaires and identification of individuals was not possible. Once returned to the researcher, consent forms were separated and questionnaires coded. Returned questionnaires and consent forms were stored separately and kept in a secure location. Access was available only to the researcher.

4.3 Measures

4.3.1 Illness Perceptions

The Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996) is a measure for assessing cognitive representations of illness. The IPQ is a theoretically derived measure comprising scales that provide information about the five components that have been found to underlie the cognitive representations of illness. The scales include identity, cause, consequences, cure/control, and timeline. Weinman et al. found the IPQ to have good levels of both
internal consistency and test-retest reliability based on samples of patients with various illness groups (see Section 1.5).

The Illness Perception Questionnaire was revised to form the Illness Perception Questionnaire Revised (IPQ-R) (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002). The revised version was utilised in the current study. The revised version added four subscales including personal control, emotional representations, illness coherence, and cyclical timeline beliefs to the original IPQ. The original IPQ was shown to have low internal reliability on the cure/control scale, closer investigation revealing that there were two separate components to this scale, personal control and belief in treatment advise. The revised scale showed good internal reliability coefficients with Cronbach alpha’s between .80 and .90 (Moss-Morris et al., 2002).

For the purposes of the current study four of the nine subscales were used from the IPQ-R, these were illness identity, illness coherence, personal control, and emotional representations. These perceptions were seen to reflect notions of masculinity and support seeking and being new concepts in illness perception research, required testing in a male population. The authors reported Cronbach alpha’s for the subscales as .82, .87, .81 and .88 respectively (Moss-Morris et al., 2002).

Illness identity is concerned with patient’s ideas about the label of the illness and the symptoms the patient views as being part of the disease. The illness identity scale is comprised of symptom items that the patient is asked to rate for frequency of occurrence on a five-point scale ranging from 0 to 4 where 0 indicates never and 4 almost constantly, according to how often the symptom is experienced as a part of the patient’s illness. The identity scale is scored by summing the number of items
endorsed at occasionally or greater. For the purposes of this study the symptom checklist was tailored to prostate cancer and treatment related symptomatology and adapted to include the symptoms of the disease under study as suggested by Weinman et al. (1996). Examples of illness identity items include pain, sexual difficulties, and urinary symptoms.

The remaining items of the IPQ-R were rated on a five point Likert type scale, from 1-5, including strongly disagree, disagree, neither agree nor disagree, agree, strongly agree, where 1= strongly disagree and 5 = strongly agree. The illness coherence subscale is an indicator of how helpful an individual’s model of illness is to them. Illness coherence is a meta-cognition reflecting the way in which the patient evaluates the coherence or usefulness of his or her illness representation giving a measure of how much patients understand or comprehend their illness. This scale was seen to reflect the cultural and informational influences on support seeking. The illness coherence subscale consists of five items, scores range from five to twenty-five with higher scores indicating a coherent understanding of the illness. Of the five items, four were reverse scored. Examples of items from this scale are “The symptoms of my illness are puzzling to me” and “I have a clear understanding of my condition”. Three of the five items of the Illness Coherence subscale were used for the purposes of this study. Two items were removed as these items appeared to be repetitive and perhaps confusing to the respondents, therefore the minimum score of this scale was three and the maximum score was fifteen for the present study.

The personal control subscale is a measure of self-efficacy beliefs a person holds in relation to the illness, that is how much control an individual feels he or she has over the illness and their ability to recover from an illness. The personal control scale was seen to reflect concepts of mastery over the disease and support seeking.
The personal control subscale consists of six items, rated on a five-point scale. Scores range from six to thirty with higher scores indicating cognitive control of disease. Two of the six items are reverse scored. Examples of items from this scale are “Nothing I do will affect my illness” and “What I do can determine whether my cancer gets better or worse”.

The emotional representations subscale measures affective responses found to be sensitive to differences in illness perception and to predict health-related responses such as seeking medical care. The emotional representations subscale consists of six items, rated on a five-point item scale. Scores on this scale range from six to thirty, with high scores representing strong emotional representations, that is strong negative responses to the illness. Of the six items of the emotional representations scale, one was reverse scored. Examples of the emotional representations scale include “My illness makes me feel angry” and “My illness makes me feel afraid”.

Cronbach alpha’s for the current study were, for three subscales combined, .62 and for the subscales separately, illness identity .72, illness coherence .76, personal control .80 and emotional representations .87.

It was originally proposed that all IPQ subscales be utilised for the purpose of the research, however unfortunately a number of restrictions prevented this. First, questions were deleted due to ethics committees’ requests. Committees had differing requirements and restrictions. Each committee objected to a different set of IPQ questions, so each of these sets of questions was omitted. Second, to keep in line with other cancer support group research conducted in Victoria at the same time. As some sets of questions were more applicable to certain types of illnesses or newly diagnosed illnesses with clearer timelines, sets of IPQ questions were chosen that could be applicable across various cancer support groups. Finally as only a short time
was available for questionnaire administration during outpatient visits, some IPQ questions were omitted for the sake of brevity.

4.3.2 Support Group Assessment

As well as the illness perception items, questions pertaining to support groups and demographic information was obtained from both members and non-members. A previous evaluation of all support groups known to the CCV was conducted in 1991 (Dobson, 1992). Based on that author’s evaluation, open-ended questions, designed to provide qualitative information on the best and least important aspects of prostate cancer support groups were included. The open-ended nature of the questions lends opportunity for elaboration of men’s experiences of the group and to allow comparison with the results from the same open-ended questions used in Dobson’s (1992) evaluation. Other questions requesting demographic information about the age, education, and marital status of the participants were included as well as cancer factors including how long had the participant been diagnosed with prostate cancer, the stage of the cancer and treatments received to determine differences between the groups on those items.

As prostate cancer support group awareness and referral were seen to be lacking in Australia, a question asking how men became aware of support groups was also included. This would identify the sources by which men hear about prostate cancer support groups and identify areas that fail to address support group referral. Other questions included barriers men experienced or perceived in attending support groups and whether prostate cancer support groups were perceived positively.

4.3.2.1 Support Group Members

Questionnaires sent to the support group members also included items regarding their support group membership. These included, the current status of the
support group member (whether a current or past member) and the length of time and frequency of attendance at groups. Members were also asked to comment on how prostate cancer support groups could be improved and whether the respondents would recommend participation in groups to others.

4.3.2.1.1 Support Group Objectives

Questionnaires sent to the support group members also included a section designed for group members to rate the objectives of the support groups. This section was added to evaluate the effectiveness of support groups in meeting men’s needs and was based on a previous cancer support group evaluation in Scotland (Deans et al., 1988). The authors devised a list of 22 expectations of group participation and asked respondents the extent to which the expectations were true of their experience of group membership. The authors calculated mean differences between the level of expectation and level of satisfaction of each expectation across 14 cancer support groups, to obtain an understanding of whether member’s expectations of support groups had been met. The current study used a modified version of Deans et al. (1988) expectations scale using a list of 12 objectives of support groups a number of which are outlined in CCV’s support group guidelines. Examples of the objectives include, ‘to avoid a sense of isolation and gain a sense of belonging’, ‘to learn how to cope better with cancer’, ‘to talk to others with similar experiences’ and ‘to feel free to talk with friends and family’.

Men in support groups were asked to rate the importance of each of the 12 listed objectives and were also asked to rate their satisfaction of each objective as met by group performance. For example, men rated how important “being able to express feelings in the group” was to them and then rated their level of satisfaction of being able to express feelings, as a result of support group participation. This section
therefore required two ratings for each question, an important rating and a satisfaction rating. Items were scored on a Likert type scale from 1 to 4 where 1 = not at all and 4 = very much. Scores ranged from 12 to 48, high scores suggesting high importance to the respondents of each objective and high levels of satisfaction of the delivery of each objective. Differences between the importance of each objective and the satisfaction of the provision of that objective within the group were calculated to evaluate whether support groups were meeting men’s cancer related needs. That is whether the importance men placed on each objective was being satisfied by group attendance.
Chapter 5

Results

5.0 Data Analysis

Data were analysed using the SPSS, version 11.0 program for Windows. The study used a non-experimental design incorporating both quantitative and qualitative analyses. The strategy for data analysis was, firstly, a comparison of differences between the two groups, prostate cancer support group members and non-members, on all demographic variables. Chi square analysis and t-tests were used to test the comparability of the two groups being analysed. Second, qualitative analyses were performed on the responses of members and non-members to examine the perceived best and worst aspects of group attendance, the barriers to attending support groups and where men were hearing about prostate cancer support groups. These were analysed using content analyses and are reported as percentage frequencies of the themes. Third, a Discriminant Function Analysis was used to identify the independent variables which best distinguished support group members from men who had never attended a support group.

A final analysis was performed on the support group members only, to examine their perceptions of the importance of support group objectives and the extent to which support group objectives were being met by the groups using paired-sample t-tests.

Comparability of the groups is revealed in Section 5.1. Section 5.2 shows the results of the qualitative analysis of non-members of prostate cancer support groups and Section 5.2.2 the results of the qualitative analysis of the members of prostate cancer support groups. Section 5.3 shows the results of the quantitative analysis and
includes the Discriminant Function Analysis in Section 5.3.1 and the evaluation of the support group members in Section 5.3.2.

5.1 Comparability of Groups

The comparability of men who were support group members and those who had never attended groups was assessed with Chi Square analysis and t-tests. The analyses were performed on cancer related and demographic variables, comparing mean differences between the groups. Table 1 shows the means and frequencies of the demographic variables and cancer related variables for both groups.

Table 1. Chi Square and t-Test Analyses of Demographic and Cancer Factors.

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Support Group</th>
<th>No Support Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>67.64</td>
<td>69.45</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married or partnered</td>
<td>92</td>
<td>59</td>
</tr>
<tr>
<td>Divorced, separated, widowed</td>
<td>13</td>
<td>16</td>
</tr>
<tr>
<td>Single, Never Married</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Junior Secondary</td>
<td>16</td>
<td>17</td>
</tr>
<tr>
<td>Years 10-11</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Year 12</td>
<td>26</td>
<td>11</td>
</tr>
<tr>
<td>Tafe</td>
<td>16</td>
<td>14</td>
</tr>
<tr>
<td>Tertiary</td>
<td>20</td>
<td>14</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>*Household</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives Alone</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>Wife/Partner</td>
<td>71</td>
<td>51</td>
</tr>
<tr>
<td>Wife and Family</td>
<td>19</td>
<td>5</td>
</tr>
<tr>
<td>Other Family</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>Friends</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Cancer Factors</td>
<td></td>
<td></td>
</tr>
<tr>
<td>*Stage of Cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t Know</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>Localised</td>
<td>42</td>
<td>44</td>
</tr>
<tr>
<td>Advanced</td>
<td>18</td>
<td>14</td>
</tr>
<tr>
<td>Recurrent</td>
<td>12</td>
<td>0</td>
</tr>
<tr>
<td>Eradicated</td>
<td>17</td>
<td>0</td>
</tr>
<tr>
<td>#Years since diagnosed</td>
<td>4.24</td>
<td>3.41</td>
</tr>
<tr>
<td>How long receiving treatment</td>
<td>8.66</td>
<td>6.38</td>
</tr>
</tbody>
</table>

*Chi Square p = < .05; # t-Test p = < .05
Results revealed a significant association between group and living arrangements, with support group members more likely to be living with a wife or partner or wife and family than men who had never attended support groups ($\chi^2(4) = 12.66, p = <.05$). There was also a non-significant trend for men in support groups to more likely be married ($\chi^2(2) = 5.01, p = <.082$). Support group members were also more likely to have been living with a diagnosis of prostate cancer longer than men who had never attended a support group ($t(170) = 3.20, p = <.05$) and to report recurrent illness or eradicated illness ($\chi^2(4) = 11.59, p = <.05$). There were no significant differences between the two groups on age, education, or length of treatment, however there was a non significant trend for age with support group members younger than non-members ($t(185) = 1.86, p = .06$).

5.2 Qualitative Analyses

Men who were or had been support group members and men who had not been in a support group were asked to record the perceived best and worst aspects of support groups, how groups could be improved (support group members only), the barriers to attending support groups, where men heard about prostate cancer support groups and what would encourage joining a support group (non-members only). In responding to questions relating to the best and worst aspects of support group participation, the support group members recorded actual experiences whilst the men never in a support group were asked to describe what they perceived as being the best and worst aspects of support group membership. Both groups were also asked whether support groups were seen as having a positive or negative meaning to the men. Men’s responses to the questions were examined to identify themes through content analysis and responses were coded according to the themes identified. Frequencies were calculated to identify the most commonly mentioned themes. The
responses of men who had never been in a support group are reported first in section 5.2.1 followed by the responses of men who were or had been members of prostate cancer support groups in section 5.2.2.

5.2.1 Qualitative Analyses for Non-Members

5.2.1.1 Perceived Worst Aspects of Support Groups for Non-Members

Men who had never attended prostate cancer support groups were asked to record the worst aspects they perceived of prostate cancer support groups. The aspects identified from the responses were, people dying or unable to be cured, negative discussions within the group, hearing other men’s stories and lack of privacy. The men were given the opportunity to answer with several responses to this question, however only one man reported more than one cost. Most men answered with single word responses, therefore few statements were given. Those that were have been included under each theme reported below. Percentages are recorded as the frequency that each theme was documented. Table 2 shows the worst and best aspects mentioned by non-members, expressed in percentages.

Of the non-members of prostate cancer support groups who responded to the question, no bad aspects of attending a support group was reported in 32% of responses. The most frequently mentioned cost was other men dying or not cured which was reported by 23% of the respondents, with men who had never attended prostate cancer support groups noting that being with men who were not able to be cured and who were suffering from their illness would be a cost of attendance which some members found distressing. This was highlighted in the following quotes.

“Being with people who are highly depressed by their illness”

“Seeing people go”

“Seeing people go, their distress”
“Too many people that are in a bad way”

“Being reminded of the worst possibilities”

Negative discussions in the group was reported as a cost with 10% of the non-members of support groups reporting a cost of group membership was, being burdened by negative discussions. The participants did not elaborate upon what constituted negative discussions. Examples of responses referring to negative discussions in support groups included:

“people with negative attitudes”

“listening to a dreary litany of men enjoying bad health and discussing it out of proportion to the rest of their lives”

A further cost mentioned by 10% of the non-members included hearing other men’s stories. Ten percent of the non-members perceived they would not like to listen to other men’s experiences with prostate cancer as suggested by the following quotes.

“The depressing aspects of dwelling on one’s own illness”

“I don’t like listening to other peoples problems”

“Talking about disease all the time”

“I am a lone and do not like to talk about my problems”

Lack of privacy was reported as a perceived cost to support group attendance by non-members with 10% of the respondents noting that being with strangers and exposing one’s feelings and thoughts in a support group forum was a perceived cost of attendance. As one participant noted being in a support group would feel like an “invasion of privacy”.

A final group representing 15% of the responses included various other perceived costs to support attendance such as:

“if the support group was not organised properly”
“it’s just not for me”

“Never knew they existed”

Other men in this group reported fear of discussing problems with sexual function and incontinence issues. Another man was concerned about “not being accepted in a group” and one felt that most group members would be “old men”.

Table 2. Perceived Best and Worst Aspects of Support Groups for Non-Members of Prostate Cancer Support Groups.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Non-Members % Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Worst Aspects</strong></td>
<td></td>
</tr>
<tr>
<td>No bad aspects</td>
<td>32</td>
</tr>
<tr>
<td>Other men dying or not cured</td>
<td>23</td>
</tr>
<tr>
<td>Negative discussions in the group</td>
<td>10</td>
</tr>
<tr>
<td>Hearing other men’s stories</td>
<td>10</td>
</tr>
<tr>
<td>Lack of privacy and strangers</td>
<td>10</td>
</tr>
<tr>
<td>Travel and Meeting Times</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
</tr>
<tr>
<td><strong>Best Aspects</strong></td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td>48</td>
</tr>
<tr>
<td>Support</td>
<td>30</td>
</tr>
<tr>
<td>Sharing experiences with others</td>
<td>25</td>
</tr>
<tr>
<td>Supporting others</td>
<td>8</td>
</tr>
<tr>
<td>No benefit</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
</tr>
</tbody>
</table>

**Note.** Percentages may add to greater than 100% due to multiple themes mentioned by some participants

5.2.1.2 Perceived Best Aspects of Support Groups for Non-Members

Men who had never attended support groups were asked to report the perceived best aspects of support groups. The themes identified were no benefit, information, sharing with men with similar experiences, support and to support others. Men were given the opportunity to give multiple responses. Several men perceived more than one benefit of prostate cancer support groups however most men mentioned only one. Further, most responses were singularly worded, for example, “information” or “support”, however some men described the perceived benefits of
support groups in greater detail. Percentages were calculated for the frequency that each theme was recorded, therefore percentages tally to greater than 100% due to multiple responses by some participants. Table 2 above shows the perceived best and worst aspects of support groups for non-members of prostate cancer support groups.

Of the men who recorded an answer to the question, the most frequently mentioned benefit was information, which was recorded by 48% of the men who had never attended support groups. That is 48% of the non-members perceived that support groups provide access to information for men with prostate cancer. Examples of responses reflecting the perceived benefit of receiving information through support group participation were:

“To share information regarding treatments and [the] impact of various treatments available”

“Information and exchanging ideas”

“sharing knowledge about prostate cancer”

The second most frequently mentioned benefit was support, with support perceived by 30% of men who had never attended support groups and who answered the question, as a benefit of prostate cancer support groups. Responses reflecting the benefit of gaining support from support groups included:

“Talking with other men about their experiences”

“... a chat to someone you know who has had prostate cancer is very helpful”

“Friends who are having trouble with the above [prostate cancer] talk to one another in a positive way I guess”

The third most frequent response was being with others which was perceived as a benefit of prostate cancer support groups by 25% of the men who had never attended support groups. Non-members perceived that sharing with like diagnosed
others, their personal stories and information, was beneficial. Examples of the benefits of sharing with others include:

“It would provide a forum for me to share my experiences with others who have just been diagnosed”

“Being with people with common problems”

“Learn about other men’s experiences, associating with others and [knowing] I’m not the only one”

Supporting others was noted in 8% of the responses. Support groups were perceived as providing a forum by which men with prostate cancer could support and advocate for others. Some examples of responses reflecting the perceived benefit of supporting others included:

“Ability to reassure other men of what to expect, an educative function to support others”

“Being with other men with prostate cancer and being able to help in some way”

“support others with similar condition”

“Trying to encourage others to believe they can recover”

Eight percent of the respondents who had never attended a support group and who answered the question, reported specifically that they perceived no benefit by attendance at prostate cancer support groups.

5.2.1.3 Barriers to Support Group Attendance for Non-Members

Men who had considered joining a prostate cancer support group were asked to rate the barriers they perceived as restricting possible membership (see Table 3). To the question “If you have considered attending a support group, what has made attending difficult for you”, 35% of respondents stated they had never considered joining and 37% did not answer this question possibly suggesting that they also were not interested in support groups. Of the remaining responses, men who had
considered attending (28%), the most frequently mentioned barrier men perceived in attending prostate cancer support groups was distance, with 21% of men who had never attended support groups but who considered joining, noting that the distance to travel to the groups prevented them attending support groups. Seven percent of the responses were made up of other factors including the time of the meeting, perceived costs and not being well enough to attend. While many men had not considered joining a prostate cancer support group, 28% of the non-members had considered joining however experienced barriers preventing their attendance, in particular the amount of travel required getting to a group.

Table 3 shows percentages of perceived barriers to joining support groups and what would encourage men to join prostate cancer support groups for non-members.

Table 3. Frequency Percentages of Barriers to Joining Support Groups and What Would Encourage Joining For Non-Members.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Non-Members % Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barriers to Join</strong></td>
<td></td>
</tr>
<tr>
<td>Distance</td>
<td>21</td>
</tr>
<tr>
<td>Time of Meeting</td>
<td>5</td>
</tr>
<tr>
<td>Not well enough</td>
<td>1</td>
</tr>
<tr>
<td>Cost</td>
<td>1</td>
</tr>
<tr>
<td>Never Considered</td>
<td>35</td>
</tr>
<tr>
<td>No Response</td>
<td>37</td>
</tr>
<tr>
<td><strong>Encourage to Join</strong></td>
<td></td>
</tr>
<tr>
<td>Time and location of meetings</td>
<td>19</td>
</tr>
<tr>
<td>Assist others</td>
<td>14</td>
</tr>
<tr>
<td>No-one else to talk to</td>
<td>10</td>
</tr>
<tr>
<td>Relapse</td>
<td>7</td>
</tr>
<tr>
<td>Not Interested</td>
<td>20</td>
</tr>
<tr>
<td>No Response</td>
<td>30</td>
</tr>
</tbody>
</table>

5.2.1.4 Encouragement of Non-Members to Join Support Groups

Men who had never attended prostate cancer groups were asked what would encourage them to join (see Table 3.). Thirty percent of respondents did not answer this question and 20% reported that support groups were not for them.
Of the remaining 50% of the responses, the most frequently mentioned factor that would encourage joining a support group was time and location of meetings, with 19% of men who had never attended support groups noting that if the time of meetings was suitable and location of groups were proximate to their locale, they would consider joining. An example reflecting time and location factors was:

“Knowing where and when [the groups are on]”

“If I could find out more information about the groups [meetings]”

The second most frequent response was being able to assist others, with 14%, of the non-members noting that assisting others would be an important factor in encouraging them to join a prostate cancer support group. As one participant observed, he would be encouraged to join if he “…could help other people who were very concerned about having cancer”

The third most frequent response was if they had no one else to talk to, with 10% of the men noting that support would be an important factor if they otherwise were unable to obtain support elsewhere. Examples reflecting support were:

“If there was no other support available”

“If there was no satisfaction with medical staff”

The least cited response was relapse, with 7% of non-members recording that if they had a relapse they would be encouraged to join a support group. As one participant suggested, he would join “If my condition becomes worse”.

5.2.1.5 Support Group Awareness for Non-Members

Men who had never attended support groups were asked whether they had heard of prostate cancer support groups. Forty-one percent of men who had never attended a support group had heard of the support groups and 59% had never before heard of them. Of the men having heard before about prostate cancer support groups, the
sources of information about prostate cancer support groups were elicited. The most frequently mentioned source where men had received information on prostate cancer support groups was through hospital staff, with 29% mentioning that doctors, nurses and volunteer staff at hospitals provided them with information regarding prostate cancer support groups. The second most frequent response was through friends, with 24% of the men hearing about prostate cancer support groups through word of mouth. The third most mentioned source was brochures and newspapers with 21% of the men reporting they had read about the groups through advertising material, the greater proportion of this response mentioned newspapers. Only a few men mentioned brochures. The fourth most mentioned source was local doctors with 9% of the men reporting that their local doctors had informed them of prostate cancer support groups. Telephone support services accounted for 3% of the men having accessed information about the groups through cancer support lines including the Ian Gawler Foundation and the CCV cancer support line. The internet was not reported to be a source by which men had heard of the groups. Fifteen percent of the men who had heard of the groups did not record where they had heard of the groups. Table 4 shows the frequency percentages of whether non-members were aware of prostate cancer support groups. Table 5 shows the reported sources by which non-members were made aware of prostate cancer support groups.

Table 4. Frequency Percentages of Support Group Awareness.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Non-Members</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>% Frequency</td>
</tr>
<tr>
<td>Aware of Groups</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>41</td>
</tr>
<tr>
<td>No</td>
<td>59</td>
</tr>
</tbody>
</table>
Table 5. How Non-Members who have heard of Prostate Cancer Support Groups are Informed of the Groups

<table>
<thead>
<tr>
<th>Theme</th>
<th>Non-Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Friend</td>
<td>24</td>
</tr>
<tr>
<td>Brochure /Newspaper</td>
<td>20</td>
</tr>
<tr>
<td>Hospital Staff</td>
<td>29</td>
</tr>
<tr>
<td>Local Doctors</td>
<td>9</td>
</tr>
<tr>
<td>Internet</td>
<td>0</td>
</tr>
<tr>
<td>Telephone Support Service</td>
<td>3</td>
</tr>
<tr>
<td>No Response</td>
<td>15</td>
</tr>
</tbody>
</table>

*Percentages calculated on men who had heard of support groups

5.2.1.6 Positive and Negative Ratings of Support Groups for Non-Members

Men who had never attended a prostate cancer support group were asked whether they perceived support groups as being a positive or negative concept for men with prostate cancer. Of the respondents 65% rated support groups as having a positive meaning to them, 26% as negative and 8% as neither positive nor negative. Table 6 shows the percentage ratings whether men perceive support groups as being positive or negative for non-members of support groups.

Table 6. Frequency Responses of Whether Non-Members Perceive Support Groups as Positive or Negative for men with Prostate Cancer.

<table>
<thead>
<tr>
<th>Rating</th>
<th>Non-Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
<td>65</td>
</tr>
<tr>
<td>Negative</td>
<td>26</td>
</tr>
<tr>
<td>Neither</td>
<td>8</td>
</tr>
<tr>
<td>No/Omitted Response</td>
<td>1</td>
</tr>
</tbody>
</table>

5.2.2 Qualitative Analyses of Support Group Members

Similar to non-members, support group members were asked to rate the worst and best aspects of support group participation, whether they faced any barriers in
attending the groups, how they were informed of the groups and whether support
groups provided a positive or negative meaning to them. Additionally members were
asked if they would recommend prostate cancer support groups to other men with
prostate cancer and how the current groups might be improved.

5.2.2.1 Worst Aspects of Support Group Membership for Past and Current
Members

A content analysis was performed to identify the main themes reflecting the
worst aspects of being in prostate cancer support groups for group members. Six
main themes were identified. The themes included no bad aspects, hearing other
men’s difficulties with prostate cancer, meeting times and distance, men who die or
cannot be cured, being with people you don’t know (including lack of privacy) and
negative talk (perceived negativity of some members). Most men reported a single
cost to attending, however some men recorded more than one cost. The results are
recorded as percentages of each reported theme. As some men gave more than one
response the percentages tally to greater than 100%. Table 7 shows the perceived
costs and benefits of support groups for members of prostate cancer support groups.
Twenty percent of respondents did not answer the question, which was taken to
indicate no costs perceived in prostate cancer support group participation. Of the men
recording a response, fifty five percent reported no costs, noting they did not
experience any cost with participation in a support group. Twenty five percent of the
members reported a number of costs to participation. The most frequently mentioned
cost was knowing some men were unable to be cured, with 16% of men who had
attended support groups noting that men who were unable to be cured and who were
dying was an emotional cost of support group participation. Some quotes
representing this theme are detailed below.
“Notice[able] distress of people who are in early state of shock and seeking answers”

“Loss of members through death”

“Hearing of worsening conditions or deaths”

“the sad stories about men not having been cured, men dying”

The second most frequently mentioned cost was negative talk, with 13% of the men noting that support groups generated discussion that was deemed negative.

“negative attitudes of some attending. Some people expect to receive something great but if you receive one small piece of information or encouragement it is well worth your visit”

“Depressing some personalities who claim to know all about treatment, people who like the sound of their own voices”

The third frequent response was hearing other men’s cancer stories, with 10% of the men noting that other men’s discussion about their cancer was difficult for them to hear. This theme is highlighted by the following quotes.

“People not coping, obsession with loss of sexual ability”

“Listening to others how prostate cancer has affected their lives”

Five percent of the men who answered the question recorded that being with people they did not know and lack of privacy was difficult for them when participating in support groups and three percent of the men observed that meeting times and distance to the groups was difficult. Two percent of the men saw women in the group as a cost to support group participation. This was suggested in the following quote.

“at first embarrassment when I met with some fellow workers and old friends, a second embarrassment when women were in the group”
Table 7. Perceived Best and Worst Aspects of Support Groups for Members of Prostate Cancer Support Groups.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Members Current/Past % Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Worst Aspects</strong></td>
<td></td>
</tr>
<tr>
<td>No bad aspects</td>
<td>55</td>
</tr>
<tr>
<td>Other men dying or not cured</td>
<td>16</td>
</tr>
<tr>
<td>Negative discussions in the group</td>
<td>13</td>
</tr>
<tr>
<td>Hearing other men’s stories</td>
<td>10</td>
</tr>
<tr>
<td>Lack of privacy and strangers</td>
<td>5</td>
</tr>
<tr>
<td>Travel and Meeting Times</td>
<td>3</td>
</tr>
<tr>
<td><strong>Best Aspects</strong></td>
<td></td>
</tr>
<tr>
<td>Information</td>
<td>80</td>
</tr>
<tr>
<td>Sharing experiences with others</td>
<td>46</td>
</tr>
<tr>
<td>Support</td>
<td>41</td>
</tr>
<tr>
<td>Supporting others</td>
<td>17</td>
</tr>
<tr>
<td>Friendship</td>
<td>17</td>
</tr>
</tbody>
</table>

**Note:** Percentages may add to greater than 100% due to multiple themes mentioned by some participants.

5.2.2.2 Best Aspects of Support Groups for Past and Current Members

A content analysis was conducted in order to identify the main themes of qualitative responses recorded by support group members. Four main recurrent themes were noted, the themes reflected the benefits of being in a prostate cancer support group by group members. The themes were, information provided by group members and guest speakers on treatment and coping, sharing experiences with other like diagnosed men, the support provided by group membership and supporting others with a similar disease. This question was answered enthusiastically with all men except one recording a response and with most men reporting a number of benefits. The results reflect the frequency of each reported benefit, therefore as multiple responses were given, the results tally to greater than 100%. Table 7 above shows percentage frequencies of the costs and benefits of support group membership for members of support groups. The following results and quotations reflect the
responses to the question “what are/have been the best things about being in the support group”.

The most frequently mentioned benefit was information, with 80% of the men in support groups noting that being provided with information was an important benefit of attending support groups. Gaining information about cancer and current treatment was the most important benefit of attending support groups for members. Some examples of the perceived benefits of being in a support group, representative of the group responses, are highlighted below.

“Once I reached 60 years old I wanted to be familiar with prostate problems. I joined the group as an outside visitor but in May 2001 I found that my prostate was enlarged and needed a trans urethral resection prostatectomy. The information I received from the group was enough for me to make a good, sound decision without fear or prejudice”

“Exchange experiences with other prostate sufferers, gather information about coping with [the] disease [and] obtaining literature and advice on how to handle and cope with disease”.

“Information of side effects. Six years ago there was little information anywhere and reluctance by all doctors to tell [any] one. They, mostly, still don’t know how to impart the knowledge”.

“Information for myself, my wife and my friends on treatments and how to communicate with others”

“Information from visiting speakers and socialising with others with similar problems”

The second most frequent response was sharing experiences with other like diagnosed members, with 46% of the men noting that being with others in a support group was a benefit of participation. Support groups were seen as a forum whereby men could share experiences and support of like diagnosed others. This was expressed most explicitly by one participant.

“When diagnosed something was wrong I wanted the answers. Eventually after taking tablets for urinary infection my PSA readings still increased. A biopsy result proved I [had] cancer in the prostate, 3-6 samples proved positive. I was sent to a surgeon whom I was told would advise to operate,
which was his advice, the earlier to operate the earlier to contain it basically. That made sense and they could help me get back to normal after the operation. The ‘op.’ was successful and it was the after effects which affected me, the incontinence was horrible. The loss of libido made me feel less than a man. Now 4 years later I wish I could have met someone who had the op. This I’m sure would have helped, I probably would have done what I have done, but would have not felt so lonely. You have to understand you have to work at your incontinence and accept the quality of life you now have...

A number of other responses reflecting the supportive experiences of being with others included:

“The positive comments from the group and the acceptance of group members [and] being with others with the same problem”

“Positive attitudes plus humour, a common bond”

“Not on your own with prostate cancer”

“I was not alone with my problems. Somehow I was luckier than some”

The third benefit was support, with 41% of the men reporting the support that came with participating in a prostate cancer support group was beneficial to them. This was suggested by the following quotes:

“Being able to openly talk about your problem”

“Some people expected to receive something great, but if you can receive one small piece of information or encouragement it is well worth your visit”

“[joining a support group is the] Best thing I ever did”

“Our charter is to minimize the time it takes for one to come to terms, accept and go on in life [after prostate cancer]”

Friendship was mentioned in 17% of the responses and supporting others was raised as a benefit of prostate cancer support group participation by 17% of the members who noted being able to offer support and information to other members was an advantage they perceived of attendance. Responses representing friendship and supporting others are highlighted below:
“The purpose of raising awareness and encouraging testing (PSA) in the hope that early detection would save lives in our community – the best therapy possible”

“Hearing other men’s stories and offering support”

“Good fun laughter, helping others in a similar situation”

“Getting other people/s point of view, more information than what a doctor can give you and you can support each other and have a good laugh”

“The spirit of the other fellow traveller and being able to make contributions”

5.2.2.3 Barriers To Support Group Participation by Past and Current Members

Of the men who responded to the question, thirty-eight percent of men attending support groups noted that they experienced no barriers in attending prostate cancer support groups. The most frequently mentioned barrier for current and past group members was distance, with 26% of the men reporting that the distance involved in travelling to the meetings was a barrier to attending the groups. The second most mentioned barrier for members was time, with 14% of the men reporting that the time the meetings were held posed a barrier for group attendance. The third most mentioned barrier was illness, with 11% reporting that feeling unwell made attending support groups difficult. Table 8 shows the barriers current and past members of prostate cancer support groups experience in attending the groups.

Table 8. Frequency Percentages of Barriers to Joining Support Groups

<table>
<thead>
<tr>
<th>Theme</th>
<th>Members Current/Past % Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barriers to Join</td>
<td></td>
</tr>
<tr>
<td>No Barriers</td>
<td>45</td>
</tr>
<tr>
<td>Distance</td>
<td>26</td>
</tr>
<tr>
<td>Time of Meeting</td>
<td>14</td>
</tr>
<tr>
<td>Not well enough</td>
<td>11</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
</tr>
</tbody>
</table>
### 5.2.2.4 Support Group Awareness

Current and past members of prostate cancer support groups were asked where they had found out about the groups. The most frequently mentioned source was friends, with 32% of the men noting that their informal network of friends had informed them of support groups. The second most cited source was brochures and newspapers, with 23% of the men finding out about prostate groups through advertising, the majority of this response comprised newspapers with only a small number of men reporting brochures. The third most mentioned source of information about prostate groups was hospital staff (including doctor, nurse or social worker), with 14% of the men learning about the groups when visiting the hospital. Telephone support lines were noted by 14% of the men the source of informing them about prostate cancer support groups. Nine percent of the men reported hearing about support groups through their General Practitioners and the least most reported source of information regarding prostate groups was via the internet, with 2% of the men noting the internet provided them with information on prostate cancer support groups. Of the remaining other responses, three men had heard through health conferences, one through a radio program and four men had individually commenced groups of their own.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Members Current/Past % Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Informed</td>
<td></td>
</tr>
<tr>
<td>Friend</td>
<td>32</td>
</tr>
<tr>
<td>Brochure /Newspaper</td>
<td>23</td>
</tr>
<tr>
<td>Hospital Staff</td>
<td>14</td>
</tr>
<tr>
<td>Telephone Support Service</td>
<td>14</td>
</tr>
<tr>
<td>Local Doctors</td>
<td>9</td>
</tr>
<tr>
<td>Internet</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
</tr>
</tbody>
</table>
Table 9 shows the frequency percentages of the sources whereby men were informed about prostate cancer support groups for both non-members and members.

5.2.2.5 Positive/ Negative Ratings of Support Groups by Members

Support group members were asked whether they perceived attending a support group as being a positive or negative experience. Ninety-two percent responded that being a part of a support group was a positive experience, 3% a negative experience and 3% mentioned that support groups were neither positive nor negative. Table 10 shows the perceptions of both non-members and members of whether prostate cancer support groups are a negative or positive resource for men with prostate cancer. Members, like non-members, perceived prostate cancer support groups as a positive way to assist men with prostate cancer.

Table 10. Frequency Percentages of Whether Members Perceive Support Groups as Positive or Negative.

<table>
<thead>
<tr>
<th>Rating</th>
<th>Members % Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive</td>
<td>92</td>
</tr>
<tr>
<td>Negative</td>
<td>3</td>
</tr>
<tr>
<td>Neither</td>
<td>3</td>
</tr>
<tr>
<td>No/Omitted Response</td>
<td>2</td>
</tr>
</tbody>
</table>

5.2.2.6 Support Group Recommendation

Members were asked whether they would recommend support groups to others. Ninety four percent suggested ‘yes’ they would recommend support groups, 5% no and 1% no response. The large percentage of men recommending prostate cancer support groups to other men with prostate cancer reflects the perceived
benefits by members through support group attendance. Table 11 shows recommendation percentage responses for members and past members.

Table 11. Frequency Percentages of Current and Past Members of Prostate Cancer Support Groups Recommending Groups.

<table>
<thead>
<tr>
<th>Recommend</th>
<th>% Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>92</td>
</tr>
<tr>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Neither</td>
<td>2</td>
</tr>
<tr>
<td>No Response</td>
<td>1</td>
</tr>
</tbody>
</table>

5.2.2.7 Prostate Cancer Support Group Improvements

A content analysis was performed to identify the main themes reflecting improvements for prostate cancer support groups. From the men who suggested improvements a number of themes were generated. Many of the themes reflected frustration of lack of group recognition rather than problems directly within the group organisation. The themes that were identified included no improvement needed, advertising, government support, media recognition, and greater representation (by doctors and hospitals), more guest speakers, up to date literature, and more discussion time. Thirty seven percent of the respondents did not answer this question. This was taken to suggest no improvements were necessary to their current group operation, by those participants.

Of the people who answered the question, twenty two percent responded specifically that no improvement was required for their group. The most frequently mentioned improvement was recognition, with 37% of the men who answered the question noting that prostate cancer support groups required much more public
recognition, advertising and funding than they currently receive. The second most mentioned improvement was more groups and closer locations with 22% of the men reporting that more groups were needed to attract men to them. The third most cited improvement was support from doctors with 21% of the men expressing a need for greater input from doctors and specialists. Sixteen percent of respondents who responded to the question noted that more information and discussion time was important. Thirteen percent of the respondents noted other improvements such as more wives, less wives, more interaction with other groups, and improvements on the venues. Percentages are calculated on the frequency of themes mentioned, therefore as some men gave several responses the percentages tally to greater than 100%.

Table 12 shows the percentage frequencies of responses to suggestions for improvements for prostate cancer support groups by current/past members.

Table 12. Suggested Improvements for Prostate Cancer Support Groups by Current and Past Members.

<table>
<thead>
<tr>
<th>Improvement</th>
<th>Improvements Frequency %</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Improvement</td>
<td>22</td>
</tr>
<tr>
<td>Media Recognition, advertising and funding</td>
<td>37</td>
</tr>
<tr>
<td>More Groups</td>
<td>22</td>
</tr>
<tr>
<td>More Doctor/Specialist recognition</td>
<td>21</td>
</tr>
<tr>
<td>Information &amp; Speakers</td>
<td>16</td>
</tr>
<tr>
<td>Other</td>
<td>13</td>
</tr>
</tbody>
</table>

Note: Percentages may add to greater than 100% due to multiple theme reporting

Taken together, the greatest proportion of responses represented a lack of recognition of prostate cancer support groups including a lack of government funding and advertising and a greater recognition from the medical professions. Responses reflecting men’s suggestions for group improvement through greater recognition, are divided below into two sections, the first section includes recognition through media and advertising and the second, medical recognition.
1) Media and Advertising to Increase Public Recognition

“*To make it more aware to the public*”

“*Make men’s health more aware to the public which will probably encourage men to be checked more regularly*”

“*... more groups and community awareness [and] financial assistance*”

“*By making the public more aware that there are groups*”

“*Greater support from medicos and a solid media campaign*”

“*Leaflets in doctors waiting rooms and RSL clubs*”

“*More government support and funding*”

“*Lack of sufficient support from the community*”

“*A more effective approach to promotion of the benefits*”

2) Greater Support from General Practitioners, Urologists and Hospitals.

The following responses represent the need for greater recognition from medical staff for the support needs of men with Prostate cancer and for recognition of prostate cancer support groups.

“*It’s hard to get much literature from the doctor’s surgery. You go into a waiting room, it’s got plenty on women’s breast cancer but nothing on men’s health*”

“*There is a complete lack of referral by specialists or GP’s ...doctors will not accept that support groups can play an important role*."

“*Support from doctors rarely evident*."

“*By closer links with other hospitals and making groups better known in communities. By receiving more information on treatments through urological society and medical professionals*”
"Why don’t hospitals advise people/patients of groups”

"[make] G P's and urologists aware of support groups and how they can help”

"Invite GP’s to our support groups to understand what our meetings are about”

"I rang a hospital [name withheld] [I was] not offered any information, left to my own initiating”

"GP’s and urologists need to realise the importance [of groups] and refer newly diagnosed patients”

"Peer counselling to help a person to come to terms with their situations specialists fail in this area in my opinion”

"More input from health professionals”

5.3 Quantitative Analyses

A Discriminant Function Analysis was performed to predict group membership from a set of variables including demographic data and illness perceptions. A second analysis involved using the guidelines of support groups as set out by the CCV, as a means by which to evaluate the support group programs. The importance members placed on each objective and the level of satisfaction with each objective was measured. The differences between importance ratings and satisfaction ratings were calculated using paired samples t-test analyses to determine the objectives that were not being met by the groups and those that exceeded men’s expectations.

5.3.1 Discriminant Function Analysis of Groups

An analysis comparing members and non-members of support groups was designed to identify the characteristics which distinguished between men who had or had not attended a prostate cancer support group. A Discriminant Function Analysis (DFA) was performed using the variables of age, time since diagnosis, illness identity, illness coherence, emotional representations and personal control to predict membership in the two groups, support group members and non-members. As there
was missing data in some cases, mean substitution (Tabachnick & Fidell, 1996) was used to replace the missing values with sample means. Means substitution was deemed an appropriate method of data replacement for the purpose of analysis in this study as missing data constituted less than 5% of the sample, and less than 5% of data for individual cases.

The Discriminant Function Analysis showed a strong association between the groups and predictors $x^2(7) = 23.89, p<.001$. Loadings of greater than .30 were interpreted as significant in the Discriminant Function Analysis, whilst lower loadings were not considered eligible for interpretation (Tabachnick & Fidell, 1996).

The best predictors for distinguishing between the two groups were age, time since diagnosis, emotional representations, illness coherence and illness identity. Table 13 shows the Discriminant Function coefficients and group means for the independent predictor variables.

Support group members were younger than those who had never attended. This finding was significant and in line with previous support group research. The difference was however small, support groups members being on average 2.3 years younger than men who did not attend support groups. While age discriminated between members and non-members in the discriminant function analysis, it was non-significant in the t-test analysis between the groups.

Table 13. Results of Discriminant Function Analysis showing Group Means for Independent Variables and Structure Matrix.

<table>
<thead>
<tr>
<th></th>
<th>Function 1</th>
<th>Support Group</th>
<th>No Support Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-.50*</td>
<td>67.32</td>
<td>69.63</td>
</tr>
<tr>
<td>Time Since Diagnosis</td>
<td>.80*</td>
<td>4.27</td>
<td>3.38</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>.35*</td>
<td>3.78</td>
<td>3.65</td>
</tr>
<tr>
<td>Emotional Representations</td>
<td>.64*</td>
<td>2.67</td>
<td>2.41</td>
</tr>
<tr>
<td>Personal Control</td>
<td>.08</td>
<td>3.60</td>
<td>3.54</td>
</tr>
<tr>
<td>Illness Identity</td>
<td>.86*</td>
<td>4.18</td>
<td>3.78</td>
</tr>
</tbody>
</table>

*p = .05, N = 187
Support group members had also been diagnosed longer with prostate cancer than men who had never attended a support group. The amount of time since diagnosis showed a significant difference between the groups for both the t-test analysis and the discriminant function analysis.

Men who attended support groups were more likely to have stronger emotional representations of the illness than men who had never attended support groups. This result suggests that men in support groups identify more emotional responses to the illness than men who do not attend. Men who were members of prostate cancer support groups also reported higher levels of illness coherence than non-members. That is men in support groups were more likely to understand and comprehend their disease than men who had never attended a prostate cancer support group. The groups also differed on illness identity. Men who were members of prostate cancer support groups were more likely to identify strongly with the illness than non-members, which may have been a factor in support seeking.

Men who were members of support groups and men who were not did not differ on personal control. Thus one’s perception of control was not a predictor of support group attendance. Men in support groups and non-members both reported high levels of personal control.

The results of the DFA indicate that support group members tend to be men who are a younger age, have been diagnosed longer with the disease, report more emotional representations and have a greater comprehension of their illness. Further support group members identify more strongly with their illness than non-members. In terms of symptom reports, men who report more symptoms both physical and emotional attend prostate cancer support groups more than men who report fewer symptoms. However an alternate explanation is that men in support groups are less
constrained in reporting their emotional and physical reactions to the illness than non-
members and men in support groups may be more willing to report symptomatology
than men not in support groups. Similarly, that men in support groups have a greater
coherence of their condition might suggest that men with a greater coherence of their
illness are more likely to attend prostate cancer support groups or alternatively, men
in support groups have a greater understanding of their disease.

5.3.2 Ratings of Support Group Objectives for Past and Current Members

The final analysis was the ratings of importance and satisfaction of a number of
support group objectives by the support group members. Ratings consisted of two
parts, how important the objective was to the participant and how satisfied the men
were with the provision of that objective within their group. Mean differences were
calculated between the importance of the objective and the satisfaction of that
objective. Some objectives were answered by all of the members and some were not
rated. The results are reported in three sections, objective importance, objective
satisfaction and mean differences between importance and satisfaction ratings.

5.3.2.1 Importance of Objectives

In general men in support groups reported that all of the objectives were an
important reason for attending a support group. For each objective the mean ratings
of importance ranged between 2.61 and 3.79 on a scale where 1 was not at all
important and 4 very important (see Table 13). The ratings indicate that each
objective was moderately important to very important to the men in support groups.
Support group participants rated the most important objectives of a prostate cancer
support group were, to talk to others with similar experiences in the group, to access
information about cancer and treatments and to be able to talk more freely with
friends and family about the disease. Although all objectives were rated as important
to the men, some were less important than others. The objectives ranked of least importance were, to gain access to other community information and for support to be provided through the group to family and friends. The third least important objective was to meet new friends.

5.3.2.2 Satisfaction with Delivery of Objectives

As shown in Table 13 the mean scores on whether the objectives were satisfied by group participation ranged from 2.73 to 3.63. Men reported that they were most satisfied that the group provided for the ability to share similar experiences with other men with prostate cancer and to express their feelings within the group, to provide support for others and to access information about cancer and treatments. Sharing experiences with other men in the group was also observed as the most important objective of support groups (see Section 5.3.2.1) as well as being most satisfied through group attendance. Men were less satisfied that the groups provided support for family and friends and to gain access to other community assistance. These two objectives were also rated as least important to group members (see Section 5.3.2.1).

5.3.2.3 Mean Differences Between Importance and Satisfaction of Objectives

Paired sample t-tests were performed to observe within subject differences between ratings of importance of each objective and satisfaction ratings. There were significant differences on four of the expectations. Two objectives were significantly less satisfied than men’s rated importance. These were to be able to talk more with family and friends about the cancer ($t(87) = -2.42, p = .018$) and to access more information about prostate cancer ($t(88) = -2.37, p = .020$). Two objectives exceeded men’s satisfaction by group participation. These were meeting new friends ($t(98) = 2.53, p = .013$) and access to other community resources and groups ($t(86) = 2.35, p = .021$).
Men in support groups reported that they made more friends and received more information on other community services as a result of their group membership than they accorded importance to as an objective of joining a support group. While men in support groups were on the whole satisfied with their groups, men were seen to be somewhat less satisfied with information provision and the ability to communicate with their family and friends. The results suggest that men, although satisfied with the delivery of the objectives of support groups, desire more information on prostate cancer and communication skills in order to speak more freely with their families. Table 14 shows the mean differences between importance men perceive of each support group objective and the level of satisfaction with that objective within their group. The table shows the objectives rank ordered from least important to most important.
Table 14. Mean differences between importance of support group objective and the level of satisfaction with that objective as delivered by support group, rank ordered from least important to most important.

<table>
<thead>
<tr>
<th>Goals</th>
<th>X Importance</th>
<th>X Satisfaction</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>To gain access to other community information/groups</td>
<td>2.61</td>
<td>2.86</td>
<td>2.35*</td>
</tr>
<tr>
<td>To access support for my family / friends through groups</td>
<td>2.68</td>
<td>2.73</td>
<td>0.51</td>
</tr>
<tr>
<td>To be provided with emotional support</td>
<td>3.02</td>
<td>3.12</td>
<td>.88</td>
</tr>
<tr>
<td>To be able to make new friends in the group</td>
<td>3.01</td>
<td>3.24</td>
<td>2.53*</td>
</tr>
<tr>
<td>To avoid a sense of isolation and gain belonging</td>
<td>3.38</td>
<td>3.40</td>
<td>.26</td>
</tr>
<tr>
<td>To be provided with practical help by the group</td>
<td>3.38</td>
<td>3.37</td>
<td>-0.12</td>
</tr>
<tr>
<td>To learn how to cope better with cancer</td>
<td>3.43</td>
<td>3.31</td>
<td>-1.15</td>
</tr>
<tr>
<td>To be able to provide support and advice to other men with prostate cancer</td>
<td>3.51</td>
<td>3.44</td>
<td>- .85</td>
</tr>
<tr>
<td>To be able to express my feelings in the group</td>
<td>3.47</td>
<td>3.51</td>
<td>-.34</td>
</tr>
<tr>
<td>To feel free to talk with friends and family</td>
<td>3.56</td>
<td>3.33</td>
<td>-2.42*</td>
</tr>
<tr>
<td>To access information about cancer and treatments</td>
<td>3.65</td>
<td>3.47</td>
<td>2.37*</td>
</tr>
<tr>
<td>To talk to others with similar experiences in the group</td>
<td>3.77</td>
<td>3.63</td>
<td>-1.72</td>
</tr>
</tbody>
</table>

Note. df ranged from 86-89 due to some missing data, *p =<, 05
Chapter 6
An Integration and Summary of Findings

6.1 Overview of Chapter

The findings of the research are integrated and summarised in this chapter. An overview of the results is provided in Section 6.2. The perceived costs and benefits of support groups reported by group members are reviewed in Section 6.3 as well as suggested improvements in Section 6.3.3 and where men hear about groups in Section 6.3.4. The perceived costs and benefits of support groups described by non-members are reviewed in Section 6.4 and where non-members have heard of prostate cancer support groups in Section 6.4.3. The similarities and differences of members and non-members perceptions of prostate cancer support groups are discussed in Section 6.5. The findings of the quantitative analyses including the illness perceptions and demographic and cancer variables that discriminate between members and non-members are discussed in Sections 6.6 and the evaluation of support groups by the members in Section 6.6.2. Section 6.7 considers the implications of the present study and the limitations of the study are observed in Section 6.8. Suggestions for further research are mentioned in Section 6.9 and conclusions noting the major issues addressed by the research are presented in Section 6.10.

6.2 Overview of Results

The results of the study revealed that members of Victorian prostate cancer support groups appeared to benefit from their support group experiences. Support group members saw little need for improvement of the groups, however more media attention, more funding, and more support and referral from doctors were seen to be desirable. Members mainly heard about the groups through friends and non-members through hospital staff. Both members and non-members perceived support groups as
organisations that provide positive assistance to men with prostate cancer. Further, both members and non-members identified barriers to support group attendance, in particular the distance to travel to the groups when there was no available local group in the area.

The factors that discriminated between members and non-members included age, time since diagnosis, illness coherence, emotional representations and illness identity. Men in support groups were more likely to be younger, have been diagnosed with their illness longer, have a greater understanding of their illness and have a greater emotional and physical response to the illness than non-members.

The support group evaluation revealed that men attending the groups were satisfied with all of the outlined objectives. Meeting new friends exceeded men’s expectations of group membership while feeling free to talk to family and friends and the provision of prostate cancer information were less satisfied by group membership.

6.3 Qualitative Findings: Members of Prostate Cancer Support Groups

The best and worst aspects of support groups and barriers to attending the groups reported by members are discussed in this section. Suggested improvements for the groups, how members found out about the groups and whether men in groups recommend them to other men with prostate cancer are also discussed.

6.3.1 Benefits of Support Groups

Support group members reported the benefits of their participation in prostate cancer support groups as gaining information about their disease and treatments, support, sharing with others their experiences with cancer and supporting others with the disease. The observed benefits of prostate cancer support groups in this study are consistent with the research on cancer support groups (Cain et al., 1986; Ferlic et al., 1979; Guidry et al., 1997; Jacobs et al. 1983; Speigel et al., 1989) and in particular
prostate cancer support group research (Coreil & Behal, 1999; Feldman, 1993; Gray et al., 1997; Gregorie et al., 1997).

Men attending support groups in this study rated the greatest benefit of support group attendance as information. The findings support the view that men with prostate cancer value information regarding their disease and treatments (Dunn et al., 1999; Gray et al., 1997; Kaps, 1994; Schapira et al., 1999). The findings were also consistent with Gray et al.’s (1997) observation that information was important in men’s descriptions of their experiences with prostate cancer self-help groups and that the most frequent reason for joining a group was information. The findings are relevant to previous studies, which indicate a need for more information for men with prostate cancer (Crawford, 1998; Wong et al., 2000). For example, as clinicians frequently underestimate patients’ wishes for information and discussion (Crawford, 1998), the results suggest that there is an informational component in support groups that could assist men who require more information than they are already getting about their disease. The results have further relevance for men who are reported to be constrained in discussions with their doctors about their cancer (Weinman & Petrie, 1997) such that the informal atmosphere of the support group may be more amenable to discussion and information provision than the doctor’s office.

Members of support groups in this study also identified gaining support and sharing their cancer experiences with others, as benefits of support group attendance. These results are not surprising as support is a primary function of support groups (ACCV, 1999) and previous Australian research points to many unmet supportive care needs for cancer patients (Sanson-Fischer et al., 2000). That men in prostate cancer support groups place importance on the sharing and support aspects of the support group is consistent with other prostate cancer support group research.
suggesting that support groups are viewed as having an important role in the psychological and educational support of the attendees (Coreil & Behal, 1999; Gray et al., 1997; Gregorie et al., 1997). Coreil and Behal (1999) also report sharing experiences with others is highly rated as a benefit of the support group.

The results of the present study are further consistent with Krizek et al. (1999) who observed that men with prostate cancer report the supportive benefits of support groups once joining and also with Gray et al.’s (1997) suggestion that men with prostate cancer benefit from communality with others and talking about difficult issues relating to their disease. The results are also consistent with the high ratings of peer support given by Australian men in prostate cancer support groups (Steginga, 2005). That men find the support of being with like diagnosed others in a support group beneficial is consistent with the normalising aspects of associating with like diagnosed others suggested by Festinger (1954).

The findings are also relevant to previous research which suggest men with prostate cancer, who may be reluctant to talk about distress related to their disease, (Kornblith et al., 1998; Pinnock et al., 1998), or seek no help at all (Whitrod, 1996), may be willing to accept support through formal peer support group settings (Calabrese, 1998) once joining.

The benefits of support group participation described in this study also included supporting others. Men felt that being able to help other men was a benefit of participation. This is similar to previous studies which suggest men like to take the role of care provider and advocate (Gray et al., 1997) and the most common reason for people joining support groups after needing help and support was to help others Dobson (1992). The findings are also consistent with Calabrese (1998) who similarly
reports men with prostate cancer like to provide support for other men with prostate cancer as a function of their group involvement.

6.3.2 Costs and Barriers of Prostate Cancer Support Group Attendance

In this study the majority of members reported they did not perceive any costs associated with participation in the groups. Those who did recorded the loss of other members to the disease the most frequent cost. This finding was consistent with Dobson’s (1992) evaluation of Victorian cancer support groups, that a number of participants, including those with cancer and their family, reported deaths of others to be a difficult aspect of cancer support group participation.

Other costs reported by some members in this study included negative talk within the group and lack of privacy. A further cost was the discomfort some men experienced when listening to other men’s experiences with prostate cancer. However these costs were reported by a small number of the members. Negative talk has been reported to be a cost of support group participation in previous studies, for example Cella et al. (1993) found that costs of support group participation for a sample of people with mixed cancer diagnoses, included conflicts with other members and upsetting discussions. The small number of members reporting costs in this study might be related to Taylor et al.’s (1986) suggestion that on the whole people joining support groups have high levels of social skills and may be less likely to engage in negative discussions.

Members of prostate cancer support groups also reported the barriers they encountered in attending their groups. Just under half of the men in prostate cancer support groups identified no barriers, while those suggesting difficulties reported that the distance to travel to the groups was the prime barrier. Given the small number of prostate cancer support groups in Victoria, this is not surprising and might suggest
that the distance to travel would prevent many men from attending at all. This is consistent with Bond and Daiter (1979) who report that geographic distance influences participation in a support group. Bond and Daiter observed that those most active in the program reported the least problems associated with attendance. However Bauman et al. (1992) suggested that distance to the hospital where leukaemia and lymphoma cancer support groups were held was not a barrier to attendance. Many of the support groups in the present study were held in community halls where no other health services were available such as is possible in hospital located groups. Attending hospitals for other appointments would explain the lack of geographic difficulty reported in Bauman’s study, as it would encourage people to travel the distance.

Other barriers members reported they encountered in attending their groups included the time at which meetings were held and difficulties associated with severity of the illness. It would stand to reason that those men feeling unwell as a result of treatment or disease progress would experience difficulties in attending their groups.

6.3.3 Suggested Improvements for Support Groups

The majority of members did not respond or reported that no improvements to their groups were necessary. Of those who commented, the greatest perceived need for improvement was recognition. A number of men in the support groups reported frustration at the lack of group recognition, asking for more advertising, government support, funding, media recognition, and greater representation by doctors. The findings support the notion that prostate cancer support groups require more publicity and is consistent with Australian reports observing a persistent difficulty promoting the benefits of prostate cancer support groups (PFA, 2003) and the observation that
many doctors do not advocate the benefits of prostate cancer support groups (Gardiner, 2002). The need for more publicity was highlighted by the PFA who report patient education and counselling are neglected areas of health for men with prostate cancer and is consistent with Lumb’s (2003) suggestion that the National Men’s Health Strategy has had little impact on men’s health initiatives in Australia (Lumb, 2003).

The need for more recognition for prostate groups has also been observed in America with members of ‘Man to Man’ prostate cancer support groups who similarly report a need for increasing access to support groups and a better outreach to newly diagnosed patients (Coreil & Behal, 1999). The finding that members advocate a need for greater recognition of prostate cancer support groups, would suggest that the members themselves anticipate other men would benefit if the groups were more widely regarded as beneficial for men with prostate cancer.

Other improvements for prostate cancer support groups suggested by the members in this study included more discussion time, guest speakers, and up to date literature, however these suggestions amounted to only a small number of responses. Taken together, they suggest a greater desire for more information for some men in the support groups. The finding that a small number of men would like more information would suggest that the majority of men are satisfied with information provision. However some men seek more information than they are given in the groups or some groups may not be providing enough information for the members. This finding is consistent with the evaluation of the support groups in this study (see Section 5.3.2 and Section 6.6.2) which revealed that while men were satisfied with information provision in their groups, their satisfaction with that information was less than the high importance placed it as a reason for joining a support group.
6.3.4 Where Men Hear about Support Groups

Support group members in this study reported that friends were the main source of information about prostate cancer support groups, followed by brochures and newspapers, hospital staff, telephone support lines and local doctors. Dobson (1992) in evaluating the general cancer support groups known to CCV reported that professionals were the most commonly cited source of information regarding prostate cancer support groups, followed by ‘word of mouth’. In the present study hospital staff and local doctors were the third and fifth most cited sources of information, falling well below Dobson’s findings. It is difficult to generalise from Dobson’s results to prostate cancer support groups as her study comprised a mixed cancer and gender evaluation of support groups and only a small proportion of her sample were prostate cancer members. It might be that men are less likely to be provided with information about support groups by medical personnel and that the support needs of women may be more likely to be discussed or addressed within the doctor patient relationship, than those of men.

In the present study the category of professionals was broken into two groups, hospital staff and local doctors (General Practitioners). This gave a more detailed account of which professionals had mentioned prostate groups to men with prostate cancer. Hospital staff were more likely than General Practitioners to have suggested prostate support groups to the members and General Practitioners were the second least likely source of how men find out about prostate cancer support groups. The results suggest that General Practitioners appear to take a minimal role in support group recommendation. This finding is consistent with Gardiner’s (2002) recommendation that more recognition and referral is needed from General Practitioners in Australia, to promote prostate cancer support groups. The findings
that local doctors are one of the least likely sources for finding out about prostate cancer support groups is also consistent with the recommendation by men in this study for a greater recognition from doctors about the groups (see Section 6.3.3). As observed by Steginga (2005) perceived clinician support plays an important role in support group satisfaction.

Newspapers and brochures were the second highest source of where members learned about prostate cancer support groups, with newspapers reported more often than brochures. This study did not examine the nature of the advertising in newspapers, however the groups may themselves be advertising or some groups, who were attached to community health centres may have the opportunity to advertise in newspapers and flyers. Unfortunately, pamphlets in doctor’s surgeries formed a smaller minority of advertised material. This too was found by Dobson (1991), with pamphlets providing a small amount of support group information in her Victorian mixed gender support group sample. As newspapers and brochures were the second highest source of where men heard about prostate cancer support groups, it would appear that many men are sourcing their own information about prostate cancer support groups which further supports the notion that discussions about support for men with prostate cancer are not widely acknowledged by medical personnel.

Members also reported the use of telephone support lines including the CCV support line as supplying them with information regarding prostate cancer support groups. Telephone support lines and hospital staff were the third most common source of referral to support groups for the members in this study. The use of telephone support lines would suggest further that many men seek information about prostate cancer support groups but must resort to locating the information themselves.
A very small number of members found out about support groups through the internet. The small number of men using the internet was seen to be related to the age of men, many of whom may not have internet access or skills.

6.3.5 Recommendation of Support Groups by Members

Overwhelmingly support group members rated their experience with prostate cancer support groups as having a positive meaning to them. Greater than 90% of the participants reported that they would recommend prostate cancer support groups to other men with prostate cancer. This was consistent with Gregoire et al. (1997) who reported 100% of the members of Canadian prostate cancer support groups recommended the groups to other men with prostate cancer. This finding was taken to suggest that the majority of men in prostate cancer support groups think the benefits they gain from groups would also assist other men with prostate cancer.

6.4 Qualitative Findings: Men Who Had Never Attended Support Groups

In this study 40% of the men who had never joined prostate cancer support groups had heard of the support groups. This is lower than that reported by McGovern et al. (2002) in an American study of non-members of prostate cancer support groups where 50% had heard of the groups before. In the present study 20% of the non-members who had heard of support groups, reported they would not join, in contrast to McGovern’s study where 3% reported they would not join. The results of the present study suggest that a larger number of Australian men are certain they would not join prostate cancer prostate cancer support groups and more Australian men had never heard of the groups, compared to the American sample.

The greater number of prostate cancer support groups in America would suggest that more men are likely to have heard of the groups and therefore more men might consider joining. The modest number of prostate cancer support groups and the
lack of support group awareness (see Section 1.3) might account for the large number of men who have not heard of prostate cancer support groups in this Australian sample.

6.4.1 Perceived Benefits of Support Groups and Joining

Many men who had never attended prostate cancer support groups did not report any perceived benefits of the groups. Those who did perceive the types of benefits to be similar to those reported by prostate cancer support group members. However men who had never been members of support groups reported fewer benefits. In particular non-members recorded information provision as a perceived benefit of prostate cancer support groups much less than members’ reports. This is consistent with Poole et al. (2001) who suggest that men who have never attended prostate cancer support groups are more likely to report their doctors as the most important source of information on prostate cancer. The findings might suggest that non-members are less likely to view prostate cancer support groups as a source of information for men with prostate cancer which raises again the lack of public recognition of prostate cancer support groups and their function in prostate care (PFA, 2000). Another possibility is that non-members are content with the information they receive and do not seek further informational assistance.

Non-members also recorded support and sharing with others and a small number of non-members reported supporting others was a perceived benefit. The results suggest that some non-members do perceive supportive benefits of prostate cancer support groups however choose not to join.

6.4.2 Perceived Costs and Barriers of Prostate Cancer Support Groups

Over one third of the non-members perceived no costs to support group attendance. A further third suggested privacy, negative discussions, and men’s cancer
stories to be a cost of attendance and a further third perceived other men dying as a cost to group attendance. These findings were similar to those of members of support groups, however the costs were reported more frequently by non-members.

The non-members in this study had never attended prostate cancer support groups and relied on their perceptions of support groups. Therefore their responses may have been socially derived conceptions of support and support groups, which might be influenced by notions of masculinity and support seeking (Gardiner, 2002). The lack of understanding about prostate cancer support groups has been raised by Krizek et al. (1999) who suggests demystifying prostate cancer support groups so as to more accurately inform men about the functions and benefits of the groups. As suggested by Krizek marketing the groups so they are seen as informative and a unique form of support for men with prostate cancer, might encourage greater participation.

Of the men who had never attended prostate cancer support groups and who perceived barriers in attending support groups, the greatest response was distance and the time of group meetings. This finding was similar to members’ experiences of attending groups and as suggested earlier in this chapter, was thought to be related to the limited amount of prostate cancer support groups in Victoria.

Of the non-members in this study who expressed they might join a group, most reported that easier access to the groups and helping others would encourage participation. Some men also suggested they would consider joining if they had no one else to talk to or their disease circumstances changed, such as a relapse. This would indicate that some non-members would be encouraged to join prostate cancer support groups were the opportunity suitable to their physical and emotional needs.
When more support was needed and informal support networks failed to meet such needs men might further seek support groups.

6.4.3 Where Have Non-Members Heard of Support Groups

Men who had never attended but who had heard about prostate cancer support groups, reported the main source of finding out about the groups was through hospital staff (including nurses, social workers and doctors) and the least likely professional source was General Practitioners (GP’s). The finding that General Practitioners are among the least likely sources of how men find out about prostate cancer support groups was also reported by members of the support groups in this study. As men are reported to experience psychological distress in relation to their diagnosis with prostate cancer (Roth et al., 1998) and that the distress may continue over a long term (Shag et al., 1994), the availability of support group referrals or an opportunity to discuss issues relating to the disease would be an important step in providing for psychological recovery. General Practitioners therefore could provide for an important link to referring men to support groups, were they to suggest to men with prostate cancer the availability and functions of such groups. Further when men are isolated, with few social contacts and rely solely on GP’s for information and support, the role of the General Practitioner in providing support, education and referral may be assisted by an affiliation with prostate cancer support groups. Also where men have poor relationships with their doctors (Pinnock et al., 1998) it would seem important that they had an alternative place to discuss their concerns in a supportive environment.

Non-Members, similar to members, rated friends and brochures/newspapers as a common source of information about support groups, both of which exceeded GP’s. Non-members did not report the use of the internet, however they did report using
telephone support services. Although hospital staff formed the larger proportion of information about prostate cancer support groups, many men relied on their own information seeking and informal network to learn of the existence of prostate cancer support groups as was observed in members’ reports.

6.5 Similarities and Differences for Non-Members and Members of Support Groups

In general both members and non-members reported similar responses to the qualitative questions. That is, both groups reported the benefits of prostate cancer support groups as information, support, sharing experiences with others and supporting others. However members reported considerably more benefits than non-members. In particular, information provision and supporting others were seen by members as being much more beneficial than non-members. This difference was seen to be a direct result of their experience in the group. Members also reported more than non-members the benefits of sharing experiences and receiving support from others than non-members’ perceptions of prostate cancer support groups.

The men who had never attended support groups reported more costs relating to support group participation than did members of prostate cancer support groups, in particular other men in the group dying and a perceived lack of privacy as a group member. Lack of privacy was seen to be a much greater issue for non-members than members. Further, negative discussions and hearing other men’s stories were reported slightly more by non-members as a cost of support groups. Both members and non-members reported that distance to travel to groups was a barrier to attending and members reported illness more often than non-members as a greater barrier to attending support groups.

As the benefits and costs of prostate cancer support groups perceived by members and non-members has not before been investigated, these findings cannot be
compared with other studies, however the results provide an understanding of men’s thoughts about prostate cancer support groups and why they are likely, or not likely to join. Therefore the findings have relevance for health professionals in understanding what men perceive as beneficial about prostate cancer support groups, what they do not, and to identify barriers to participation that might encourage joining. This is important as suggested by Coreil and Behal (1999) because earlier referral to support groups would enhance patient’s access to shared experiences, support and resources for guidance with treatment decisions relating to their cancer.

Members were more likely to have heard of prostate cancer support groups through friends, newspapers, and brochures than non-members. Men who had never attended support groups (those who had heard of support groups) were more likely to cite hospital staff as supplying them with information regarding the groups. Both members and non-members reported General Practitioners to be an unlikely source of information regarding prostate cancer support groups. Members reported the internet as the source least used for finding out about prostate cancer support groups and non-members did not report the use of the internet at all. The majority of both members and non-members of prostate cancer support groups perceived the groups to be a positive concept for men with prostate cancer, however a greater number of members perceived them to be positive.

The findings have further relevance for health promotion professionals for targeting areas that fail to advance prostate cancer support groups. This could be done by endorsing the benefits of prostate groups to medical professionals, promoting literature to be readily available in doctor’s surgeries, and promoting the use of telephone cancer support lines.
6.6 Quantitative Findings

The findings of the quantitative analyses are discussed below. The illness perceptions that distinguish between members and non-members of prostate cancer support groups are highlighted. The cancer related factors that influence attendance to the groups are also discussed. Further, the findings of the evaluation of the support groups is discussed, with reference to the objectives of support groups the members found most beneficial and which were not.

6.6.1 Predictors of Support Group Attendance

It was hypothesised that there would be differences between members and non-members of prostate cancer support groups on the illness perceptions of emotion, personal control, identity, and coherence. The findings of this study suggest illness identity, illness coherence, and emotional perceptions of the illness distinguish members from non-members of prostate cancer support groups. It is possible that men who identify more strongly with their illness, who have a greater understanding of their illness, and who have more emotional representations of their illness tend to join support groups. Contrary to expectations, men in prostate cancer support groups and men who had never attended prostate cancer support groups did not differ on personal control. Age and time since diagnosis were also predictors of attendance.

6.6.1.1 Illness Perceptions Discriminating between Members and Non-Members

Illness identity was a factor that distinguished between the groups in this study, with prostate cancer support group members reporting a stronger illness identity than non-members. This was consistent with the prediction that members and non-members differ in how they perceive their illness. The results suggest that men who identify more strongly with their illness attend prostate cancer support groups more than men who endorse a lesser identity with their illness. As previous studies
have shown, a strong illness identity has been reported to be related to psychological impairment (Moss-Morris et al., 1996) and sexual impairment (Petrie et al., 1996) in various illness groups. Although illness identity has not before been studied in a sample of men with prostate cancer or with support groups these results are contrary to research with myocardial infarction patients (Petrie et al., 1996), which found that illness identity did not differentiate between attendees and non-attendees at a rehabilitation program. It is difficult to compare the findings of this study and Petrie et al.’s for several reasons. Rehabilitation programs offer a different structure and purpose than cancer support groups, cardiac patients are usually advised to attend their groups by medical professionals, and cardiac illness is not associated with the stigmatising effects experienced by men with prostate cancer (Davison, 2000). The findings of the present study may be likened more with Moss-Morris et al.’s (1996) observation that illness identity was positively related to planning and venting emotions. The association between planning and illness identity might suggest that men who identify more strongly with their illness are more likely to seek or plan ways to adjust to their illness such as joining a support group. Further the association between illness identity and emotional venting suggested by Moss-Morris implies that men who identify more strongly with their illness, seek support groups to address their emotional needs. That men in support groups report more illness symptoms may also attest to satisfaction with the peer support process (Steginga, 2005) which may increase the likelihood of symptom reports due to the familiarity of symptom discussions held during group meetings.

As predicted, men attending prostate cancer support groups in this study reported more emotional responses to the illness such as fear, anxiety and anger than men who were never members of prostate cancer support groups. This finding is
consistent with Moss-Morris et al. (2002) who report high emotional perceptions of the illness is a predictor of support seeking. The finding was seen to be similar to Krizek et al.’s (1999) findings that the reasons both men with prostate cancer and women with breast cancer join support groups, is to compare their emotional progress with others.

Another explanation for why men with higher emotional representations of their illness attend support groups may be social constraint (Lepore & Helgeson, 1998). Difficulties talking about the cancer are due in part to the fact that prostate cancer is not well understood or recognised (Sharp et al., 1993) and also due to an inability for many men to disclose their thoughts about the disease (Lepore & Helgeson, 1998). Thus men in support groups may feel more socially constrained in talking about the disease to their close others, however seek to facilitate discussion about their illness with a group of like diagnosed men who share similar experiences. The results also support Festinger’s (1954) notion that individuals search for a sense of normality and accuracy about their world by seeking the familiarity of others with similar experiences and diagnoses. Further that in times of uncertainty or anxiety, affiliative behaviours increase as people seek opinions of like persons. As the majority of people in support groups are married (Cella, 1993), the existence of support might not be a factor in support group attendance but rather the type of communications or the ability to communicate or disclose to others (Gray et al., 2000; McGovern et al., 2002; Pinnock et al., 1998) that leads to support seeking. As suggested by Gray et al. (2000) most older men avoid disclosure regarding their prostate diagnosis unless necessary. The majority of men would not entertain discussions about the stigmatising aspects of their disease in order to minimise the impact of the disease on their personal lives.
The lack of difference between members and non-members of prostate cancer support groups on personal control possibly suggests that a man’s sense of personal control is not a factor that influenced support group attendance. Both members and non-members of prostate cancer support groups in this study reported reasonably high group means for personal control suggesting that despite their illness the men perceived they had control over the destiny of their health. As personal control is associated with active coping, planning and positive reinterpretation in illness groups and has been associated with positive effects of illness outcomes (Moss-Morris et al., 1996) the results would indicate that the men in this sample generally felt that they had influence over their illness outcomes. Petrie et al. (1996) reported that patients who believe more strongly in the curability and control of their illness were more likely to attend a rehabilitation program for myocardial infarction. These findings differ from the present study as both members and non-members scored high on personal control, despite their attendance at support groups. The different findings could be attributed to the use of the curability/control scale by Petrie et al. that was found to later consist of two subscales, personal control and treatment control of the disease (Petrie et al., 1996). The current study examined personal control which does not explore notions of treatment control and therefore it is difficult to compare the findings of other illness perception research which use the original personal control measure. Further, as previous research on illness perceptions has included both male and female responses to the disease (Moss-Morris et al., 1996; Petrie et al., 1996) it is possible that the results of this study provide information that is more pertinent to men’s responses to the illness which is likely to differ to women’s illness responses regarding personal control (Pinnock et al., 1998). A lack of literature on the concept
of personal control in prostate cancer research would suggest further exploration is required.

In addition to illness identity and emotional perceptions of the illness, illness coherence was a predictor of prostate cancer support group attendance in this study. The men in prostate cancer support groups showed a greater coherence of their illness than men not in support groups. As illness coherence is described as how one understands their disease (Moss-Morris et al., 2002), the findings possibly suggest that men who have a greater coherence or understanding of their disease are more likely to attend support groups than men who do not. Whether men in support groups are more likely to seek information regarding their disease than non-members and thus are more informed about their illness may be one explanation for this finding and is consistent Krizek et al. (1999) who suggests wanting to learn more about the illness is a reason for joining cancer support groups. The results may also be linked to previous support group research which shows that most members of support groups tend to be well educated and this would possibly influence a more coherent understanding of the illness. Little research has been conducted on illness coherence which is a new concept in illness perception research (Moss-Morris et al., 2002). It is therefore difficult to interpret the findings in light of previous research.

That men in support groups have more symptom responses, emotional responses, and greater coherence may reflect not that these men were in more need of support but represent the benefits of prostate cancer support groups. That is, the greater illness coherence finding may represent men are learning more about prostate cancer in support groups in an environment that facilitates learning and discussion. Further as support groups allow the emotional expression of concerns in a supportive environment, members might report more emotional representations of their illness as
they are able to express them in the support group forum. Thus the different emotional perceptions seen between members and non-members may represent differences in self-disclosure, that is whether men are inclined to report their perceptions and symptoms or not. Support group discussions may influence the members to report more openly the perceptions they hold of their illness than non-members and this would increase the reporting of such perceptions. Further that non-members report less emotional representations of their illness may be associated with the previously mentioned masculine tendency of non-disclosure of emotions and a lack of health information and support seeking. That is the non-members in this study are more likely to avoid health discussions, in line with masculine social norms, as opposed to members who have developed a more coherent understanding of their disease and therefore seek support. As having a greater understanding of the illness and disclosing emotions, play an important role in the longer-term adjustment and response to the illness (Moss-Morris et al., 2002), the results offer the suggestion that the men in this study who attend prostate cancer support groups may adjust to the illness better than non-members. Further as positive regulatory behaviour requires concrete information about the disease and methods of coping, attending prostate cancer groups, would further imply a greater opportunity for positive reinterpretation of the health threat with consequential psychological recovery.

6.6.1.2 Demographic and Disease Differences Between Support Group Members and Non-Members

Other factors that differentiated between men in support groups and non-members were how long the men were diagnosed with prostate cancer, their marital status, the stage of the cancer and the type of treatment received.

The finding that younger men join prostate cancer support groups is in line with previous support group research suggesting in general, younger persons attend
support groups more than older persons (Cella et al., 1993; Krizek et al., 1999) however the age difference was not large in this study.

The finding that men in support groups have been diagnosed longer with their illness suggests that they have passed the immediate treatment requirements and continue to deal with ongoing needs for further information and emotional support for their illness. This was suggested by Poole et al. (2001) who proposed that after their initial diagnosis, men with prostate cancer may have immediate concerns that they do not believe can be addressed by support groups. Thus joining a support group was seen to occur as a secondary response to the illness. That is, dealing with the practicalities and treatment of the illness may take precedence over seeking support in the early stages of the disease and attendance at support groups is considered after the immediacy of treatment has diminished. As prostate cancer support groups are likely venues to assist men making decisions about their treatment, it might seem more pertinent that men seek the support and advice offered in the groups to confirm decisions about treatment before commencing treatment. Also to know that there are other men who have experienced the same diagnosis as they have. This could serve to alleviate anxieties and provide added information before procedures are begun. At present most groups consist of men who have already undergone treatment.

The present study also revealed that there was a trend toward support group members to more likely be married than non-members and for support group members to more likely be living with other people, than men who had never joined a prostate cancer support group. The findings that married people are more likely to join support groups is consistent with previous support group research which suggests that married persons and people who live with others are more likely to join cancer support groups (Cella et al., 1993; Deans et al., 1988). The findings are further
consistent with prostate cancer support group research which suggests a trend toward married men more than single or never married men in joining support groups (Krizek et al., 1999; Poole et al., 2001). Conversely, Bauman et al. (1992) reported unmarried people to be most likely to join a support group, contradicting most support group literature, however this was not found for the current sample of men with prostate cancer.

Previous support group research has reported that members are well educated (Bauman et al., 1992, Coreil & Behal, 1999; Krizek et al., 1999) however this was not supported in this study. While a greater proportion of members than non-members in this study were educated at the level of, or greater than year twelve, the finding was not significant. Determining education as a factor in support group attendance in elderly populations might be difficult to draw conclusions from as many may not have had the opportunity for continuing education or were encouraged to seek a trade.

In the present study support group members reported recurrent disease more than never members and were more likely to be receiving hormone therapy than non-members, suggesting these factors may influence support group attendance. As hormone therapy is often used for high risk localised cancers or advanced cancers (Australian Prostate Cancer Collaboration (2003), this may suggest that members of support groups are more likely to have advanced or high risk tumors than non-support group members, the effect of which may prompt support seeking.

6.6.2 Evaluation of Support Group Objectives

The prostate cancer support groups were evaluated by means of an appraisal of 12 objectives identified in the guidelines of the Cancer Council’s support groups of Victoria. The findings suggest that the support groups met the member’s expectations as measured by men’s ratings of the objectives. The two objectives that were reported
as being the most important reasons for men joining support groups were to talk to others with similar experiences within the group and to access information about cancer and treatments.

Of the twelve objectives, two exceeded men’s expectations and two objectives were reported as below men’s expectations. Objectives that exceeded men’s expectations were making new friends in the group and gaining access to information about other community assistance relating to the disease. The support group members made more friends than they expected through their participation in the support group. This is consistent with Deans et al. (1988) and Gray et al. (1997) who report that self-help cancer support groups enable members to make new friends and meet others facing similar difficulties. Members also received more information about other community organisations that might assist in health information and practical advise than they expected. This would suggest that the support groups were helpful in enabling men to link with other organisations than men expected by group participation.

Objectives that were less satisfied included, to feel free to talk with family and friends and to access information about cancer and treatments. The finding that feeling free to talk with family and friends was less satisfied by group membership might suggest that men would like more communication skills when talking to family and friends or that men would prefer more family access to the groups. However this finding may not reflect all groups. Some groups may offer more family time than others.

The findings that men in support groups would like more information than is currently provided in the groups, shows that some men seek more information than they are currently receiving. This would suggest that despite members rating
information a very important part of support group participation which was well satisfied by group participation, men continue to desire more information about their disease. The finding that information is important to men with prostate cancer is consistent with prostate cancer research suggesting information is the most important reason for joining a prostate cancer support group (Gray et al., 1997). Again this finding may not reflect all support groups, it might be that some groups provide less information than others. The differences between the individual support groups was not observed in this study.

6.7 Implications of the Study

The present study has several important implications for prostate cancer research, prostate cancer support groups, and for health professionals. The majority of research on cancer support groups has included responses of both females and males in mixed cancer support groups. The present research regarding men’s perceptions about prostate cancer support groups, therefore, has allowed an examination of men’s perceptions of support and support group attendance without ignoring the influence of gender and disease type that has influenced previous support group research.

The findings of the present study suggest that a large number of men with prostate cancer perceive benefits to prostate cancer support groups, and support previous research that prostate cancer support groups provide a function for support and information for men with prostate cancer (Krizek et al., 1999; Gray et al., 1996; Coreil & Behal, 1999). Information, support, and sharing experiences with others were perceived as the main benefits while the distance to the groups and hearing about other men dying were seen as the most difficult aspects of prostate cancer support group attendance. For health care professionals who work with men who
have prostate cancer, the results suggest the importance of recognising that both members and non-members report benefits of prostate cancer support groups report. This would suggest that more men might join groups were the reported benefits imparted from the professional to the patient.

Another implication for health professionals observed from this study is understanding the importance of men’s perceptions of their illness in contributing to attendance at support groups and the subsequent beneficial aspects of recovery. The early identification of illness perceptions and referral to groups by health professionals, may serve an important role to address misconceptions men may hold about the illness and to address any psychological distress that may be assisted through the sharing of experiences with like diagnosed men that is not be offered sufficiently in the marital or medical support network.

A further finding of the present research is the relative lack of awareness about prostate cancer support groups. This was observed by the large number of non-members who had not before heard of prostate cancer support groups and was further highlighted by the high proportion of support group members suggesting the need for promotion and recognition of prostate cancer support groups by both medical professionals and governments. The small number of men hearing about the groups through General Practitioners and the large number of men in groups who heard about them from a friend would also suggest a need for a targeted public promotion of the groups. The findings imply that medical professionals could play a greater role in understanding the benefits men gain from support groups and in the promotion and referral to the groups for men with prostate cancer.

The study has additional implications for the facilitators of the existing prostate cancer support groups. Although members rated all objectives as
satisfactorily delivered by their support group, men continued to perceive a need for more information about the cancer and treatments. Given the importance men place on information provision and that the main benefit perceived of joining prostate cancer support groups was information, it would seem important that the groups review their current information input. Further, this finding has implications for the marketing of prostate cancer support groups. As men seek information as a way of coping with their illness (see Section 1.4.1), promoting the informational component of the groups may attract a greater number of men.

Facilitators might also consider opening the groups more extensively to men making pre-treatment decisions and who experience anxiety over their treatment decisions and their future. At present most groups cater for the needs of diagnosed men only.

The fact that only a few men with prostate cancer join groups relative to the amount diagnosed each year was seen to be influenced by the men’s perceptions of their illness, a lack of awareness and referral to the groups, and also the distance to travel to the groups. Non-members would gain assistance from the groups were they informed of the groups, if the groups were close, and if they were marketed in a way that attracted the men.

6.8 Limitations of the Research

The study has important implications for prostate cancer research, however there are number of limitations which suggest that the findings be viewed with caution. First the design of the study was restrictive in drawing causal relationships between illness perceptions and support group attendance. Thus, whether men came to the support groups with pre-existing illness perceptions or the illness perceptions were the result of support group attendance cannot be determined. Although causal
relationships cannot be drawn from the study, the findings make an important contribution to research on prostate cancer and to illness perception research because of the limited literature on illness perceptions in a cancer population and, more specifically, on men with prostate cancer and support groups.

A second limitation was that the men who had never attended support groups were recruited from a radiation oncology clinic so that more of the never members experienced radiation therapy than support group members. This may have influenced the results, in particular in terms of treatment related symptom reports and illness identity findings. For example the Cancer Council of Australia (1999) report greater rates of sexual impotence in men undergoing a prostatectomy, than men receiving radiotherapy.

A third limitation was the reporting of the evaluation findings as representative of all prostate cancer support groups evaluated in this study. The study did not allow for the evaluation of the functioning of individual groups. As support groups vary in their content and structure, the findings for example that men would like more information about their disease and treatments may be pertinent to some groups but not necessarily representative of all of the groups.

A final limitation was the members of support groups included both past and present members. This may have influenced responses as past members may have different responses than current members on their perceptions of support groups, and their illness perceptions, the reporting of which may have been influenced by the amount of time since departure from the group and the reasons for leaving the group.

6.9 Suggestions for Future Research

Future research might focus on the other illness perceptions suggested by Moss-Morris (1996). Whilst some research has suggested that the cause of an illness
does not predict attendance at support groups (Davison et al., 2001), perceptions of causes, time, treatment control, and the perceived consequences of the illness would facilitate further exploration of men’s perceptions of their illness. Exploring additional illness perceptions would help to identify other factors that influence support seeking for men with prostate cancer and may assist to reveal the myths that men may hold in relation to their disease. Using more illness perceptions would help to compare with other illness perception research.

Future research would benefit by including measures of masculinity, coping and quality of life. These measures might reveal more about the influence masculinity may have on attendance at support groups in men with prostate cancer in Australia, and would serve to compare with international studies of members and non-members of prostate cancer support groups on quality of life and coping (McGovern et al., 2002; Poole et al., 2001). Also, examining cultural differences on support group attendance might reveal more about the influence different cultures have on support seeking.

Further a longevity study comparing the illness perceptions of men in support groups and men not in groups over time would reveal more about the long-term effects of support groups on men with prostate cancer. This has not before been performed in a group of men with prostate cancer, however observing changes in illness perceptions over time might show more about how men adjust to their illness as a result their support group membership. Previous studies suggest that women with breast cancer in support groups showed significantly greater longevity than women not in groups as a result of their ability to express emotional concerns within a group (Spiegel et al., 1989). This finding may also prove to occur for men in prostate cancer support groups.
Finally understanding the spousal communications of the wives and partners of men with prostate cancer might reveal more about the types of family relations that influence support seeking. Observing what partners report, compared to the men’s actual ratings would offer additional information about how partners believe men deal with their illness and the level of denial or disclosure experienced in the partnership. Not only would this allow an understanding of men’s discussions about their illness but also whether the type of or lack of personal communications influences the decision to join a cancer support group.

6.10 Conclusion

This study provides an important contribution to prostate cancer support group research and the experiences of Australian men. The study differs from much of the previous research in that it reports both members and non-members experiences of prostate cancer support groups.

The study highlighted the fact that many men are unaware of prostate cancer support groups, suggesting a need for a greater dissemination of information about the benefits of prostate cancer support groups. More men with prostate cancer might benefit from group support if there was a greater public recognition of these groups. Although informal links with health professionals may exist through guest speakers at the groups, the current finding suggest a need for a greater involvement of General Practitioners in early referral of prostate cancer patients to support groups. General Practitioners may play a vital role in raising awareness of the potential benefits of support groups, both for men in the early stages of cancer making treatment decisions and for men post treatment coping with symptom related and psychological distress. Lack of government and media representation of prostate cancer support groups were seen to be further factors associated with many men not knowing about prostate cancer support groups.
The study attests to the unique contribution support groups can make in catering for the specific needs of men with prostate cancer, with both members and non-members reporting benefits. Members observed more benefits than non-members, suggesting that many non-members may not fully understand or value the benefits of prostate cancer support groups. Non-members perceptions’ may be driven more by social dictations which might be demystified by increased awareness of prostate cancer support group functions. However many non-members observed advantages to support group membership which might suggest some men might be amenable to support group attendance. The reported benefits of prostate cancer support groups suggests that the groups provide a safe place for disclosure and recovery from the psychological burden of having the disease as well as informing men about the illness and treatments.

The findings suggest that illness perceptions may play a role in men’s decisions to join a prostate cancer support group. Certain factors were consistent with support group attendance. Men who identify more strongly with their disease tend to join prostate cancer support groups more than men with lower levels of symptom reports. This would suggest that men perceiving more symptom related distress seek support groups. Further men who identified stronger emotional representations of their illness were more likely to attend prostate cancer support groups. Finally having a greater understanding of one’s illness appeared to generate support seeking. These factors have further implications for health care providers in understanding why men join support groups and in particular why many men do not. The findings may be further suggestive of the socio-cultural influences on masculine help seeking and the lack of prostate information, two factors that are important in the formation of illness perceptions. That is, members may be less likely to be influenced by dominant
masculinities than non-members and may have a greater awareness and understanding of their illness, than non-members. This is not to suggest that non-members were not coping, as suggested by the high levels personal control in both groups, but that non-members may be more reluctant to disclose to others their illness related concerns, an attitude that is assumed to be widespread amongst the broader population of men with prostate cancer (Gray et al., 2000). As noted however the findings may be related to the direct influence of the groups in allowing a greater disclosure in the reporting of symptomatology and therefore might reflect the benefits of the groups.

High levels of satisfaction were observed by members of their support group experiences, with most of the members recommending the groups. Members were most satisfied with information provision and sharing with other men about their cancer experiences. Similarly men in groups reported that the most important aspect of prostate cancer support groups was information and promotion of discussion with like diagnosed others. While men were satisfied with the provision of information within their groups, it would appear that men thirst for more knowledge about the disease and treatments. A high value is placed on keeping up with new treatments and research related to prostate cancer. Information is seen to be particularly important for understanding treatments and making treatment decisions. This has important implications for the facilitators of some support groups who might require a greater informational component in their groups.

The study has important implications for health professionals in understanding the needs of men with prostate cancer and understanding who is most likely to join. Although many men do not join prostate cancer support groups, the study observes that many men report benefits. They share experiences about their illness and discuss issues that may not otherwise be raised. These aspects of support group participation
were seen to assist Australian men in this study cope with their cancer experience and it is suggested that prostate cancer support groups can have a greater impact on the lives of men with prostate cancer given more public recognition of the reported benefits. As the incidence and mortality of prostate cancer escalates, it can only be assumed that more men with prostate cancer might wish to join groups as hospital stays become shorter and men have little time to absorb the stigmatising impact of their disease and associated treatments on their sexuality and continence.
References


attend cardiac rehabilitation: Role of intentions and illness beliefs. *Heart, 82, 234-236.*


Appendix A

Questionnaire for Non-Members of Prostate Cancer Support Groups

Information Sheet

Consent Form

Recruitment Letter
Prostate Cancer: Your Experiences

Please answer the following questions. The information you provide is completely confidential.

PART 1: Questions About You

1. When were you first diagnosed with prostate cancer? (approximate date).
   ________________________________________________

2. What was the stage of prostate cancer at diagnosis? (please tick one box).

   - Localised (within the prostate)
   - Advanced (extending outside the prostate)
   - Don’t know

3. What is the stage of prostate cancer now? (please tick one box).

   - Localised (within the prostate)
   - Advanced (extending outside the prostate)
   - Recurrent
   - Don’t know

4. What was the first treatment you received for prostate cancer? (please tick one box).

   - Hormone therapy
   - Prostatectomy (removal of prostate)
   - Radiation
   - Chemotherapy
   - Other (please state). ______________________
5. What treatment are you currently receiving for prostate cancer? (please tick one box).

□ Hormone therapy
□ Prostatectomy (removal of prostate)
□ Radiation
□ Chemotherapy
□ Other (please state). ________________________

6. Approximately how long have you been receiving your current treatment for prostate cancer?
_______________________________________________________

7. What is your age in years? _________________________________

8. What is your highest level of education? (Please tick one box).

□ Primary School
□ Junior secondary school (Year 9)
□ Senior secondary school (Year 12)
□ TAFE (Trade/certificate)
□ Tertiary (college, university)
□ Post graduate
□ Other (please specify) ________________________________

9. What is your current relationship status. (Please tick one box).

□ Married/Defacto/Partnership
□ Divorced/Separated/Widowed
□ Single/Never married

9 a. What is your residential postcode? __________
10. What language do you speak at home? (please state)

First Language _______________________________________
Second Language _______________________________________
Third Language _______________________________________

11. Please tick the individuals who live in your household.

☐ Mother  ☐ Son/s
☐ Father  ☐ Daughter/s
☐ Sister/s  ☐ Friend/s
☐ Brother/s  ☐ Other (please state)
☐ Wife  _________________________

12. Do you currently have any other medical and/or mental health conditions? (If so, please list conditions and rate according to how distressing it is for you at present by circling a number below).

<table>
<thead>
<tr>
<th>Condition</th>
<th>0</th>
<th>2</th>
<th>4</th>
<th>6</th>
<th>8</th>
<th>10</th>
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<tr>
<td>1.</td>
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<td>2.</td>
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<td>3.</td>
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Part 2: Your Views about Support Groups

13. Have you ever heard about prostate cancer support groups? (please tick one box).

☐ Yes  ☐ No

14. If you answered yes to the above question - Where did you hear about prostate cancer support groups?

☐ Local Doctor  ☐ Internet
☐ Hospital Doctor/ Nurse  ☐ Brochures
☐ Social Worker  ☐ Telephone Support Line
☐ Friend  ☐ Other (please state)

15. Have you ever considered joining a prostate cancer support group?

☐ Yes  ☐ No
16. If you have considered attending a support group what has made attending difficult for you?

☐ Distance
☐ Time of meeting
☐ Feeling Unwell
☐ Cost
☐ Other (please state).

________________________________________________________

17. What do you think would be the best things about being in a support group? (ie: support, information, being with other men with prostate cancer).

1. ______________________________________________________
2. ______________________________________________________
3. ______________________________________________________
4. ______________________________________________________

18. What do you think would be the worst things about being in a support group?

1. ______________________________________________________
2. ______________________________________________________
3. ______________________________________________________
4. ______________________________________________________

19. What would encourage you to join a support group?

________________________________________________________

________________________________________________________

20. Does the term 'support group' have a positive or negative meaning to you? (please tick).

☐ Positive  ☐ Negative

21. Would the term "prostate cancer information group" be preferable to the term "support group"? (please tick).

☐ Yes  ☐ No

22. Can you think of other terms that would make support groups more attractive to men (please list).

1. ______________________________________________________
2. ______________________________________________________
3. ______________________________________________________
## Part 3: Questions about Cancer and You

Using the following rating scale please tick one response that best describes you.

<table>
<thead>
<tr>
<th>No.</th>
<th>Questions</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither disagree or agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>There is a lot which I can do to control my symptoms</td>
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<td>2.</td>
<td>When I think about my illness I get upset</td>
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<td>3.</td>
<td>What I do can determine whether my cancer gets better or worse</td>
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<td>4.</td>
<td>My cancer makes me feel angry</td>
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<td>5.</td>
<td>The course of my cancer depends on me</td>
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<td>6.</td>
<td>My cancer does not worry me</td>
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<td>7.</td>
<td>I get depressed when I think about my cancer</td>
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<td>8.</td>
<td>My actions will have no effect on the outcome of my cancer</td>
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<td>9.</td>
<td>I have the power to influence my cancer</td>
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<td>10.</td>
<td>My illness makes me feel afraid</td>
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<td>11.</td>
<td>Having cancer makes me feel anxious</td>
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<td>12.</td>
<td>Nothing I do will Affect my cancer</td>
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<td>13.</td>
<td>I don't understand my illness</td>
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<td>14.</td>
<td>The symptoms of my condition are puzzling to me</td>
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<tr>
<td>15.</td>
<td>I have a clear understanding of my condition</td>
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</table>
Using the following rating scale please indicate if you have had the symptoms below during the past week and if so how often it occurred.

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<tbody>
<tr>
<td>1. Feeling sad</td>
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<tr>
<td>2. Worrying</td>
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Thankyou For your Assistance
You are being invited to take part in a research study for men with prostate cancer.

The staff at Peter MacCallum Cancer Institute study the nature of disease and try to develop better methods of diagnosis and treatment. In order for you to decide whether you should agree to be part of this study, you should understand enough about its risks and benefits to make an informed decision. This process is known as informed consent.

This is a study for patients with prostate cancer. At present there is little Australian literature on the support needs of men with prostate cancer. This study examines men’s personal experiences with prostate cancer and men’s thoughts about prostate cancer support groups.

The overall aim of the study is to gain a greater understanding of the support needs of men with prostate cancer and provide feedback of such needs to the Anti-Cancer Council of Victoria and the Peter MacCallum Cancer Institute. The information you provide will help to improve existing support networks, assist service providers in understanding the support needs of men with prostate cancer and where possible create new avenues for support.

There are no foreseeable risks in participating in this study. Should a participant feel that support is required as a result of this study, a trained counsellor will be available to speak with. The counsellor can be contacted through the patient representative at the Peter MacCallum Cancer Institute, telephone number 96561870.

There may be no direct benefit to you as a result of participating in this study, however other patients may benefit in the future from information gained in this study.

Your treatment will in no way be affected, whether you choose to participate in this study or not. Should you choose to participate you will be required to complete a short confidential questionnaire.

Thankyou for your consideration of this study. Should you agree to participate, the information you provide will be most valuable. Please refer to page two of this patient information form for a description of your rights as a research participant at the Peter MacCallum Cancer Institute.
Your Rights

a) You may ask questions regarding this study and can expect clear and understandable answers in return.

b) Participation in the study is voluntary, and you are not obliged to participate if you do not wish to do so. You may withdraw from this study at any time you wish without jeopardising further treatment at this hospital. Your doctor may withdraw you from this trial at any time if it is felt that continuing would incur a serious risk to you. If you wish to withdraw please notify Dr Hedy Mameghan whose contact number appears below under ‘whom to call’.

c) Any information obtained in connection with this study and that can identify you will remain confidential. It will only be disclosed with your permission, except as required by law. If you give us your permission (by signing the attached Consent Form), your medical records will be released in confidence to the study sponsors, its employees or agents, to the regulatory authorities here and overseas and the institutional Ethics Committee with the understanding that these records will be used only in connection with carrying out our obligations relating to this study. You will not be identified as an individual in any of these reports or subsequent publications.

All consent forms and data collected for the purposes of this study will be secured in a locked filing cabinet, marked as confidential and accessible only to the researcher. Data will be stored for a period of fifteen years after completion of the study.

d) If any complications of the disease or of this treatment occur, the Peter MacCallum Cancer Institute will provide appropriate treatment for these problems.

e) If any new information becomes available that may influence your decision to continue with this study, such information will be given to you.

f) Your participating in this study will not influence the amount of money (if any) you have to pay for your treatment at the Peter MacCallum Cancer Institute.

This study will be conducted in accordance with the National Health & Medical Research Council’s National Statement on Ethical Conduct in Research Involving Humans (June 1999), developed to protect the interests of research participants. The ethical aspects of this research project have been reviewed by the Ethics Committee of the Peter MacCallum Cancer Institute and has been duly approved. Ethical concerns can be discussed with the Secretary of the Ethics Committee on telephone number (03) 9656 1043. Any concerns about the way the study is conducted, or questions about your rights as a research participant can be discussed with a person not directly involved with the study by contacting one of the Patient Liaison Coordinators, Ms Anna Keating or Ms Louise Vecchi on telephone number (03) 9656 1111, pager 1097.

Whom to Call

The doctor you should contact should any problems arise is Dr Mameghan. The hospital telephone number is (03) 9656 1111. During working hours, you can also call the Research Student Sandra Walker on (03) 94813246. If after hours, ask for the medical oncologist on call at the hospital or call the research student on the above number.
PROSTATE CANCER SUPPORT GROUPS: AN EVALUATION

Dr. Mameghan has discussed this study with me. I have had the opportunity to ask questions about this study and I have received answers that are satisfactory to me. I understand that I can withdraw from this study at any time without prejudicing my further management. I consent to the publishing of results of the study provided my identity is not revealed. I have read and kept a copy of the attached Patient Information Sheet and understand the general purposes, risks and methods of this study. I agree to participate in this study. I hereby give permission for medical practitioners, other health professionals, hospitals or laboratories outside this hospital to release information to Peter MacCallum Cancer Institute concerning my disease and treatment which is needed for this trial and understand that such information will remain confidential.

PATIENT’S NAME ________________________________

please print

PATIENT’S SIGNATURE __________________________ DATE __________

WITNESS’ NAME ______________________________

please print

WITNESS’ SIGNATURE __________________________ DATE __________

I, the supervising physician confirm that I have fully explained the nature, purpose and reasonably foreseeable risks to the patient taking part in the study. I confirm that he/she has read and kept a copy of the Patient Information Sheet and that he/she freely agrees to participate in the study.

PHYSICIAN’S NAME ________________________________

please print

PHYSICIAN’S SIGNATURE __________________________ DATE __________
PROSTATE CANCER SUPPORT GROUPS: AN EVALUATION
A Study with Peter MacCallum Cancer Institute and The Anti-Cancer Council of Victoria

Dear Sir,

My name is Sandra Walker, I am studying for a Masters degree in Health Psychology at Swinburne University of Technology. As a part of this study I am working with the Anti-Cancer Council of Victoria and Peter MacCallum Cancer Institute, to understand men’s personal experiences with prostate cancer and to obtain information about men’s need for support including thoughts on prostate cancer support groups.

Men with prostate cancer experience their illness in different ways. Many men seek support after the diagnosis of prostate cancer, however there is little information on where men are obtaining such support. Through this study, the information you provide will help to improve existing support networks, assist service providers in understanding the support needs of men with prostate cancer and where possible create new avenues for support.

The study involves completing a brief questionnaire taking approximately 10 minutes. All information written on the questionnaire will be non-identifiable. Once completed the questionnaire can be handed back to the researcher directly or returned by mail using the reply paid envelope provided. The study is completely voluntary, whether or not you choose to respond will not affect your future at this hospital.

Should you choose to participate the information that you provide will be most valuable.

Yours Sincerely,

Sandra Walker
Appendix B

Questionnaire for members of Prostate Cancer Support Groups

Cover letter to facilitators

Recruitment Letter to Members of Prostate Cancer Support Groups

Consent Form
Prostate Cancer: Your Experiences

Please answer the following questions. The information you provide is completely confidential.

PART 1: Questions About You

1. When were you first diagnosed with prostate cancer? (approximate date)

_____________________________________________________________________

2. What was the stage of prostate cancer at diagnosis? (please tick one box)
   - Localised (within the prostate)
   - Advanced (extending outside the prostate)
   - Don’t know

3. What is the stage of prostate cancer now? (please tick one box)
   - Localised (within the prostate)
   - Advanced (extending outside the prostate)
   - Recurrent
   - Don’t know

4. What was the first treatment you received for prostate cancer? (please tick one box)
   - Hormone therapy
   - Prostatectomy (removal of prostate)
   - Radiation
   - Chemotherapy
   - Other (please state). ________________________________
5. What treatment are you currently receiving for prostate cancer? (please tick one box)

- Hormone therapy
- Prostatectomy (removal of prostate)
- Radiation
- Chemotherapy
- Other (please state). _______________________

6. How long have you been receiving your current treatment?

________________________________________________________________________

7. What is your age in years? ____________________________________________

8. What is your highest level of education? (Please tick one box)

- Primary School
- Junior secondary school (Year 9)
- Senior secondary school (Year 12)
- TAFE (Trade/certificate)
- Tertiary (college, university)
- Post graduate
- Other (please specify)

________________________________________________________________________

9. What is your current relationship status? (Please tick one box)

- Married/ Defacto/ Partnership
- Divorced/ Separated/ Widowed
- Single/ Never married
10. What language do you speak at home? (please state)

First Language ___________________________
Second Language _________________________
Third Language _________________________

10a What is your residential postcode? ____________

11. Please tick the individuals who live in your household.

☐ Mother  ☐ Son/s
☐ Father  ☐ Daughter/s
☐ Sister/s  ☐ Friend/s
☐ Brother/s  ☐ Other (please state)
☐ Wife/Partner __________________________

12. Do you currently have any other medical and/or mental health conditions? (If so, please list conditions and rate according to how distressing it is for you at present by circling a number below)

<table>
<thead>
<tr>
<th></th>
<th>No Distress</th>
<th>Very Distressing</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
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<td>2.</td>
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<td>3.</td>
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</tbody>
</table>

Part 2: Your Views about Support Groups

13. Where did you hear about prostate cancer support groups? (please tick)

☐ Local Doctor  ☐ Internet
☐ Hospital Doctor/Nurse  ☐ Brochures
☐ Social Worker  ☐ Telephone Support Line
☐ Friend  ☐ Other (please state)
14. How long have you been/were you a member of the support group? (please tick one box)

- [ ] Less than 6 months
- [ ] 6 - 12 months
- [ ] 1 - 2 years
- [ ] 2 - 4 years
- [ ] 4-6 years
- [ ] 6-10 years
- [ ] More than 10

15. Generally, how often do/did you attend group meetings? (please tick one box)

- [ ] Weekly
- [ ] Fortnightly
- [ ] Monthly
- [ ] Other (please state).

16. What have been/were the best things about being in the support group? (ie: support, information, being with other men with prostate cancer)

1. 
2. 
3. 
4. 

17. What have been/were the worst things about being in the support group?

1. 
2. 
3. 
4. 

17a. What is your current support group status? (please circle one)

- [ ] Current Attendee
- [ ] Past Attendee
- [ ] Group Facilitator
18. How do you think support groups can be improved?

1. 
2. 
3. 
4. 

19. Would you recommend participating in support groups to other men with prostate cancer? (please tick one box)

☐ Yes  ☐ No

20. Do any/did any of the following make attending the support group difficult for you? (please tick one box)

☐ Distance  ☐ Time of meeting  ☐ Feeling Unwell  ☐ Cost  ☐ Other (please state).

__________________________________________________________________________________
__________________________________________________________________________________
__________________________________________________________________________________

21. Does the term ‘support group’ have a positive or negative meaning for you? (please tick one box)

☐ Positive  ☐ Negative

22. Do you think that the term “prostate cancer information group” be preferable to the term “support group”? (please tick one box)

☐ Yes  ☐ No

23. Can you think of other terms that would make support groups more attractive to men (please list)

1. ___________________________________________________________
2. ___________________________________________________________
3. ___________________________________________________________
Below is a list of common expectations often expressed by people with cancer. Using the rating scale below, please indicate how important you think each expectation is to you in the first column and whether that expectation was/is addressed by attending a support group.

1= Not at all  
2= Slightly so 
3= Moderately so 
4= Very much

<table>
<thead>
<tr>
<th>EXPECTATION</th>
<th>IMPORTANCE TO YOU (eg. 4)</th>
<th>OPPORTUNITY PROVIDED BY SUPPORT GROUP (eg. 2)</th>
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</thead>
<tbody>
<tr>
<td>1. To be able to express my feelings in the group</td>
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<tr>
<td>2. To be able to make new friends in the group</td>
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<tr>
<td>3. To be provided with practical help by the group</td>
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<td>4. To learn how to cope better with cancer</td>
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<tr>
<td>5. To feel free to talk with friends and family</td>
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<tr>
<td>6. To be provided with emotional support by the group</td>
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<tr>
<td>7. To avoid a sense of isolation and gain a sense of belonging through group participation</td>
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<td>8. To talk to others with similar experiences in the group</td>
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<td>9. To gain access to other community information/groups</td>
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<td>10. To access information about cancer and current treatments</td>
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<td>11. To access support for my family/friends through group participation</td>
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<tr>
<td>12. To be able to provide support and advice to other men with prostate cancer</td>
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</table>
### Part 3: Questions about Cancer and You

Using the following rating scale please tick *one* response that best describes you.

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<tr>
<th>No.</th>
<th>Questions</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither disagree or agree</th>
<th>Disagree</th>
<th>Strongly disagree</th>
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<tbody>
<tr>
<td>1.</td>
<td>There is a lot which I can do to control my symptoms</td>
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<td>2.</td>
<td>When I think about my illness I get upset</td>
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<td>3.</td>
<td>What I do can determine whether my cancer gets better or worse</td>
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<td>4.</td>
<td>My cancer makes me feel angry</td>
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<td>5.</td>
<td>The course of my cancer depends on me</td>
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<td>6.</td>
<td>My cancer does not worry me</td>
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<td>7.</td>
<td>I get depressed when I think about my cancer</td>
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<td>8.</td>
<td>My actions will have no effect on the outcome of my cancer</td>
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<td>9.</td>
<td>I have the power to influence my cancer</td>
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<td>10.</td>
<td>My illness makes me feel afraid</td>
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<td>11.</td>
<td>Having cancer makes me feel anxious</td>
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<td>12.</td>
<td>Nothing I do will Affect my cancer</td>
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<td>13.</td>
<td>I don’t understand my illness</td>
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<td>14.</td>
<td>The symptoms of my condition are puzzling to me</td>
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<td>15.</td>
<td>I have a clear understanding of my condition</td>
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</table>
Using the following rating scale please indicate if you have had the symptoms below *during the past week* and if so how often it occurred.

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<tbody>
<tr>
<td>1. Feeling sad</td>
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<td>2. Worrying</td>
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Thankyou For your Assistance
PATIENT INFORMATION STATEMENT

Project Title: Prostate Cancer Support Groups: An Evaluation

You are being invited to take part in a research study for men with prostate cancer. In particular we are interested about men’s attitudes about their cancer experiences and about prostate cancer support groups. The study will include an equal number of men who are members of a prostate cancer support group and of men who have never joined such a group or are no longer members of support groups. It is hoped that the information provided will contribute to improving the support services available to men living with prostate cancer.

If you choose to participate, your involvement requires you to complete a confidential questionnaire taking approximately 10 minutes.

Once completed the questionnaire can be handed back to the researcher directly or returned by mail using the reply paid envelope provided.

You are not obliged to complete the questionnaire, you may withdraw from the study at any time. Once the questionnaire has been forwarded to the researcher, however, it will be processed since it is not possible to identify the responses of individual participants. There are no identified risks pertaining to this study.

This research being conducted by Ms Sandra Walker, a student for the degree of Master of Psychology (Health) at Swinburne University of Technology as a part of her work for the degree. It will be supervised by Dr Susan Roberts of the Anti-Cancer Council of Victoria and Dr Elizabeth Hardie of Swinburne University, and is conducted in conjunction with the Peter MacCallum Cancer Institute.

If you have any questions about the study please ring Ms Sandra Walker on (03) 94813246 at any time, Dr Susan Roberts on (03) 96355422 or Elizabeth Hardie on (03) 92145297. Any complaints concerning the study should be addressed to the chair, Human Research Ethics Committee, Anti-Cancer Council of Victoria, C/- Ms Woody Macpherson, Head Research Management Unit, 1 Rathdowne Street, Carlton, 3053. regarding (Swinburne University). Thankyou for your consideration of this study. Your participation would be most valuable.
I have read and kept a copy of the attached Patient Information Statement and understand the general purposes, risks and methods of this study. I understand that I can withdraw from this study at any time before I submit the questionnaire, after which time I will not be able to be identified. I consent to the publishing of results of the study knowing that confidentiality and anonymity will be preserved. I agree to participate in this study.

NAME


SIGNATURE ________________________  DATE __________